‘Struggling in silence’: Unrecognised autistic needs and school non-attendance in adolescent girls- A grounded theory study

Louise E. Brackpool

A thesis submitted for the degree of M4: Child, Community and Educational Psychology

Tavistock Education and Training - North London Foundation Trust / University of Essex

May, 2026

Acknowledgements

I would like to express my sincere gratitude to my supervisor, Dr Kate Farmer for her guidance and steady encouragement throughout this research. Her expertise and thoughtful critique have shaped both the direction and the quality of this grounded theory thesis.

I am deeply grateful to the participants who generously shared their time, experiences, and perspectives. I feel privileged that they felt able to share their stories with me. This work would not have been possible without their openness and willingness to contribute.

I would also like to thank my placement Educational Psychology Service, whose conversations and feedback have enriched this project. And to my cohort; I could not have done this without them, and I will be forever grateful I was able to share this journey with them.

Finally, I dedicate this thesis to my husband James, for his unwavering support and patience. To my family for their understanding, encouragement and grounding and, lastly, to Mum. It is painful to have not been able to share this experience with her. However, I have still felt her pride and support which has been a constant source of motivation.

AI tools (Microsoft Copilot and Grammarly) were used as proofreading aids during the preparation of this thesis, supporting conciseness, and formatting. All conceptualisation, analysis, interpretation, and writing presented in this thesis are my original work.

Contents

1. ABSTRACT 13

2. INTRODUCTION 15

2.1 KEY TERMINOLOGY AND CONCEPTS 16

2.1.1 Terminology and theoretical perspectives 16

2.1.2 Conceptual Boundaries 20

2.2 NATIONAL CONTEXT AND SIGNIFICANCE 21

2.3 BRIEF LITERATURE OVERVIEW 23

2.3.1 Summary of major empirical findings 23

2.3.2 Knowledge Gaps 25

2.3.3 Relevance to EP practice 26

2.4 RESEARCHER'S POSITION AND PHILOSOPHICAL STANCE 27

2.4.1 Ontology and Epistemology 27

2.4.2 Researchers Axiology 29

2.4.3 Theoretical and Methodological Positioning 30

2.4.4 Researcher Motivations and Preconceptions 31

2.5 RESEARCH AIMS, OBJECTIVES AND QUESTIONS 32

2.6 THESIS STRUCTURE AND CHAPTER OVERVIEW 33

3. LITERATURE REVIEW 35

3.1 CHAPTER OVERVIEW 35

3.2 THEORETICAL FRAMEWORKS AND CONCEPTUAL MODELS 36

3.2.1 Overview of dominant theoretical perspectives in the field 36

3.2.2 Historical development of key theoretical concepts 39

3.2.3 Conceptual models relevant to EBSNA 40

3.3 INTRODUCTION TO THE LITERATURE REVIEW 44

3.4 REVIEW METHODOLOGY 45

3.4.1 Literature Search Strategy 45

3.4.2 Search Terms, parameters and matches 45

3.4.3 Quality assessment of included studies *51*

3.4.4 Data Extraction and Synthesis *57*

3.4.5 Limitations of the search strategy *61*

3.5 REVIEW OF LITERATURE 62

3.5.1 Methodological Critique of Literature *69*

3.5.2 Themes relating to Review Question 1 ..... *74*

3.5.3 Themes relating to review question 2 ..... *84*

3.6 RESPONSE TO REVIEW QUESTIONS 87

3.6.1 Knowledge Gaps and Research Needs *89*

3.7 CHAPTER SUMMARY 90

4. METHODOLOGY 92

4.1 CHAPTER OVERVIEW 92

4.1.1 Research Aims and Questions *92*

4.2 RESEARCH PURPOSE AND PARADIGM 94

4.2.1 Research Purpose *94*

4.2.2 Philosophical positioning *94*

4.2.3 Influence on research decisions *96*

4.3 METHODOLOGICAL APPROACH 96

4.3.1 Grounded Theory *97*

4.3.2 Critical realism and Constructivist Grounded Theory (CGT) *101*

4.4 RESEARCH DESIGN 103

4.4.1 Participant Selection and Sampling *103*

4.4.2 Research Setting and Context *112*

4.5 DATA COLLECTION METHODS 113

4.5.1 Data Collection *113*

4.5.2 Timeline and evolution of data collection *120*

4.6 DATA ANALYSIS PROCESS 124

4.6.1 Coding processes *124*

4.6.2 Visual representations of analysis process *140*

4.7 Assessing Quality 143
4.7.1 Credibility 143
4.7.2 Limitations and methodological challenges 145
4.8 Ethical Considerations 147
4.8.1 Informed consent procedures for vulnerable participants 148
4.8.2 Anonymity, data protection and storage protocols 149
4.8.3 Ethical challenges specific to grounded theory 149
4.8.4 Reflexive discussion on ethical dilemmas encountered 151
4.9 Methodological Reflexivity 152
4.9.1 Critical reflection on methodological choices 152
5 FINDINGS 154
5.1 Chapter Overview 154
5.2 Overview of findings 156
5.2.1 Finding 1- Early needs remained invisible 156
5.2.2 Finding 2- Chronic stress led to escalating anxiety and withdrawal 156
5.2.3 Finding 3- Re-engagement was possible under the right conditions 157
5.3 Findings from the visual sorting activities 157
5.3.1 Mapping the Landscape of Fear 157
5.3.2 School Wellbeing Cards 158
5.4 Developing theoretical framework- Accumulating Barriers to Education 159
5.5 Presentation of Theoretical Codes 162
5.5.1 Balance of systemic barriers and early protective factors 163
5.5.2 Unnoticed distress, lack of autonomy and defence mechanisms 179
5.5.3 Activated threat response and consequences of being unable to act 197
5.5.4 Long term outcomes- Re-engagement, autonomy and resilience 216
5.5.5 Retrospective critical insight and reflection 227
5.5.6 Section summary 240
5.6 Chapter Summary 241
6. DISCUSSION 243

6.1 SUMMARY OF KEY FINDINGS 243

6.2 *PART ONE*- EMERGING THEORETICAL FRAMEWORK AND EXISTING THEORIES 247

6.2.1 Ecological Systems Theory 247

6.2.2 Continuum of school refusal behaviour 249

6.2.3 Self-Determination Theory (SDT) 250

6.2.4 Resilience 251

6.2.5 Models of disability 253

6.2.6 Current theoretical framework and integration of existing theories 255

6.2.7 Summary 257

6.3 PART TWO- COMPARISON WITH EXISTING LITERATURE 258

6.3.1 Balance of systemic barriers and early protective factors 259

6.3.2 Emotional response to unnoticed distress and lack of autonomy. 260

6.3.3 Activated threat response and consequences of being unable to act 261

6.3.4 Long Term Outcomes- Re-engagement, autonomy and resilience 264

6.3.5 Retrospective critical insight and reflection 265

6.4 PART THREE- STUDY EVALUATION 267

6.4.1 Evaluation of findings and conceptual contributions 267

6.4.2 Study Strengths 269

6.4.3 Unique Conceptual contributions 271

6.4.4 Research Limitations 273

6.4.5 Further research 275

6.4.6 Researcher reflections 276

6.4.7 Chapter Summary 279

7. CONCLUSION 281

7.1 IMPLICATIONS 281

7.1.1 Implications for Educational Psychology practice (service and individual EPs) 283

7.1.2 Implications for schools 285

7.1.3 Implications for policy and approaches to EBSNA 288

7.2 DISSEMINATION STRATEGY 289

7.3CONCLUDING THOUGHTS 289

8. REFERENCES 294

9. APPENDICES 314

APPENDIX 1- INITIAL SCOPING REVIEW SEARCH TERMS 317

APPENDIX 2- LITERATURE APPRAISAL TOOL EXAMPLES 318

APPENDIX 3- EXCLUDED LITERATURE MAPPING TABLE 346

APPENDIX 4- CRITICAL APPRAISAL FINDINGS PER PAPER 352

APPENDIX 5- EXAMPLE THEMES FROM WRITING HELPER- NB ALL ARE DIRECT QUOTES FROM THE PAPERS 362

APPENDIX 6- LITERATURE METHODOLOGICAL APPROACH MATRIX 366

APPENDIX 7- HISTORICAL OVERVIEW OF GROUNDED THEORY 386

APPENDIX 8- RECRUITMENT FLYER 387

APPENDIX 9- PARTICIPANT INCLUSION AND EXCLUSION CRITERIA 388

APPENDIX 10- ETHICS APPROVAL AMENDMENT 390

APPENDIX 11- ADDITIONAL MEASURES FOR THOSE WITH MENTAL HEALTH NEEDS 395

APPENDIX 12- EMAIL FOR PARTICIPANTS WITH ADDITIONAL MENTAL HEALTH NEEDS 396

APPENDIX 13- COLLEGE EMAIL 397

APPENDIX 14- INTRODUCTORY EMAIL TO PARTICIPANTS 398

APPENDIX 15- PARTICIPANT INFORMATION SHEETS STANDARD 400

APPENDIX 16- CONSENT TO PARTICIPATE STANDARD 403

APPENDIX 17- PARTICIPANT INFORMATION SHEET ACCESSIBLE 405

APPENDIX 18- PARTICIPANT CONSENT FORM ACCESSIBLE 408

APPENDIX 19- MICROSOFT FORM 410

APPENDIX 20- EMAIL CONFIRMATION 415

APPENDIX 20- REMINDER EMAIL....416

APPENDIX 22- APPOINTMENT REMINDER EMAIL....417

APPENDIX 23- EMAIL RESPONSES TO PARENTS....418

APPENDIX 24- ADDITIONAL PROCEDURES FOR VULNERABLE PARTICIPANTS....419

APPENDIX 25- INTERVIEW POWERPOINT AND SCRIPT....420

APPENDIX 26- CARD SORTING TOOLS....428

APPENDIX 27- CARD SORT TOOL RESPONSES....431

APPENDIX 28- REFLECTIVE DIARY EXAMPLES....433

APPENDIX 29- ADDED INTERVIEW QUESTIONS....438

APPENDIX 30- EXAMPLES OF INITIAL CODES AND MEMOS....439

APPENDIX 31- EXAMPLES OF LINE BY LINE CODING....441

APPENDIX 32- EXAMPLES OF INITIAL CODES SPLIT INTO EARLY FOCUSED CODES....445

APPENDIX 33- EARLY FOCUSED CODES, INITIAL CODES AND DATA SELECTION....448

APPENDIX 34- FINAL FOCUSED CODES, INITIAL CODES AND QUOTES....450

APPENDIX 35- EARLY CONCEPTUAL CODE DIAGRAMS....457

APPENDIX 36- EARLY THEORETICAL FRAMEWORK DIAGRAMS....459

APPENDIX 37- ETHICAL APPROVAL....461

APPENDIX 38- DISTRESS PROTOCOL....462

APPENDIX 39- FOLLOW UP THANK YOU EMAIL....463

APPENDIX 40- RESEARCHER RISK ASSESSMENT....464

APPENDIX 41- THEORETICAL CODE ORDER AND RELATED MEMOS....465

APPENDIX 42- EXAMPLE RESPONSE PATHWAY FOR SCHOOLS....467

APPENDIX 43- GRADUATED RESPONSE....469

APPENDIX 44- EARLY IDENTIFICATION SCREENING TOOL N.B. IN DEVELOPMENT- WORKING EXAMPLE 470

Table of Figures

Figure 1- Factors Involved In Under-Recognition And Diagnosis In Women And Girls 24
Figure 2- Adapted Continuum Of School Refusal Behaviour 42
Figure 3- Ecological Systems Framework 43
Figure 4- PRISMA Diagram 50
Figure 5-Thematic Synthesis Process 58
Figure 6- Line by Line/Segment Coding Example 58
Figure 7-Examples of Iinitial Themes from Literature 59
Figure 8- Examples of Higher and Initial Themes 60
Figure 9- Themes and Related Text 60
Figure 10- Representation Of A Grounded Theory 99
Figure 11- Recruitment Steps 106
Figure 12- Mapping the Landscape of Fear Scale 119
Figure 13- School Wellbeing Sorting Activity 119
Figure 14- Simplified Stages Of Coding 125
Figure 15- Code Construction 125
Figure 16- Memos For Development Of ‘Friendship Breakdowns And Social Pain’ 128
Figure 17- Example Comparison Of Initial Codes Across Participants 129
Figure 18- Visual Representation Of The Analysis Process 141
Figure 19- Current Theoretical Framework 159
Figure 20- Diagram Of Balance Of Systemic Barriers And Early Protective Factors 164
Figure 21- Diagram Of Unnoticed Distress, Lack Of Autonomy And Defence Mechanisms 180
Figure 22- Diagram Of Activated Threat Response And Being Unable To Act 198

Figure 23- Conceptual Diagram Of Long Term Outcomes 217

Figure 24- Conceptual Diagram Of Retrospective Critical Insight And Reflection 227

Figure 25- Illustration Of Where Research Questions Are Addressed 244

Figure 26- Overlay Of Theoretical Framework Mapped On To Ecological Systems 248

Figure 27- Existing Theories And Frameworks Mapped On To Emerging Framework..... 256

Figure 28-Findings Supported by the Current Study 269

Figure 29- Pathway from Camouflaging to EBSNA 272

Tables content

Table 1 Rates Of Persistent Absence From Academic Year 2022-2023 22

Table 2 Rates Of Persistent Absence Per Gender And SEN Status 22

Table 3 Functions Of School Non-Attendance..... 41

Table 4 Search terms..... 46

Table 5 Literature Inclusion and Exclusion Criteria 48

Table 6 Critical Appraisal Tools Used..... 52

Table 7 Summary Of Literature Review Themes Related To Review Questions..... 63

Table 8 Summary Literature Findings..... 64

Table 9 Types Of Camouflaging 78

Table 10 Known Demographic Information..... 110

Table 11 Participant's Educational Contexts 111

Table 12 Initial Interview Questions 115

Table 13 Memo Examples 123

Table 14 Example Of Line By Line Coding..... 126

Table 15 Example Memos for theoretical codes..... 131

Table 16 Examples Of Initial Codes And Memos 134

Table 17 Focused Code, Initial Code, Memos And Quotes..... 136

Table 18 Theoretical Code Formation + Memo Example 139

Table 19 Theoretical Code Order 163

Table 20 Initial Codes For 'Barriers To Earlier Recognition And Response' 165

Table 21 Participant Quotes for 'Not Realising Or Understanding Own Distress' 166

Table 22 Quotes for ‘Achievement, Diligence And Presentation Masking Extreme Struggles’ 167
Table 23 Participant Quotes Highlighting ‘Too Little, Too Late’ 169
Table 24 Participant Quotes Highlighting ‘It Depends’ 171
Table 25 Participant Quotes Highlighting ‘Not Wanting To Appear Different’ 172
Table 26 Participant Quotes Highlighting ‘All Or Nothing, No Grey Area’ 173
Table 27 Participant Quotes Highlighting ‘All Or Nothing, No Grey Area’ 174
Table 28 Initial Codes For ‘Moments Of Visibility And Recognition’ 174
Table 29 Quotes for ‘Knowing That Teachers Tried And Expression Of Empathy For The Adults’ ... 175
Table 30 Participant Quotes Highlighting ‘Difference Made By Positive Teacher Relationships’ 176
Table 31 Participant Quotes Highlighting ‘Relying On And Catching Up With Friends’ 178
Table 32 Constituent Initial Codes For ‘Invisible Path Of Distress To Absence’ 181
Table 33 Participant Quotes Highlighting ‘Avoiding Specific Lessons Or Events’ 181
Table 34 Participant Quotes Highlighting ‘Early Physiological Symptoms’ 183
Table 35 Participant Quotes Highlighting ‘Leaving’ 184
Table 36 Quotes for ‘Preferring To Be At Home And Difficulties Separating From Parents’ 185
Table 37 Participant Quotes Highlighting ‘Covid Made Me Realise’ 187
Table 38 Initial Codes For ‘Landscape Of Distress And A Lack Of Belonging And Autonomy’ 188
Table 39 Participant Quotes Highlighting ‘Feelings Of Frustration, Anxiety And Distress’ 189
Table 40 Participant Quotes Highlighting ‘Experiencing Fear And Perceived Threat’ 191
Table 41 Participant Quotes Highlighting ‘Isolation, Invisibility And Struggling In Silence’ 192
Table 42 Participant Quotes Highlighting ‘Lacking Control, Safety And Hope’ 194
Table 43 Participant Quotes Highlighting ‘Lacking A Sense Of Belonging And Fearing Judgement’ 195
Table 44 Initial Codes For ‘Cumulative Stressors And Overwhelm In The School System’ 199
Table 45 Participant Quotes for ‘Feeling Forced, The Use Of Threats, And Consequences’ 199
Table 46 Quotes Highlighting ‘Autism Traits Making School Confusing And Stressful’ 202
Table 47 Quotes Highlighting ‘Anxiety In Response To School Environment And Expectations’ 204
Table 48 Quotes Highlighting ‘Lack Of Support, Nurture And Approachability From School Adults’ . 206
Table 49 Codes For ‘Impact Of Stressors On Their Mental Health And Ability To Attend School’ 209
Table 50 Quotes Highlighting ‘Mental Health Crisis, Shut Down And Feelings Of Paralysis’ 210
Table 51 Participant Quotes Highlighting ‘Physiological Signs Of Distress And Anxiety’ 212

Table 52 Participant Quotes Highlighting ‘School Experience Causing Trauma’ 214
Table 53 Constituent Initial Codes For ‘Resilience, Achievement And Hope’ 218
Table 54 Participant Quotes Highlighting ‘Experiencing Success And Achievement’ 218
Table 55 Quotes Highlighting ‘Developing Coping Strategies, Resilience And Facing Challenges’ .. 220
Table 56 Codes For ‘Conditions Enabling Re-Engagement And Feelings Of Safety And Belonging’ 222
Table 57 Quotes for ‘Having Autonomy And Choice And Taking Control Of Their Learning’ 222
Table 58 Participant Quote Highlighting ‘Fresh Start’ 224
Table 59 Participant Quote Highlighting ‘Fresh Start’ 224
Table 60 Participant Quotes Highlighting ‘Parental Support And Fight’ 225
Table 61 Constituent Initial Codes For ‘Participant Hindsight On Missed Opportunities’ 228
Table 62 Participant Quotes Highlighting ‘Teachers Should Have Recognised Needs’ 229
Table 63 Participant Quotes Highlighting ‘Earlier Recognition, Diagnosis And Support’ 230
Table 64 Participant Quotes Highlighting ‘I Got Lucky’ 232
Table 65 Initial Codes For ‘Diagnostic Journey And Impact On Identity, Acceptance, And Support’ . 233
Table 66 Participant Quotes Highlighting ‘Positive Feelings About Diagnosis’ 234
Table 67 Participant Quote Highlighting ‘Positive Qualities From Late Diagnosis’ 235
Table 68 Participant Quotes Highlighting ‘Positive Qualities From Late Diagnosis’ 236
Table 69 Participant Quotes Highlighting ‘Stigma, Stereotype And Journey Of Acceptance’ 238
Table 70 Participant Quotes Highlighting ‘Impact Of The Diagnosis’ 239
Table 71 Theoretical Codes And Linked Focused Codes 258

1. Abstract

There is increasing evidence highlighting the different presentation of autism in women and girls, often leading to their needs being unrecognised until much later than for male peers. Emotionally based school non-attendance (EBSNA) is more common in autistic children and young people (CYP), yet limited research examines the intersection of autism and EBSNA, particularly the impact of unidentified autistic needs on well-being and EBSNA experiences.

Using a retrospective grounded theory approach, this study explores how unidentified (and unmet) autistic needs in adolescent girls may impact school experiences and attendance. Semi-structured interviews were conducted with five autistic young women aged 17–25, each of whom experienced EBSNA prior to receiving an autism diagnosis. Participants reflected on their mainstream secondary school experiences, highlighting themes such as masking, cumulative overwhelm, fear of negative judgement, and relationships with school adults and peers.

Findings indicate missed opportunities for earlier recognition; participants did not initially realise, or then understand why they were struggling, and early signs were overlooked by school staff. Emotional burnout, significant school non-attendance, and mental health needs followed for most participants, including anxiety, depression and eating disorders. The paper highlights their struggles and the impact on mental health and school attendance, while also emphasising their resilience, and positive outcomes. Participants stressed the importance of early recognition, noting that by the time their non-attendance was acknowledged, it was "too late." The paper concludes by proposing strategies for earlier identification of

school-based anxiety, and a support pathway for schools to follow to assist CYP at earlier stages of EBSNA.

‘Struggling in silence’: Unrecognised autistic needs and school non-attendance in adolescent girls- A grounded theory study

2. Introduction

Since the COVID-19 pandemic, school non-attendance has become a significant issue, with rates having doubled between 2020 and 2023 (Bond et al., 2024; DfE, 2024a). Improving attendance is a priority for the Government and educational professionals, including Educational Psychologists (EPs) (Bond et al., 2024). Alongside this, there is increasing research into the different presentation of autism in girls and the difficulties this creates in identifying their needs, with substantial impacts on their mental health noted (e.g. Tomlinson et al., 2022; Wood-Downie et al., 2021). Diagnostic criteria and tools often fail to identify this consistently (Cruz et al., 2024), and girls often mask their difficulties (Belcher et al., 2023), which schools may not recognise, leading to unmet needs (Ayirebi & Thomas, 2024; O’Hagan et al., 2024).

This research aims to explore this intersection to explain what was experienced by five autistic girls with unidentified needs who experienced Emotionally Based School Non-Attendance (EBSNA) in mainstream secondary schools. The study will:

- Explore how unidentified autism and related unmet needs might have affected their school attendance;
- Explore the barriers these individuals faced in attending school and how these relate to autism;

- Gather their views on what support they believe could have helped them and whether they think earlier identification of autism or their differences might have safeguarded their attendance.

Using the perspectives of a small group of young people at the heart of this issue, this research aims to bridge the gap in our understanding of the needs of girls with unidentified autism and their experiences of EBSNA. It seeks to emphasise the importance of and improve early identification and support, with particular focus on the role of EPs.

This chapter will provide the background and context for the study, outline the key concepts and terminology to be used throughout this thesis, and briefly describe the researcher's philosophical stance, the existing literature, and the current research, including its aims, rationale, and methodology.

2.1 Key Terminology and Concepts

2.1.1 *Terminology and theoretical perspectives*

Terminology in this thesis reflects current perspectives, while recognising experiences and interpretations vary among autistic individuals, families, and professionals. These constructs have real effects but are understood and lived differently by each person.

Autism. Autism is a neurodevelopmental condition, presenting differences in social communication and interaction and restricted or repetitive patterns of thought, interests or behaviour, which impacts how individuals perceive, communicate and interact with their environment (American Psychiatric Association [APA], 2013;

Guldberg et al., 2019). The level of impact these differences have on an individual is variable, with some presenting with substantial support needs, and others experiencing more independence (Guldberg et al., 2019). In the current study, the terms ‘autism’ and ‘autistic’ are used to refer to autism, autism spectrum condition/disorder, and what was previously termed Asperger Syndrome. Identity-first language (e.g., “autistic girl”) is used to reflect the views of many autistic individuals who consider autism integral to their identity. Consistent with contemporary literature, autism is framed as a difference rather than a deficit, unless in reference to a particular model.

Historically, autism has been viewed through a deficit based lens in the form of the ‘triad of impairments’ initially identified by Wing and Gould (1979). However, more recently, the neurodiversity paradigm has gained prominence and instead promotes a model based on human difference and variation, where a person's strengths are considered alongside areas of difficulty.

Autism has long been regarded as predominantly affecting males, with historical figures suggesting a ratio of 4:1 for autistic men and boys to women and girls (e.g., Gray et al., 2021). However, more research now acknowledges that females are significantly underrepresented in these figures. The actual ratio varies between 3:1 and nearer equality, depending on the specific study considered (Gray et al., 2021; Tomlinson et al., 2022; Wood-Downie et al., 2021).

Female Autistic Presentation. Research identifies that autism may present differently in some women and girls, when compared to autistic men and boys. The core differences underlying the female presentation of autism are the same as for males. However, the behavioural presentation of it differs (Tomlinson et al., 2022).,

Autistic women and girls can present as being socially motivated and competent, have better imagination skills, and show interests in line with their peers (e.g. Belcher et al., 2023; Gould, 2017; Lai et al., 2011). But upon closer observation, the way in which they interact, the friendships they develop and the fixed interests they develop can be qualitatively different (Gray et al., 2021). Restricted interests can appear similar to their peers but they may differ in intensity. Their friendships could also be intense, with them showing controlling behaviours towards peers and frequent disagreements meaning sustaining friendships is hard for them (Gray et al., 2021).

Camouflaging. Camouflaging is also seen more frequently in autistic women and girls compared to autistic men and boys and neurotypical peers (McKinney et al., 2024). Camouflaging is understood as an individual hiding their autistic traits, either consciously or subconsciously, to fit in with their peers. This is achieved to varying degrees of success through various strategies including: masking, which is defined as hiding their struggles and pretending they are coping (McKinney et al., 2024); compensation, such as using alternative cognitive routes to achieve a goal or reducing the appearance of their autistic differences (Cook et al., 2024); and assimilation, which is using learnt strategies and behaviour to conform to neurotypical rules (Cook et al., 2024).

The different presentation of autism in women and girls, including their higher use of camouflaging, means that they are often diagnosed later, or misdiagnosed (Gray et al., 2021). Early identification of autistic needs is associated with more positive outcomes (Gray et al., 2021). In contrast, delayed or absent identification is linked to unmet needs and reduced access to support (Gray et al., 2021), increased

mental health difficulties and social isolation (Tomlinson et al., 2022), poorer developmental trajectories (Gray et al., 2021), and heightened risk of experiencing EBSNA (Ayirebi & Thomas, 2024). More broadly, autistic CYP experience poorer outcomes across education, well-being, and quality of life compared to their neurotypical peers (Cook et al., 2024). Taken together, those whose needs remain unidentified (such as autistic women and girls) may face a double disadvantage.

Emotionally Based School Non-Attendance (EBSNA). EBSNA replaces earlier terms like school refusal/avoidance or anxiety-based school avoidance, emphasising external and contextual barriers rather than deliberate absence. Government data uses ‘persistent school absence’ for attendance below 90%, and so this figure is also used within the current study. Although Government data includes all types of absence in their data, the focus of the current study is ‘EBSNA’. This term has been chosen to reflect participants’ actual experiences of non-attendance and the broader term ‘barriers to attendance’ is also used where appropriate.

Models used to explain EBSNA include the continuum of school refusal (Kearney, 2008), from early stages to chronic non-attendance, the functions of EBSNA, including to escape or avoid situations or to gain something from remaining at home (Kearney & Silverman, 1993), and ecological systems theory (Bronfenbrenner, 1979), which views EBSNA within the context of different systems relevant to the child of young person (CYP), both immediate and in society at large, and the interactions between these.

Female. For this research, female refers to individuals assigned female at birth who identify as female. This operational definition is used solely to support the study's focus and does not reflect a fixed view of gender diversity.

2.1.2 Conceptual Boundaries

This study examines the EBSNA experiences of girls whose autistic needs were unidentified at the time of their school attendance difficulties. To reduce additional variables that may influence EBSNA, participants were required to be biologically female and identify as female, recognising that barriers to attendance can be present for those who are gender diverse. Furthermore, women and girls remain currently and historically under-represented in autism studies. However, it is acknowledged that concepts such as masking and EBSNA are also experienced by autistic males.

EBSNA is defined as a CYP displaying reduced absence due to emotional distress, with parental knowledge and their efforts to facilitate attendance (Totsika et al., 2020). Unlike truancy, these CYP often want to attend but are prevented by barriers, causing them emotional distress. Other absence types are excluded in this definition (such as holidays, illness, and medical absences), but inconsistencies in the recording of EBSNA absences make true prevalence difficult to ascertain.

Debate continues over the usefulness of diagnostic labels and models of disability offer contrasting views on this. This research adopts a critical realist stance, drawing on social, neurodiversity, and medical models, recognising that these concepts exist, but that no single framework captures all experiences, and that support should be available for those who experience the greatest impact, irrespective of diagnosis.

2.2 National context and significance

Reduced attendance is linked to poorer long-term outcomes (Prosser & Birchwood, 2024) and so improving this is a current Department for Education (DfE) priority. New guidance outlines that support should be provided for any pupil missing 10% or more of their education ('persistent absence'), and particular attention should be given to those with below 50% attendance, or 'severe absence' (DfE, 2024a; Totsika et al., 2020), and aims for 94% attendance nationwide by 2028-2029 (DfE, 2026a). Parents have a legal duty to ensure attendance and can face prosecution in extreme cases where support has been ineffective and parental engagement is a barrier (DfE, 2024a; Education Act, 1996).

Since the COVID-19 pandemic, the government has placed significant focus on school non-attendance, which, despite slight improvement, remains almost twice the pre-pandemic rate of 10.9% (Bond et al., 2024; DfE, 2024a). Table 1 below shows the rates in the years which followed.

Breaking these figures down, however, shows that persistent absence rates for 2024-2025 are higher in secondary schools (24.3%), representing a +10% increase from primary schools, highlighting that persistent absence is greater in secondary education (DfE, 2025a).

Examining persistent absence data (DfE, 2025a) further within secondary schools reveals additional considerations. Table 2 shows the proportion of persistent absence experienced by CYP across special educational needs (SEN) status and gender.

Table 1

Rates Of Persistent Absence From Academic Year 2022-2023

Academic Year (Sept-Jul)	Persistent absence	Source
2022-2023	21.2%	DfE, 2024b
2023-2024	20.7%	DfE, 2024b
2024-2025	18.7%	DfE, 2025a

Table 2

[1]*Rates Of Persistent Absence Per Gender And SEN Status*

No SEN	SEN support	EHCP	Male	Female
21.6%	38.3%	44.2%	23.0%	25.7%

Those with SEN experience higher rates of persistent absence than those without, and the rate is slightly higher for women and girls and autistic CYP have the highest EBSNA rates (Totsika et al., 2020). Autistic women and girls are often diagnosed later due to camouflaging and are more likely to experience mental health

[1] Percentages represent the proportion of those within each category who experience persistent absence. For example, out of those with no identified SEN, 21.6% are persistently absent. Or 25.7% of females.

difficulties (Ariyebi & Thomas, 2024), which raises questions about how those with unidentified needs are managing. Early identification and support are crucial for CYP with SEN and this forms a key part of the Special Educational Needs and Disability (SEND) Code of Practice [CoP] (DfE & DoH, 2014). This should also extend to EBSNA, especially considering that factors affecting EBSNA are multi-systemic, involving home, school, and society and possible unidentified SEN.

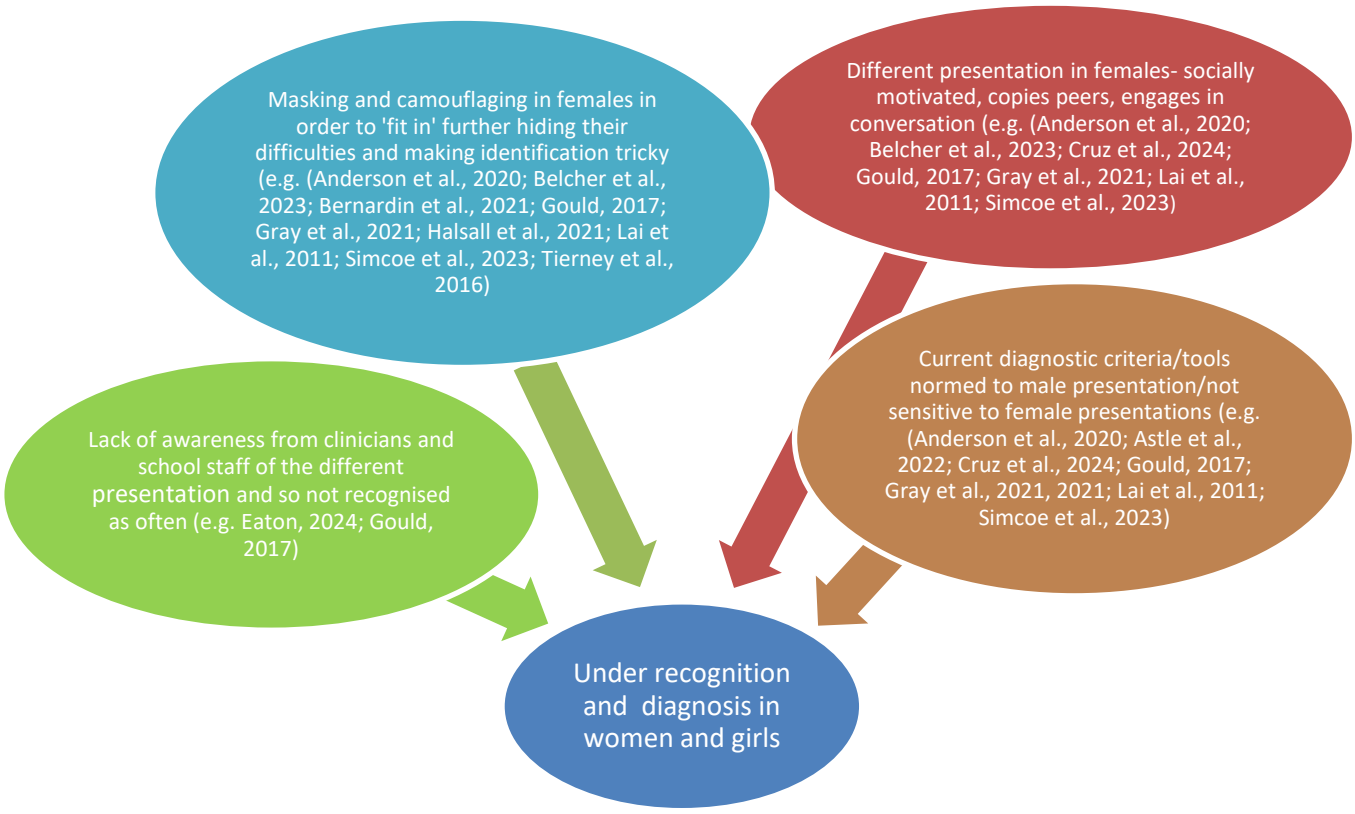
2.3 Brief Literature Overview

2.3.1 Summary of major empirical findings

An initial scoping review was conducted for the purposes of a research proposal required of the Researcher (see Appendix 1 for search terms). The literature reviewed as part of this, provides evidence of a male bias in autism identification and that autistic women and girls are more likely to be diagnosed later, misdiagnosed, or remain undiagnosed (Gray et al., 2021; Tomlinson et al., 2022). Several potential reasons were identified in the literature, an overview of which is presented in the below diagram for context.

Figure 1

Factors Involved In Under-Recognition And Diagnosis In Women And Girls



The review also identified that mental health issues are also more common in autistic women and girls compared to both autistic males and neurotypical peers, including depression, anxiety, eating disorders, self-harm, and suicidal ideation (Anderson et al., 2020; Tomlinson et al., 2022; Halsall et al., 2021; O'Hagan et al., 2024). Higher rates of EBSNA is identified as occurring more frequently in autistic CYP, with this being the most common reason for school non-attendance among them (e.g., Totsika et al., 2020). Autistic girls find school increasingly more difficult as they grow older, with their risk of EBSNA rising (O'Hagan et al., 2024), with potential reasons identified in literature (e.g. O'Hagan et al., 2024) . Supportive factors have also been identified to help autistic women and girls maintain or

improve attendance, (e.g. Gray et al., 2021; O'Hagan et al., 2024; Tomlinson et al, 2022).

2.3.2 Knowledge Gaps

CYP with SEN and autism are already at increased risk of EBSNA, even when their needs are recognised and supported. However, autistic women and girls are less likely to be identified, leaving them without the protective factors that help reduce these barriers. This may place them at even greater risk of EBSNA than both identified autistic CYP and their neurotypical peers. Therefore, it is plausible that some CYP experiencing EBSNA, male and female, may have unidentified autistic needs. This intersection has not yet been explored in existing research.

A notable gap in the literature concerns autistic girls' school experiences before they are identified. Without recognition, the adaptations and supports outlined in existing research are unlikely to be implemented. No studies were found that examine these pre-identification experiences, particularly through a retrospective lens, unique to the current study.

Autism research also remains mostly focused on males, partly because boys are often identified earlier and thus eligible for inclusion in studies. This reinforces a male-centric view of autism and influences assumptions about what autistic traits "should" look like, leading to ongoing under-recognition of girls. There is a clear demand for research that centres the voices of autistic girls (Eaveson, 2024; Higgins, 2022).

Finally, current research is mainly descriptive and uses methods such as interpretive phenomenological analysis (IPA) or reflective thematic analysis (RTA).

While these are very useful for exploring experiences and the meaning people assign to them, they do not help us explain potential underlying processes.

2.3.3 Relevance to EP practice

There is substantial political, professional, and media concern about the challenges women and girls face in having autistic needs identified, increased school absence since Covid-19, and rising autism assessment referrals and wait times. This research aims to improve understanding and support for autistic CYP struggling in mainstream schools, and the role that EPs could have in this.

Currently, most EP services provide EBSNA resource packs for schools and/or parents (e.g. Trafford Council, 2021; West Sussex, 2022), with EPs often becoming involved once attendance has reduced to a concerning level. The National Association of Principal Educational Psychologists guidance (NAPEP, 2026) highlights that EPs contribute psychological expertise and can bridge the gap between school and home to support non-attendance. The researcher's placement Authority has quite an extensive support pathway, facilitating multi-agency network meetings through case conferences and supporting individual schools with increasing levels of EBSNA cases. However, it currently seems as though most of the EP involvement is at the stage of reduced attendance, and so there could be other mechanisms for change through which EPs could offer the expertise which have currently not been fully identified. By exploring the participants views of their experiences before their needs were identified, this research could illuminate opportunities for earlier systemic intervention.

The study will contribute to research on EBSNA, autism, and the importance of early intervention before EBSNA becomes entrenched. By identifying possible

mechanisms for change, suggestions for a range of professionals can be made across both schools and EP services. By identifying *where* these changes would be most effective, guidance can be more specific. It will emphasise the crucial role of EPs in raising awareness of autism in girls, understanding their unique challenges, and collaborating with parents.

2.4 Researcher's Position and Philosophical Stance

This section will be written in first-person terminology and outlines my personal, experiential, and philosophical viewpoints, as well as pre-conceived ideas, which I will challenge at all stages of data collection and analysis.

2.4.1 Ontology and Epistemology

Ontologically, I adopt a critical realist (CR) perspective and view both autism and EBSNA as real phenomena. Autism is a neurodevelopmental condition with genetic and neurobiological foundations, supported by a growing body of research (Cook et al., 2024). EBSNA, while terminologically fluid, has long been recognised in educational and psychological literature and is substantiated by empirical data. However, the way these concepts are understood and experienced varies across individuals, cultures and contexts. Thus, while there are underlying truths to these phenomena, there are multiple lived realities in how they are experienced and interpreted. A constructivist grounded theory approach aligns with this positioning (Fletcher, 2017; Sutcliffe, 2016), allowing theory to be generated from participants' lived experiences rather than imposed frameworks.

Epistemologically, I also take a CR position, acknowledging that the underlying mechanisms of autism and EBSNA (the causes) are not directly observable, but they can be conceptualised through theoretical models and frameworks. However, their effects are observable in terms of behaviour, well-being and educational outcomes. Furthermore, research, literature, and experience have advanced our understanding of both concepts, as reflected in evolving models and terminology.

Critical realism was developed by Bhaskar (1989) as an approach to research which acknowledges that our understanding of phenomena evolves and grows with changing conditions and new information (Corson, 1991). It is a particularly helpful approach to adopt when researching phenomena which occur in complex, open systems, such as schools and education (Corson, 1991) or when exploring ‘social problems’ (Samsonsen & Heggdalsvik, 2024). Critical realist positions have also been adopted in other research with vulnerable participant groups in relation to education (e.g. Doolan Maher et al., 2025; Larkins, 2019; Powell, 2016). Powell (2016) sought to develop a framework for understanding peer mentoring relationships, using the views of four peer mentors and five mentees, ranging Year 7 to Year 13, from two secondary schools. The participants in this study are deemed vulnerable due to their ages, however there may be other characteristics not recorded which add further aspects of vulnerability. Powell (2016) viewed that peer mentoring was the underlying reality, but that how this is experienced and the outcomes gained from it can differ for individuals. This suggests that multiple realities exist from the experience of peer mentoring, and she wished to explore these realities from the experiences of her participants.

2.4.2 Researchers Axiology

Personal Background. I am a white, British woman in my mid-40s, living in the South of England. Although my journey has not been easy, I recognise that I have certain privileges related to my race, ethnicity, and education. While the participants in my study are self-selecting and I do not know how my characteristics relate to the participants, apart from their biological sex; there may be cultural, economic, and educational similarities and differences I need to consider, rather than making assumptions about familiarity and meaning.

My own educational experience was one of challenge and struggle. School did not make sense, friendships were a source of upset and anxiety, and achievement was never where I wanted it to be. However, despite this, I now find myself in a doctoral-level programme, highlighting that education was the issue rather than my ability. In this way, I may share some experiences with the participants.

Professional Experience. I have worked in the field of autism for over 20 years. My interest in this research topic has evolved over the last decade, shaped by direct work with CYP and their families, many of whom experienced EBSNA for extended periods.

Over time, I observed that autistic women and girls often presented differently from males, leading to their needs being overlooked or misinterpreted. Although awareness of a female autistic phenotype has grown, in my experience, this has not consistently translated into improved identification or support. This disconnect led me to question whether undiagnosed autism might be a contributing factor in EBSNA

among girls, and whether their unmet needs, rather than behavioural choices, were driving their difficulties with school attendance.

Through roles in adult services, specialist and mainstream schools, and Educational Psychology services, I have likely assessed or worked with over 1,000 autistic CYP. Their presentations have varied widely, from profound learning and language needs to high cognitive ability paired with significant mental health challenges. Each presentation has reshaped my understanding of autism, challenging assumptions and expanding my awareness of its complexity and variation of impact, and forming my CR positioning.

2.4.3 Theoretical and Methodological Positioning

Over the course of my professional and academic journey, my understanding of autism and the role of diagnosis has evolved significantly. Initially shaped by medicalised frameworks through my roles in specialist autism provisions, I viewed diagnosis as a necessary gateway to support. However, through ongoing engagement with emerging research and models of ‘difference’, I have come to question the assumption that diagnosis is universally helpful, wanted, or required for needs to be met.

While diagnosis can be transformative for many, providing clarity, validation, and access to resources, for others, it can be viewed as unhelpful, damaging and limiting. For those at the heart of my study, it can also be delayed, denied, or misunderstood, particularly for girls whose presentations differ from the traditional diagnostic profiles. I now adopt a more nuanced stance: recognising that support

should be responsive to individual needs, regardless of formal diagnosis, but also advocating that for many, a diagnosis is helpful, validating and affirming.

This perspective aligns with neurodiversity and social models of disability, emphasising societal barriers and the importance of recognising difference rather than deficit. However, in line with the CR perspective, it also recognises the value of the medical model and so my current position is that autism should be understood as a collection of cognitive and social differences that interact with a neurotypically focused world in terms of work, social and environmental demands in complex ways. Diagnosis may be one helpful tool, but it should not be the sole determinant of support, understanding, or legitimacy.

These foundations inform my decision to adopt grounded theory, a methodology that privileges participant voice and allows theory to be created from lived experience rather than preconceived frameworks.

2.4.4 Researcher Motivations and Preconceptions

I hope to contribute to a shift in understanding and practice that means girls' needs are more routinely identified, and subsequently met, which *could* improve their school experiences and reduce the likelihood of developing EBSNA and more significant mental health needs.

I acknowledge that I have mostly been involved with CYP whose needs have not been recognised and met, and that there are professionals who do identify needs and put adaptations in place, working supportively with CYP and their families to reduce their impact. It is hoped that this research will also capture more positive

experiences to identify what can work for this vulnerable group of CYP and challenge my assumptions that mainstream schools are not able to adapt. A reflexive process will be used throughout the research process to ensure that these biases are acknowledged and considered so that the participants views are acknowledged and their voices heard.

2.5 Research Aims, Objectives and Questions

This study explores the experiences of five autistic young women aged 16-25 who faced EBSNA (defined as 10% or more non-attendance for at least one term) and whose autistic needs were only recognised after their school non-attendance began. In doing so, the study will aim to explain how unrecognised and unsupported autistic needs impacted their school experiences and how this may have led to their school non-attendance.

It will gather their views on what support could have helped them and whether they believe that earlier identification of their additional needs would have improved their attendance. By proposing a framework for the processes underlying their experiences and outcomes, it will aim to identify clear mechanisms for change.

This qualitative research will be a constructivist grounded theory (CGT) study, grounded in a CR ontology and epistemology. CGT is suitable for exploring participants' views or experiences (Cresswell & Cresswell, 2023), is commonly used in qualitative studies that employ semi-structured interviews (e.g., Dowd, 2024; Walker, 2019), and has been applied in other research adopting a critical realist perspective (e.g., Daulby, 2017; Grant, 2020). Therefore, CGT is an appropriate

method for this study, aiming to go beyond merely describing experiences to develop a theory.

As such, the research questions are:

- What are the experiences of autistic adolescent girls prior to their autistic needs being recognised, and how could this contribute to school non-attendance?
- What are the barriers and supportive factors that influence school attendance for adolescent girls before their autism diagnosis?

The GT approach (and a key strength) enables the researcher to follow the data and explore concepts arising from participants (Charmaz, 2014). A new line of enquiry was revealed through the participants accounts of their experiences which led to a third research question being generated which is introduced in the Discussion Chapter.

2.6 Thesis Structure and Chapter Overview

The chapters that follow include the literature review, methodology, research findings, discussion, and conclusion chapters.

The literature review introduces the key theories, concepts and studies that inform the thesis, and explains the search strategy used to identify relevant research. It highlights the gaps in current knowledge, which shape the study's research questions and lead into the methodology chapter, which outlines the methodological choices made, the rationale behind them, and the procedures used to conduct the research.

The findings chapter then presents the central codes constructed from participants' accounts, tracing their experiences from the early development of anxiety through to their eventual school non-attendance. The discussion chapter interprets these findings in relation to existing literature and theoretical frameworks, identifying where the study supports, extends or challenges current understanding. It also offers a critique of the study.

The thesis concludes by summarising the main findings and outlining the implications, and possible next steps for research and practice, including an early screening tool and support pathway, which is being developed by the researcher and her linked schools.

3. Literature Review

3.1 Chapter Overview

This chapter begins by outlining the dominant models that inform understandings of autism and EBSNA, establishing the theoretical lens through which the current research is framed. It then details and critiques the methodology used to conduct the literature review, before presenting a critical synthesis of key findings and identified gaps.

While the chapter concludes by linking these insights to the empirical focus of the thesis, it should be situated within the context of a grounded theory (GT) study. Glaser and Strauss (1967) originally advocated delaying the literature review to prevent the premature imposition of theoretical preconceptions on emerging data. However, others (e.g. Charmaz, 2014; Thornberg, 2012) have challenged this stance, arguing that researchers inevitably bring prior knowledge, values, and conceptual frameworks into the research process. Thornberg's (2012) concept of 'informed grounded theory' supports engaging with existing literature while upholding the core principles of GT.

This study adopts that approach, recognising the researcher's familiarity with the evolving conceptual landscape and the importance of identifying gaps and starting points. Accordingly, although a literature review was conducted prior to data collection, the questions posed and thus the data gathered are not constrained by it. Additional themes may develop inductively and will be explored further in the discussion chapter. This is discussed in more detail in the Methodology Chapter, which follows.

3.2 Theoretical Frameworks and Conceptual Models

This section outlines the dominant perspectives conceptualising autism and EBSNA, alongside their historical evolution relevant to the current study. The researcher's positionality and axiology detailed within the introduction should be borne in mind to highlight the interpretive lens through which the study and its findings are constructed. First-person language is used where appropriate to distinguish the researcher's reflections from the literature. This approach acknowledges the researcher's professional involvement in the field, and that values, perspectives, context and extensive experience shape the knowledge created through qualitative research.

While this study adopts difference-based terminology as discussed previously, some deficit-based language is retained in this section to reflect the original framing of the theories discussed. This decision acknowledges the evolving understanding and positioning of autism and its models.

3.2.1 Overview of dominant theoretical perspectives in the field

This section introduces the main theoretical perspectives on autism; however, many other theories and frameworks exist. The models outlined are particularly relevant to the current researcher's critical realist stance and her conceptualisation of autism and EBSNA, drawing on a combination of social, neurodiversity, and medical models. These frameworks also help explore central concepts in this study, including gender disparities in diagnosis, under-identification of autism in women and girls, and the social and environmental impact on the wellbeing of autistic CYP.

Medical model. The medical model traditionally adopts a deficit-based approach, focusing on symptoms or 'impairments' (Boucher, 2009). In the UK, the National Institute for health and Care Excellence (NICE; 2017) recommends using the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) (American Psychiatric Association [APA], 2013) or the International Classification of Diseases, 11th Edition (ICD-11) (World Health Organisation [WHO], 2022) criteria for diagnosis. However, this model is widely criticised for aiming to reduce or cure symptoms in pursuit of ‘normality’ (Kapp et al., 2013), without considering environmental and societal factors that may contribute to disadvantage (Casanova & Widman, 2021). It also has limitations for conditions like autism, which lack biological markers and rely on behavioural characteristics for diagnosis (Kapp et al., 2013; Masataka, 2017).

Gender-based models. These models explore biological and genetic factors underlying diagnostic discrepancies between males and females and are considered alongside the medical model. The 'extreme male brain' (EMB) theory suggests males are more likely to develop autism (Baron-Cohen & Hammer, 1997), while the 'female protective effect' (FPE) theory posits that women and girls require more risk factors to develop autism (Hull et al., 2020). Both theories face criticism; no specific protective factors have been identified, and evidence for genetic mechanisms is mixed. Increasing diagnosis rates among women and girls suggest susceptibility may be equal, and other factors may better explain the discrepancy, which will be explored further in the literature review.

Social model of disability. This model proposes that disability is created by societal, environmental, and cultural barriers (Casanova & Widman, 2021) rather

than within-person causes. In autism, the disabling factor is often the neurotypical world's expectations (Halsall et al., 2021). While influential in shaping disability policy and opening up debates on disability, it has been criticised, including by the current author, for potentially neutralising or oversimplifying disability and the impact it has for many. It has also been rejected by some disability rights communities, including parts of the neurodiversity movement (Casanova & Widman, 2021).

Neurodiversity paradigm. The neurodiversity paradigm views cognitive variation as a natural part of human diversity and identity (Casanova & Widman, 2021; Long, 2023; Masataka, 2017). It supports autism-first terminology and a strengths-based approach, challenging deficit narratives and the pursuit of a cure. Closely linked to social constructionism, it sees autism as shaped by societal norms, though some view it as blending social and medical models with an acceptance of the usefulness of diagnosis for some (Masataka, 2017). The movement has increased neurodivergent involvement in research and advocacy, promoting inclusivity and acceptance. However, it has also faced critique by members of the neurodivergent community for downplaying the significant impact of neurodivergence on individuals with higher support needs, and for marginalising voices less able to self-advocate. It is also criticised for rejecting interventions aimed at teaching skills such as social and friendship development, which some view as important (Casanova & Widman, 2021).

All three models inform the researcher's understanding of autism, each offering valuable insights but also facing critique. In line with a critical realist perspective, the researcher advocates for a combined approach, recognising

individual strengths and differences, while acknowledging that some are significantly impacted and benefit from the structure and guidance offered by the medical model.

3.2.2 Historical development of key theoretical concepts

Autism was first understood by Leo Kanner (1943) and Hans Asperger (1944) as a group of behaviours and ‘deficits’ seen in some of the children they worked with. The current diagnostic criteria still closely reflects these original descriptions (Boucher, 2009).

Wing and Gould (1979) observed the variability of autism and developed the 'triad of impairments' model, identifying three main areas of 'deficit': social interaction, social communication, and flexibility of thought and behaviour. They described autism as a 'spectrum' where individuals might be mildly or severely affected.

Until recently, autism was primarily seen as a male condition, with about four males diagnosed for every one female (Boucher, 2009). However, research has recognised different presentations of autism, particularly in women and girls (Cruz et al., 2024; Gould, 2017). This differential presentation is harder to identify, resulting in them being undiagnosed, misdiagnosed, or diagnosed much later (Eaton, 2023; Gould, 2017). This is discussed in detail in the literature review section below. It is suggested that, as a result of the difficulties in diagnosing women and girls, many more may have unidentified autism, potentially bringing the ratio closer to 2:1 males to females, or equal (Gould, 2017).

3.2.3 Conceptual models relevant to EBSNA

As previously outlined in the introduction, the terminology used to describe the pattern of school non-attendance, characterised by the child's inability to attend school due to emotional factors, varies, and many terms are found in the literature and frameworks. In line with the sections on autism, whilst the preferred term used by the current researcher and throughout this study is 'EBSNA', to reflect the models and landscape at the time they were created, some of the terminology used within the models is also employed. This section will briefly outline some key models and frameworks.

Functional Model and Continuum of school refusal behaviour. Kearney and Silverman (1993) examined 'school refusal behaviour' in America with the aim of developing a theory that could guide both assessment and intervention. Their study included 42 CYP (26 boys and 16 girls) with an average age of 10–11 years, all of whom were referred because school refusal behaviour was identified as their primary difficulty. Information about additional needs or neurodiversity was not included. Four children were described as African-American and the remainder as Caucasian. Data was collected using the School Refusal Assessment Scale (SRAS), which was previously developed by the primary author to identify maintaining factors for school refusal behaviour, alongside parent interviews and rating scales. These measures were used to determine the frequency with which four pre-identified functional maintaining factors were present for each child. Based on their findings, they identified four primary functions maintaining school refusal behaviour outlined in Table 3.

Table 3

Functions Of School Non-Attendance

Function	Experience
Avoidance	Of school experiences causing distress (busy environments, exams, toilets)
Escape	From stressful social situations (group work, friendship issues, public speaking)
Maintaining parental attention	Reducing separation anxiety
Home-based reinforcement	For example, TV, games, safe environment

While the essence of the functions might be accurate, the current researcher has some criticism of this model being quite behaviourist based, potentially reinforcing the notion of EBSNA as a choice. It is possible that the 'functions' may be more complex than this. For example, the current research has added 'safe environment' to the home-based reinforcement category as she feels that this is more likely to be the motivator for the majority of 'clear' EBSNA cases, rather than being able to watch TV.

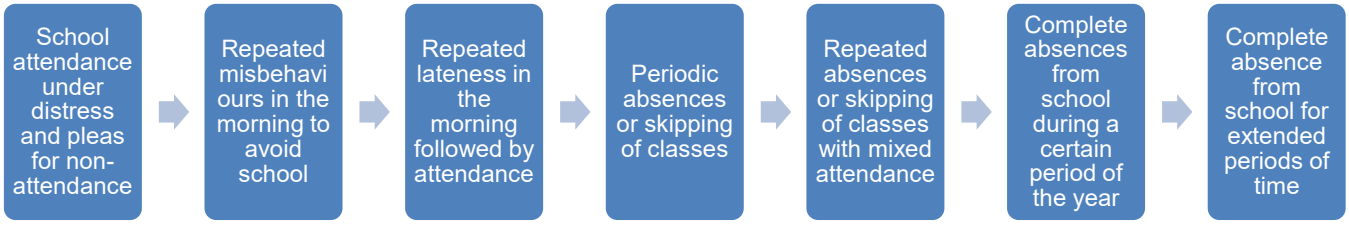
Kearney (2008) highlighted that EBSNA exists on a continuum, from initial school attendance with significant distress at home, to complete school avoidance as shown in Figure 2.

This model is helpful in highlighting that difficulties could be present long before the non-attendance starts, however, in the current researcher's experience, interventions are only put in place at the later stages of this model. While both of these models are helpful, they continue to suggest a focus on the difficulty being a 'with-in' child one

without reference to the causes and external factors which may be involved, as highlighted by Corcoran and Kelly (2023).

Figure 2

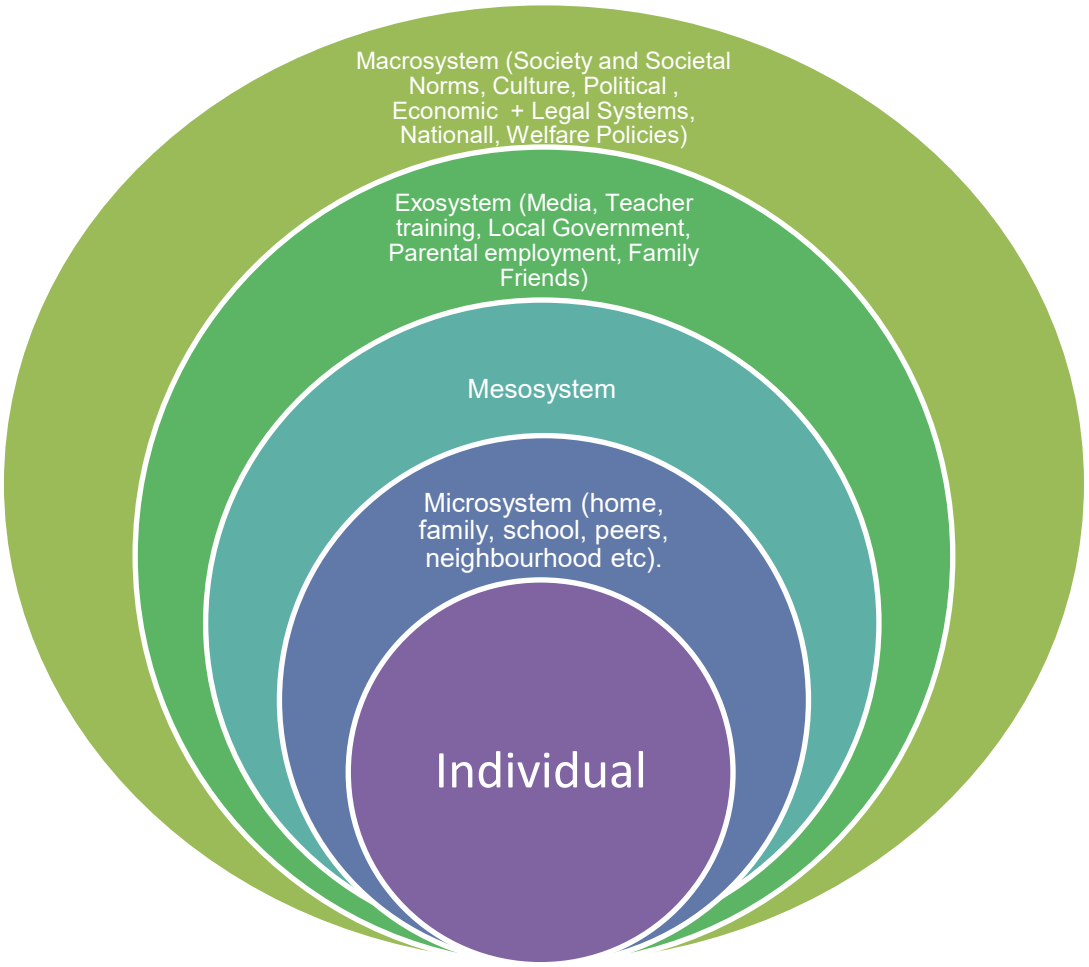
Adapted Continuum Of School Refusal Behaviour From Prosser & Birchwood (2024) P. 32.



Ecological systems theory. Bronfenbrenner's ecological systems theory (1979) represented in Figure 3, provides a comprehensive framework for understanding EBSNA, which can be viewed through this model as a complex interplay between systems around the CYP and recognises individual, familial, environmental, socioeconomic, systemic, policy and societal influences (e.g. Bond et al., 2024; Gregory & Purcell, 2014; Melin et al., 2022; Smart et al., 2024; Thambirajah et al., 2008; Want & Gulliford, 2024). This model emphasises interactions between different systems and the individual, with the mesosystem representing crucial interactions between microsystems like home and school.

Figure 3

Ecological Systems Framework Adapted From Drew (2022)



However, this model has been criticised by some arguing it overlooks the interaction between the individual and their biological and cognitive differences with the systems, and encourages a view of them placed within these contexts (Tong & Shidong An, 2024). This led to the refinement to the bioecological model which does consider this in more detail, however this is not often referred to in the literature (Tong & Shidong An, 2024).

In summary, this section has introduced some of the dominant models and frameworks relevant to autism and EBSNA. While these are commonly referred to in research to conceptualise autism and EBSNA, the intention of this research is to offer a critique of these models in relation to this participant group which will be considered in the Discussion Chapter. The next section details the literature process and findings relevant to the current study.

3.3 Introduction to the Literature Review

The literature review is guided by two core questions to support the identification of literature on the educational experiences of autistic adolescent girls, particularly in relation to camouflaging, mental health needs and EBSNA. As such, the questions are:

- What does the literature tell us about the mainstream school experiences of autistic adolescent girls, the role of camouflaging and EBSNA?
- What does the literature tell us is important for supporting autistic adolescent girls experiencing EBSNA to feel included in school?

The current study focuses on the views of autistic young women aged 16-25 who had unidentified autism and experienced EBSNA during secondary school. By examining literature on the diagnostic process and mainstream school experiences of diagnosed adolescent girls, this review aims to identify the barriers and support mechanisms potentially relevant to the participants in the current study. This will inform the exploration of whether such supports were offered, implemented, or might have been beneficial. The themes emerging from the literature affirm the relevance of the review questions and search strategy and are discussed in detail below.

3.4 Review Methodology

3.4.1 Literature Search Strategy

The literature search was conducted on 15 March 2025, using the EBSCO search platform. Through this platform, multiple databases (including APA PsychInfo, CINAHL, APA PsychArticles, Complementary Index, Education Source, and Psychology and Behavioural Sciences Collection) were searched simultaneously, and duplicates were removed from the results automatically. Most of the articles found through this search and included in this review came from either the Complementary Index or the Psychology and Behavioural Sciences Collection.

Additional databases were searched individually (ERIC and SCOPUS) using the same search terms in different combinations to identify additional papers. ERIC returned no matches, while SCOPUS returned four matches. Two of these were already included in the review, one had been excluded, and the other was a book with a different topic focus.

Ancestral searching was used to identify papers referenced in the included articles by scanning the reference sections of the articles as they were read in full. Papers were excluded by date and title at this stage. The abstracts of those that fitted the date range and appeared appropriate from the title were then reviewed, and the additional criteria applied, with a further two papers included.

3.4.2 Search Terms, parameters and matches

First, two searches were conducted using the term outlined in Table 4. These were then combined using the AND Boolean operator, resulting in 1624 matches.

The search string can therefore be viewed as autism OR autism AND spectrum AND disorder AND emotionally-based AND school AND non-attendance OR emotionally-based AND school AND avoidance OR school AND refusal OR school AND avoidance OR persistent AND school AND absence AND masking OR camouflaging AND girls OR women OR females.

Table 4

Search terms

	Search terms and Boolean Operators	**Truncation and wildcards**	**Number of matches**
Search 1	Autism OR Autism Spectrum Disorder AND girls	Autis*	137,875
Search 2	emotionally-based school non-attendance OR emotionally-based school avoidance OR school refusal OR school avoidance OR persistent school absence AND masking OR camouflaging AND girls OR women OR females		21,109

The following parameters were set to narrow the matches down from 1624 further:

- 2020-2025 to reduce matches to the start of the Covid-19 Pandemic which caused a significant disruption to education and led to a significant increase in CYP experiencing EBSNA (Bond et al, 2024; Hamilton, 2024). This reduced matches to 784.
- Articles published in English language reduced matches to 709
- 'Academic journals only' were included to increase the rigour and research base of the literature, reducing the returned matches further to 567. Please see PRISMA diagram below.

Table 5 below shows the inclusion and exclusion criteria which were then applied to these matches and Figure 4 shows the process in a PRISMA diagram.

Table 5

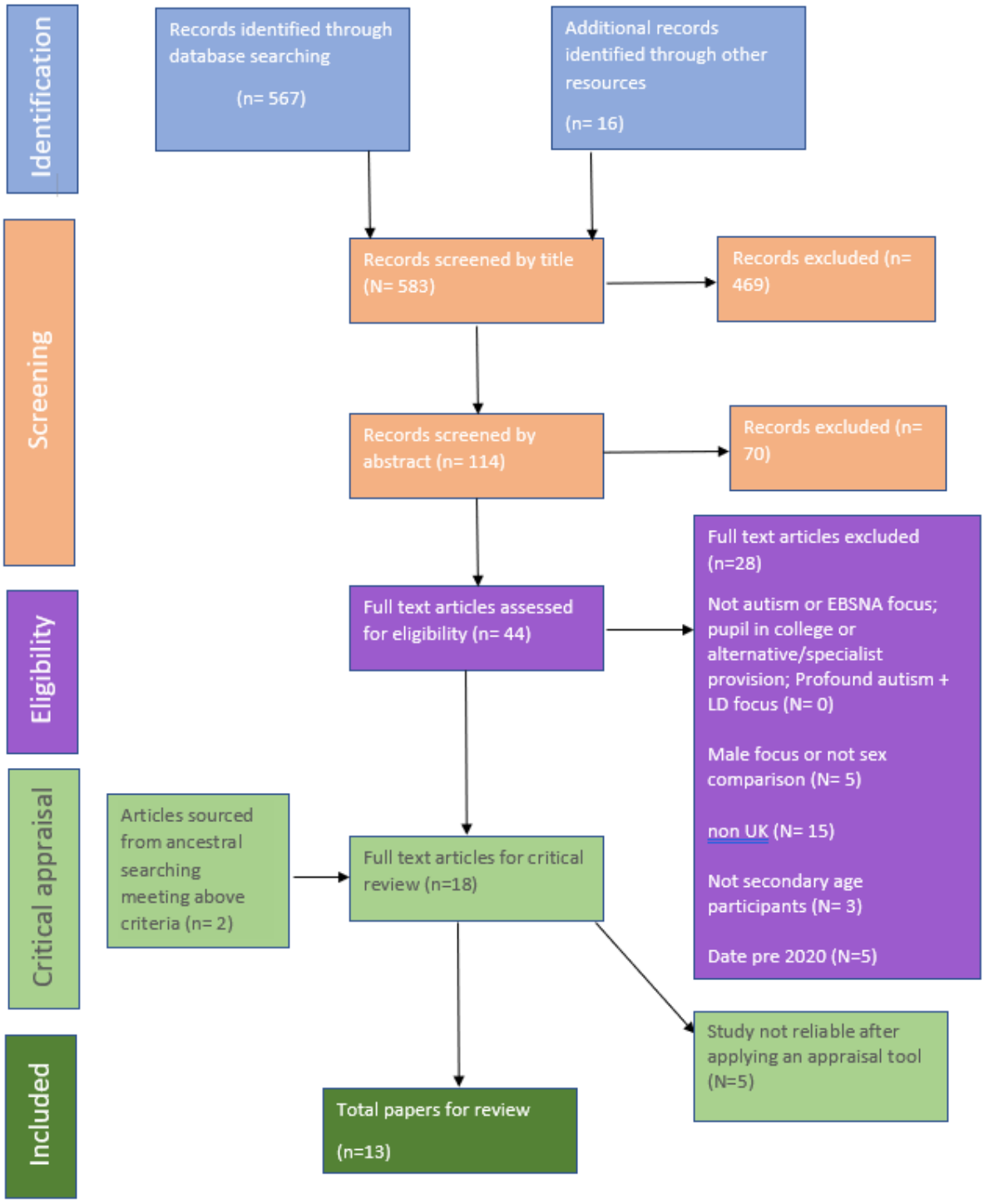
Literature Inclusion and Exclusion Criteria

No.	Inclusion criteria	Exclusion criteria	Rationale
1	Focus is on autism or EBSNA in girls, or includes both sexes, with a comparison between the sexes	Not autism or EBSNA related Male focus, or no comparison between sexes.	The literature review question seeks to understand the school experiences of girls with autism who experience EBSNA.
2	UK-based study.	Originates from a non-UK country.	To ensure contextual consistency, only UK-based studies were included due to international variation in education, diagnosis, and autism awareness.
3	Participants included girls attending mainstream secondary school, ages 11-18.	Only participants are those attending primary school (4-11), college (16-25), an alternative or specialist	This research focuses on the experiences of adolescent girls in mainstream secondary school, so the literature must include participants of a similar age.

No.	Inclusion criteria	Exclusion criteria	Rationale
		provision (0-25), or are adults (18+).	
4	Participants are reported as 'cognitively able' (i.e. They do not have additional learning disability) or there is a mixed ability within the participant cohort.	All participants in the study are reported to have an additional learning disability.	To reflect the learning needs of the participants in the current study.
5	The study is assessed to be good quality following a critical review using relevant tools such as CASP and MMAT.	Studies with reduced reliability and robustness as identified through the relevant tool.	To ensure the reliability of the literature that is being drawn upon.

Figure 4

PRISMA Diagram



583 papers were screened by title and key words, through which 469 were excluded if it was clear from this that the article was not relevant to the study; such as that it did not include secondary age girls with autism or experiencing EBSNA. For example, match 43 was *'what is know about adolescent dysmenorrhea in (and for) community settings'* which was discounted, as was '*The social withdrawal and social anxiety feedback loop and the role of peer victimization and acceptance in the pathways'* due to neither referring to autism or EBSNA (criteria one).

The abstracts of 44 articles were then reviewed to apply inclusion and exclusion criteria two to four, considering where the study was conducted and the participants included in the study, which led to a further 28 articles being excluded. At this stage, the references of the included studies were searched, applying the above methodology which led to a further two studies being identified for inclusion.

The section below outlines the critical appraisal steps for the remaining articles.

3.4.3 Quality assessment of included studies

After applying the initial inclusion and exclusion criteria, 18 studies were critically reviewed to apply criteria five between April and June 2025, using a relevant critical appraisal tool for each study type, as outlined in Table 6.

Table 6

Critical Appraisal Tools Used

Methodological approach of study	Tool used
Qualitative Research	Critical Appraisal Skills Programme (CASP) checklist for Qualitative Research (CASP, 2024a)
Quantitative research	CASP checklist for Descriptive/Cross-Sectional Studies (CASP, 2024b)
Systematic literature review	CASP checklist for Systematic Literature Review (CASP, 2024c)
Mixed methods	Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018)
Narrative reviews	Scale for the Assessment of Narrative Review Articles – SANRA (Baethge et al., 2019)

Description of Appraisal Tools. The CASP checklist for Qualitative Research comprises ten questions, each with guidance on what to consider. Responses are recorded as *yes*, *no*, or *can't tell*. Items were rated *yes* when the relevant information was clearly presented in the article; *can't tell* when the issue was mentioned but insufficiently detailed; and *no* when there was no reference to the criterion.

In O'Hagan et al. (2024), the relationship between researchers and participants was not described, resulting in a *no* for this item. Although detail about ethical issues was not included, it is reasonable to assume that ethical standards were met because approval from an ethics board was granted. Because all remaining CASP items were rated *yes*, the study was included in the review.

The CASP Checklist for Descriptive/Cross-Sectional Studies (quantitative research) includes 11 questions that parallel the qualitative checklist but focus on issues relevant to quantitative design. These include whether measures were accurately administered to minimise bias, whether data collection procedures addressed the research question, and whether the sample size was sufficient to reduce the role of chance. As with the qualitative CASP, guidance is provided for each item and responses are recorded as *yes*, *no*, or *can't tell*.

Wood-Downie et al.'s (2021) study was appraised using this tool, and the information reported allowed all items to be rated *yes*. One area required consideration: the extent to which the measures reduced bias. The study relied on parent-completed self-report tools, which can introduce bias; however, the primary measure, the Social Communication Disorders Checklist (SCDC), is a standardised and widely used instrument, mitigating some of these concerns, and so a 'yes' response was given for this question.

The MMAT includes seven questions for mixed-methods studies, with full appraisal recommended only when the first two items, clarity of research questions and alignment between questions and data, are answered *yes*. The remaining questions assess the rationale for using a mixed-methods design and the extent to

which qualitative and quantitative components are effectively integrated to address the research question.

Gray et al.'s (2021) study provided sufficient information to answer *yes* to all but one item. The paper did not explicitly justify its use of a mixed-methods design; however, the approach appeared appropriate and successfully addressed the research questions. On this basis, the study was included in the review. The CASP checklist for Systematic Reviews contains ten questions, with criteria and response options aligned with the other CASP tools. Two items require qualitative responses (e.g., outlining the overall results of the review), while others focus on issues specific to systematic review methodology, such as whether the authors selected appropriate types of studies, whether the included papers were adequately appraised for quality, and whether all relevant studies were captured.

Ayirebi and Thomas' (2024) paper was assessed using this checklist, and the paper addressed all but one item. The question *"Do you think all the important, relevant studies were included?"* was rated *can't tell*, as this cannot be confirmed without replicating the search. However, the authors provided sufficient detail for the search to be conducted if required, so this was considered more appropriate than *no*. With all other criteria met, the study was included in the review.

The SANRA is a measure of narrative reviews designed for medical papers. A tool for social science research assessing the quality of narrative reviews was not found, and so the current author amended this to make it more relevant to social research. The SANRA tool includes six questions, each scored from 0 to 2. Although the wording varies slightly across items, the scoring generally reflects whether

information is absent (0), briefly mentioned (1), or explicitly and sufficiently detailed (2).

Hull et al.'s (2020) narrative review was appraised using SANRA, with four items receiving a score of 2. A score of 1 was given for the statement of concrete aims, which were present but not clearly formulated. The search strategy was not described and therefore received a score of 0. However, during the appraisal process it became clear that many narrative reviews do not provide detailed search strategies. Given this, and considering the broader criteria for assessing qualitative review quality outlined by Gough (2007) in Section 3.5.1, the study was still judged to be of sufficient quality for inclusion.

Please see Appendix 2 for completed examples of each tool, and the original version on the SANRA with amendments made and the rationale for these.

The quality of the article was deemed sufficient if over two-thirds of the key questions could be answered 'yes' (or 2 in the case of the SANRA), and the information was clearly available in the article. Articles which had more than two '0' or '1'; 'no' or 'could not tell' were excluded. See Appendix 3 for the mapping table of literature excluded at this stage, including the justification for this in relation to the appraisal tools above.

Using the appraisal tools outlined above provided a systematic way of evaluating the core quality markers relevant to each study type. Different tools were applied to different designs because each method requires distinct indicators of rigour; for example, applying a quantitative checklist to a qualitative study or a systematic review would risk excluding high-quality papers on inappropriate grounds.

Selecting the correct tool for each study ensured that appraisal was both relevant and methodologically coherent. For example, Elliott et al. (1999) reported that qualitative research is often assessed with quantitative standards in mind, and that assessing qualitative research on more appropriate guidelines can improve the validity of the reviews. The tools were also straightforward to use, offered clear guidance on what to look for, and supported critical reflection on study quality. For instance, one study (Sturrock et al, 2021) was excluded because it did not describe its search strategy and all included papers were authored by the same researcher, suggesting selective use of literature.

However, these tools can oversimplify what is inherently a complex evaluative process and still rely on subjective judgement, particularly when determining what constitutes “sufficient information.” In addition, published articles are constrained by word limits, meaning omissions may reflect space restrictions rather than methodological weakness. As a result, some robust studies may appear to lack detail and risk exclusion based solely on reporting rather than actual practice.

Each of the tools contained a different number of questions and only one of the tools (SANRA) used a numbering system to score the items. As such, it would not be robust or appropriate to assign an overall score to each paper because this will give an inaccurate view as to the relative strength of the paper. However, Appendix 4 shows a table of each included study, the responses to each question in the relevant tool, and the number of ‘yes’ answers achieved. The literature used within the review were all of high quality, and all received only one or two ‘no’ or ‘can’t tell’ responses. This means that there is little difference in their quality, as

highlighted through the tools used. As such, the literature review is not weighted towards particular studies over others.

Nonetheless, the tools facilitated deeper reflection on each study and, when used alongside the additional quality markers outlined below, were valuable in determining whether studies were suitable for inclusion. Data Extraction and Synthesis

The above led to the inclusion of 13 papers, from which initial themes were generated from the findings using a thematic synthesis approach (Gough, 2007; Thomas & Harden, 2008). These were categorised into higher-order themes. For example, gender: incidence, presentation, assessment and diagnosis included initial themes of male bias, female presentation and diagnostic tools. The first article reviewed was the one considered the most relevant to this study (Tomlinson et al., 2022) due to the title, participant group and methodology.

The steps taken are outlined in Figure 5, and broadly follow the steps outlined by Thomas and Harden (2008). Writing Helper software was used to categorise and synthesise the information from the papers into these themes (see Appendix 5). Each article was loaded onto the software and lines or segments of text were highlighted and assigned codes by the researcher where there were conceptual similarities. This colour coded the text, as shown in figure 6 below.

Figure 5

Thematic Synthesis Process

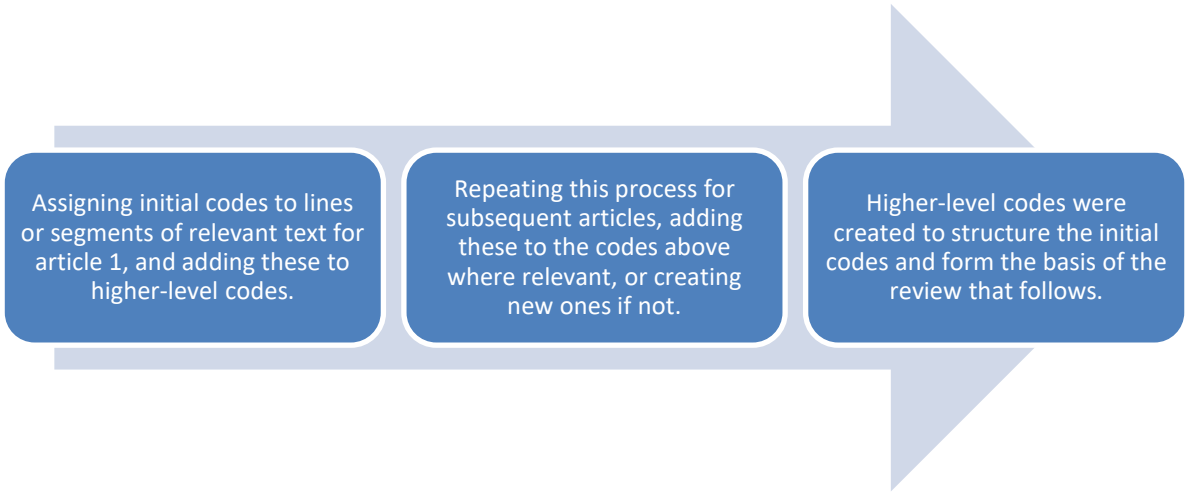
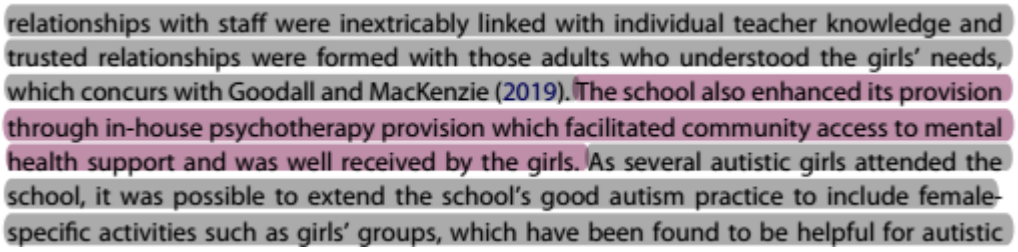


Figure 6

Line by Line/Segment Coding Example from Writing Helper


relationships with staff were inextricably linked with individual teacher knowledge and trusted relationships were formed with those adults who understood the girls' needs, which concurs with Goodall and MacKenzie (2019). The school also enhanced its provision through in-house psychotherapy provision which facilitated community access to mental health support and was well received by the girls. As several autistic girls attended the school, it was possible to extend the school's good autism practice to include female-specific activities such as girls' groups, which have been found to be helpful for autistic

Text above from Tomlinson et al. (2022) In the above example, the grey highlight corresponds to the studies implications, and the purple to the study findings.

Some examples of the themes created by the researcher are shown in figure 7 below.

Figure 7

Examples of Initial Themes from Literature



In the above examples, the green highlight corresponds to supportive factors for autistic girls.

Higher level themes were identified from these, by the researcher, which were then organised to make the synthesis more robust. For example, teacher/adult relationships, peer relationships, and sense of belonging were identified in the literature as being supportive factors for autistic girls, and so this became the higher level theme. On occasion, the higher level themes were identified first such as mental health, and then broken down into subthemes, or if a possible theme was not immediately evident, it was initially given a neutral colour to consider and code at a later point, when more themes had been identified. They were then reassigned a new colour representing the new theme. Examples of higher order themes and their initial themes are shown in figure 8.

Figure 8

Examples of Higher and Initial Themes

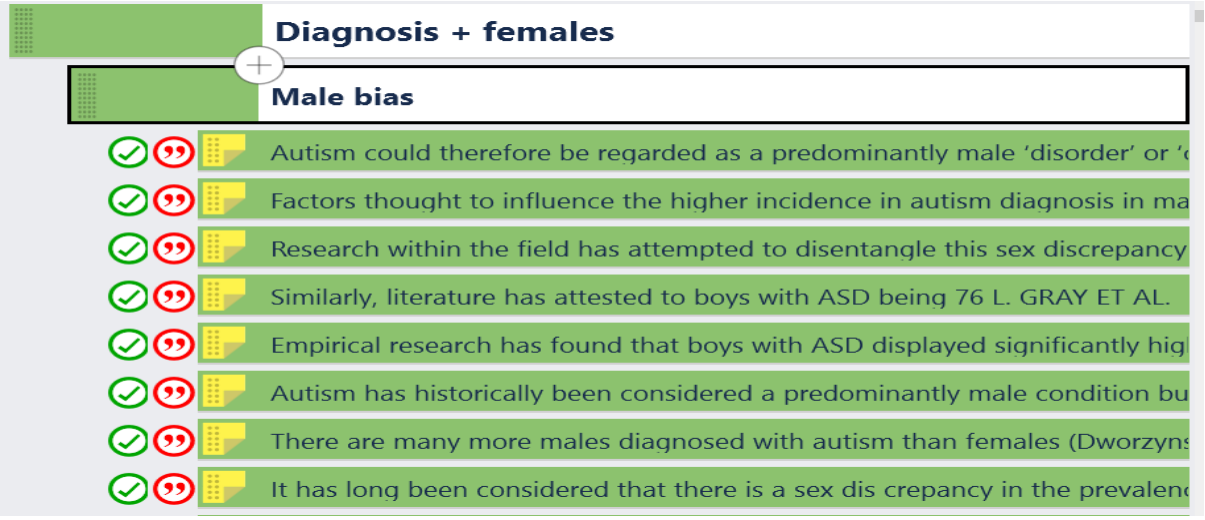


In the above example, mental health in autistic girls and EBSNA are the higher level themes, with those below them in the same colour being their subthemes.

The lines/segments of text from the articles that had been coded were then available under each heading (see figure 9), with these being marked as quotes to indicate direct text from the articles.

Figure 9

Themes and Related Text



When the literature review section was written, it was then clear to see the literature relevant for that theme and aided the synthesis of the information.

3.4.4 Limitations of the search strategy

The EBSCO Discovery platform was used, which, whilst having strengths and benefits, may have led to additional matches being missed that could have been found if the individual databases had been searched separately. To mitigate this limitation, the author repeated the searches with two primary databases, which did not yield any additional results.

Setting the date parameter to 2020 was justified and reduced the matches to a more manageable number; however, given the time required to publish a research article, it is likely that the data was gathered before the pandemic. It also meant that relevant research may have been excluded.

Grey literature was not included (such as theses), which could also have limited the inclusion of emerging information; however, this decision was made due to the high volume of initial matches.

Finally, only one researcher conducted the literature review. This is typical in doctoral research, where a single researcher works within an 18-month timeframe alongside university requirements and placement commitments. However, this inevitably limited the time available for appraisal and may have influenced the breadth of literature included, the application of the appraisal tools, and judgements about what constituted an adequate response to each criterion. Even so, the use of

structured tools and software helped to systematise the process and provided additional support in maintaining consistency.

3.5 Review of Literature

This section reviews the literature contained within the 13 papers, beginning with a methodological critique of the literature, including its relevance to the current study. The review of the literature is then presented thematically, based on the review questions, and includes subthemes that synthesise the information from the relevant studies and their key findings. The themes for question one are presented in a logical order but are also interrelated and may overlap. Any contradictions within the literature will also be highlighted. The main themes identified in the research findings are highlighted in Table 7and the included studies and a summary of their main findings are presented in table 8 below.

Table 7

Summary Of Literature Review Themes Related To Literature Review Questions

Review question	Main findings themes
What does the literature tell us about the mainstream school experiences of autistic adolescent girls, the role of camouflaging and EBSNA?	Gender: incidence, presentation, assessment and diagnosis Camouflaging Internalisation: Anxiety and reduced mental health EBSNA and autism
What does the literature tell us is important for supporting autistic adolescent girls experiencing EBSNA to feel included in school?	Eliciting student voice Fostering Positive Relationships Embedded autism friendly approaches Flexible and personalised support Supporting mental health Sense of belonging Challenges

Table 8

Summary Literature Findings

Paper	Main Findings
Anderson et al (2020) When the Mask Comes Off: Mothers' Experiences of Parenting a Daughter with Autism	Highlights the gender bias in autism and that the challenges faced by mothers of autistic girls are related to this in terms of the lack of understanding around how autism presents in girls, camouflaging, and the dominance of male-based theories in the literature.
Tomlinson et al (2022) The Mainstream School Experiences of Adolescent Autistic Girls	Findings highlight challenges for the participants in mainstream settings across environmental, social and personal aspect, but identifies the importance of supportive relationships and personalised planning for maintaining successful placements. Other key factors including the wider school environment and inclusive ethos and the provision of in house therapeutic support.
Gaffney (2025) "It's Autism, It's Just a Name": Adolescent Girls' Experiences of Receiving an Autism Diagnosis	Autism diagnosis was associated with 'problematic behaviour', difference and stigma, with participants being

Paper	Main Findings
	considered positively or negatively by participants. A diagnosis was found to enable making sense of past experiences. No common understanding of autism amongst participants, other than difficulties with friendships and social communication.
O'Hagan et al (2024) Autistic girls and emotionally based school avoidance: supportive factors for successful re-engagement in mainstream high school	Study found that trusting relationships between the child and a key adult were the foundation for their reintegration into school, supporting other research outlining the importance of positive student-teacher relationships. Ongoing support for social skills and friendships was also identified as important.
Halsall et al (2021) "Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators	Findings showed that within both mainstream and resource base classes, camouflage strategies were used by the participants to hide their learning challenges and their autistic differences. However, they found that these attempts were often inconsistent and ineffective. Consequences of

Paper	Main Findings
	camouflaging included isolation and a lack of belonging.
Totsika et al. (2020) Types and Correlates of School Non-Attendance in Students with Autism	Findings suggest that school non-attendance is common among sutistic students, with 43% showing persistent levels of non-attendance. Factors elevating the likelihood include older students in mainstream schools, CYP from single parent households, or those whose parent(s) is unemployed. 'School refusal' was the most common reported reason for absence.
Wood-Downie et al (2021) Sex/Gender Differences in Camouflaging in Children and Adolescents with Autism	Findings suggest that camouflaging is a key component of the female autism phenotype, with it being more prevalent in autistic girls compared to autistic boys.
McKinney et al (2024) 'Camouflaging in Neurodivergent and Neurotypical Girls at the transition to adolescence and its relationship to mental health: A participatory methods research study'	There was no difference identified between the neurodivergent and their neurotypical matched peers in two of the three camouflaging components (masking and compensation). However, the neurodivergent group showed

Paper	Main Findings
	higher levels of the assimilation component which relates to pretending or 'acting' to try and fit in. There was a strong relationship found between camouflaging and poor mental health present in the adolescent participant group.
Gray et al. (2021) Towards a Better Understanding of Girls on the Autism Spectrum	Findings showed that SENCos understood the male autistic presentation, but were less confident in identifying and supporting autism in girls. It identified a significant gap between the needs of autistic girls and the understanding and availability of support within mainstream educational setting.
Ayirebi & Thomas (2022) What Could Be Considered as Effective Support for Autistic Females in high school?	Themes identified relating to support found to be effective included: mental health; identification of specific needs and post-diagnostic support; friendship interventions and skills development; tiered support; relationships between home and school; transitions between

Paper	Main Findings
	levels of education; self, peer and staff advocacy, and sense of belonging.
Cook et al (2021)- Camouflaging in Autism: A Systematic Review	1. Adults who reported greater autistic traits, also reported greater efforts to camouflage 2. Most studies showed that autistic girls and women demonstrate higher levels of camouflaging than autistic boys and men across all ages, which could partly explain higher rates of missed or late diagnosis. A small number of studies showed no difference. 3. Adults who reported higher levels of camouflaging experiences increased symptoms of mental health needs, but that this may be more related to their belief that they need to camouflage, rather than their ability to do so.
Hamilton (2024) Emotionally Based School Avoidance in the Aftermath of	Findings from the review suggest that for a significant minority of pupils, particularly those who are

Paper	Main Findings
the Pandemic: Neurodiversity, Agency and Belonging in School	neurodivergent, school is experienced as a hostile environment, with absence an anxiety response to this. Multi-tiered systems of support to develop school belonging and agency for young people, with compassionate regard for their individual circumstances.
Hull et al (2020) The Female Autism Phenotype and Camouflaging: A Narrative Review	Review of the evidence shows some support for the existence of a female autistic phenotype, with camouflaging as a component. Though further research is required.

3.5.1 Methodological Critique of Literature

The literature reviewed was assessed systematically using the tools as outlined in the Review Methodology Section to make judgements on the quality and relevance of the papers (Gough, 2007). This critique evaluates the literature collectively under three headings: relevance of methods, quality of methods, and relevance to the current study, which is more typical for qualitative research (Gough, 2007). A mapping table, a methodological matrix and study summaries of the included literature are in Appendix 6, which outlines the findings from this process.

Relevance of methods to this study. Thirteen studies were included: qualitative (n=5), quantitative (n=3), mixed methods (n=1), systematic reviews (n=2), and narrative reviews (n=2).

The five qualitative studies reviewed used semi-structured interviews with autistic adolescent women and girls or their parents. Methodologies used included Interpretive Phenomenological Analysis (IPA) (n=2: Anderson et al., 2020; Gaffney, 2020), Reflective Thematic Analysis (RTA) (n=2: Halsall et al., 2021; O'Hagan et al., 2024), or a case study design (n=1: Tomlinson et al., 2022). These were included due to their methodological alignment with the current study (qualitative, semi-structured interviews and participant group) and their topical relevance.

The three quantitative studies varied in design: McKinney et al. (2024) compared 70 autistic women and girls with 49 neurotypical peers aged 11–14, closely matching the current study's age range; Wood-Downie et al. (2021) compared 40 autistic and 44 neurotypical males and women and girls aged 8–14; and Totsika et al. (2020) surveyed parents/carers of 486 autistic CYP aged 2–18 without sex-based comparison. Although differing in methodology and slightly in participant profiles, their group comparisons and thematic relevance warranted inclusion, and is discussed further below.

One mixed-methods study (Gray et al., 2021) combined quantitative data from 53 school Special Educational Needs Coordinators (SENCos) with a group semi-structured interview involving three parents of autistic girls aged 7–12. While it differs methodologically to the current study, its focus on lived experience and its relevance justified including it within this review.

Two systematic reviews (Ayirebi & Thomas, 2024; Cook et al., 2021) and two narrative reviews (Hamilton, 2024; Hull et al., 2020) were also included because of their relevance to the research topic.

Quality of methods used.

Qualitative. Several of the studies triangulated data sources or used reflexive diaries (Anderson et al., 2020; Halsall et al., 2021; O'Hagan et al., 2024; Tomlinson et al., 2022), with Tomlinson also employing member checking. Gaffney (2020) offered member checking, though participants declined. Common limitations include small sample sizes (3–8 CYP) and limited demographic detail, affecting transferability. Nonetheless, these studies provided rich experiential insights and followed the relevant methodological designs closely and so were considered methodologically robust.

Quantitative. The three quantitative studies featured larger samples (n=88–486), with two using comparison groups: McKinney et al. (2024) included neurotypical women and girls, and Wood-Downie et al. (2021) included both autistic and neurotypical males and females. Standardised measures were used in two studies (McKinney et al., 2024; Wood-Downie et al., 2021), and regression models were applied in two (McKinney et al., 2024; Totsika et al., 2020) to control for variables. Limitations of the studies included reliance on self-report and lack of qualitative context, but overall, these studies were informative and relevant to the current research.

Mixed Methods. Gray et al.'s (2021) study integrated quantitative data from 53 SENCos with qualitative details from three mothers of autistic girls. While the rationale for the mixed-methods approach was not clearly stated, the comparison

between these perspectives was valuable. The questionnaire, designed specifically for the study using National Autistic Society input, was not standardised but suited the research aims. The analysis was thorough, identifying contradictions and offering nuanced insights, however the sample for the qualitative data was very small (n=3) and all schools were from the same authority, limiting its transferability.

Systematic Literature Reviews. Cook et al. (2021) and Ayirebi & Thomas (2024) detailed their search and appraisal processes, and included 29 and 12 studies, respectively. Cook's review combined data from 2254 autistic adults (mean age 36.47) and 1077 CYP (mean age 11.9), totalling 3331 participants with diagnoses or high autistic traits. It aimed to gain a greater understanding of camouflaging, including sex and gender differences, age and its relationship with mental health, among others. Ayirebi & Thomas reviewed studies involving autistic women and girls aged 9–19 to identify effective support strategies. Together, the studies included an estimated 129 individual experiences. However, both reviews lacked demographic detail and inconsistently defined key concepts (e.g., camouflaging), which affected direct comparability. Nonetheless, their inclusion criteria were robust and the findings thematically relevant.

Narrative Reviews. The reviews by Hamilton (2024) and Hull et al. (2020) both lacked transparency in search strategy, lacking PRISMA diagrams and raising concerns about bias and study selection. Neither specified the number of papers reviewed. However, both scored highly on the SANRA scale (5/6) and so were considered comparatively robust for this type of review. They were also retained for their conceptual relevance, however, their limitations must be considered when interpreting their findings.

Summary. Overall, the studies were methodologically sound when assessed using relevant appraisal tools. Recurrent limitations included small sample sizes, reliance on self-report, and limited demographic data, which restrict applicability to minority groups. Notably, in studies involving parents (n=6), only one (Totsika et al., 2020) included fathers — and even then, just 2.7% of responses came from them.

Relevance of the research to the current study. All studies are highly relevant, addressing core concepts explored in this research and aligning to the literature review questions. They address autistic female presentation and gender differences (Gray et al., 2021; Hull et al., 2020), camouflaging and gender comparisons (Anderson et al., 2020; Cook et al., 2021; Halsall et al., 2021; Hull et al., 2020; McKinney et al., 2024; Wood-Downie et al., 2021), school experiences and supportive factors in mainstream settings (Ayirebi & Thomas, 2024; Tomlinson et al., 2022), diagnosis and identity (Gaffney, 2020), and EBSNA in the context of autism and neurodiversity (Hamilton, 2024; O'Hagan et al., 2024; Totsika et al., 2020).

Two studies sat slightly outside the inclusion criteria due to differences in participant groups but were retained for their conceptual relevance:

Totsika et al. (2020) gathered quantitative data from caregivers (n=486) on EBSNA characteristics and risk factors compared to the general population. While the sample included both sexes (69% male) without sex-based comparison, the findings offer valuable insight into prevalence and risk factors within an ecological systems framework. The lack of gender comparison limits direct applicability but does not diminish its relevance.

McKinney et al. (2024) compared camouflaging and mental health correlations across neurotypical (n=49) and neurodivergent (n=70) participants.

Although the neurodivergent group included women and girls with autism, ADHD, and/or DCD, differing slightly from the current study's focus, diagnostic overlap and thematic relevance justified inclusion.

3.5.2 Themes relating to Review Question 1

What does the literature tell us about the mainstream school experiences of autistic adolescent girls, the role of camouflaging and EBSNA?

Gender: incidence, presentation, assessment and diagnosis. This topic has received extensive research, and based on the literature reviewed, several subthemes have been identified and are crucial to include in this review to provide context regarding female presentation and the challenges in recognising the need.

Male bias. As outlined in the introduction chapter, the ratio of autistic males to females is shifting, however it is thought that the actual ratio is different to the official diagnosis rates, with the incidence being higher in women and girls than is currently diagnosed. This under-representation is thought to arise from several factors including; male-biased research samples (Gaffney, 2020), limitations in 'gold standard' diagnostic tools for identifying autism in women and girls (Anderson et al., 2020; Gray et al., 2021; Totsika et al., 2020), and the differing presentation of autism in girls, who often mask or internalise their difficulties (Gaffney, 2020; Tomlinson et al., 2022). As a result, autistic women and girls are more likely to be diagnosed later, misdiagnosed, or remain undiagnosed (Gray et al., 2021; Tomlinson et al., 2022). Furthermore, while autistic males may display externalised traits such as solitary play or challenging behaviour, girls often present with greater social competence on

the surface, hiding underlying difficulties (Gray et al., 2021), and tend to internalise their distress (Ayirebi & Thomas, 2024; Tomlinson et al., 2022).

Exploring the views of 53 SENCos in one Authority, Gray et al. (2021) found inconsistencies in their ability to recognise need, and support autistic girls. While some reported high confidence in identifying female presentations, their other responses contradicted this and they lacked confidence in applying gender-specific strategies, a pattern echoed by the parent focus group. These findings suggest a discrepancy in professional awareness and support the hypothesis of a misconception of autism as a male-dominated condition. However, the study's generalisability is limited by its localised context and small parent sample, although it is important to acknowledge that these patterns represent broad generalisations; traits described as 'more common' in girls (Hull et al., 2020) may also be present in boys. This presentation is explored in the next sub-section.

Female presentation. These is growing evidence that autism presents differently in girls and women (e.g. Anderson et al., 2020; Gray et al., 2021). Using semi-structured interviews with mothers of ten autistic girls (aged 12–18), focusing on presentation and the diagnostic process, Anderson et al. (2020) identified themes including misdiagnosis and scepticism from others regarding the validity of their daughters' diagnoses, reinforcing the view that female presentations are less readily recognised. However, a small sample size and reliance solely on mothers' perspectives, without triangulation from the girls or school staff does pose limitations and, while very important and valid, limit transferability which should be considered when interpreting findings.

Differences relating to female presentation were identified across the studies, including greater social motivation and more friendships (Anderson et al., 2020;

Ayirebi & Thomas, 2024; Gaffney, 2020; Gray et al., 2021; Tomlinson et al., 2022), subtler restricted interests aligned with neurotypical peers (Anderson et al., 2020; Gaffney, 2020), and stronger language and imagination skills (Gaffney, 2020). These traits can mask underlying difficulties, leading to apparent social competence despite significant anxiety and distress (Ayirebi & Thomas, 2024; Halsall et al., 2021; McKinney et al., 2024). Girls are also considered more likely to experience mental health difficulties (Cook et al., 2021), which will be considered later in this section.

These patterns often lead to delayed recognition and referral, with many girls only being assessed once their needs become more severe (Hull et al., 2020; O'Hagan et al., 2024). While Hull et al.'s (2020) study offered some support for a specific female autism phenotype (FAP) they note that further research is needed. In addition, their findings should be interpreted cautiously due to the limited transparency in their literature search.

Diagnostic tools. As indicated above, there is growing evidence that the autism assessment tools recommended by NICE are less effective at identifying the subtler behavioural presentation often seen in women and girls (Gray et al., 2021; Hull et al., 2020). These tools were developed using predominantly male samples and prioritise traits that may not apply to girls (Anderson et al., 2020; Tomlinson et al., 2022). Anderson et al. (2020) argue this perpetuates a cycle of underdiagnosis: males are more likely to be diagnosed, leading to male-centric research and criteria that further exclude women and girls.

As a result, even when referrals occur, the combination of unsuitable tools and limited clinician awareness (Gray et al., 2021; Halsall et al., 2021) means that many could be remaining undiagnosed and unsupported, contributing to a cycle of unmet needs and misunderstanding.

Impact. Two key issues emerge: unrecognised differences and lack of diagnosis. Although diagnosis should not be a prerequisite for support, in practice it often is. Ayirebi and Thomas's (2024) review found that autistic girls whose needs go unnoticed receive less intervention and support, which increases their risk of mental health difficulties. The studies they included used inconsistent definitions of key concepts and included limited demographic data, which affects comparability across studies, and so these findings should be used cautiously.

However, their findings are supported by O'Hagan et al (2024), who found that autistic girls' needs were less likely to be identified compared to boys, impacting the availability of support. However, their sample was small (n=3), limiting transferability, though these findings also align with anecdotal accounts and the current researcher's experience.

Unmet needs have been shown to significantly affect autistic girls' educational experiences, emotional well-being, and mental health, with studies reporting exhaustion, anxiety, and emotional dysregulation at home (Ayirebi & Thomas, 2024; Gray et al., 2021; Tomlinson et al., 2022). Camouflaging, explored next, is thought to contribute to their needs going unnoticed.

Camouflaging.

Types. Camouflaging is described as the conscious or unconscious minimising of autistic traits to appear more neurotypical and 'fit in' socially (Cook et al., 2021; Gray et al., 2021; Hull et al., 2020; McKinney et al., 2024). Identified as a key feature of female autistic presentation (Hull et al., 2020; Wood-Downie et al., 2021), and most used in school and social settings (Anderson et al., 2020; Halsall et al., 2021). It is typically categorised into three components, as outlined in Table 9.

Table 9

Types Of Camouflaging

Type	Description
Masking	Concealing autistic traits (Cook et al., 2021; Halsall et al., 2021)
Compensation	Using learned strategies to appear neurotypical (Halsall et al., 2021; Hull et al., 2020)
Assimilation	Imitating social norms without fully understanding them (Halsall et al., 2021).

Cook et al.'s (2021) systematic review (n > 3000) found that individuals with greater autistic traits reported more camouflaging, with women and girls showing higher levels than males. High camouflaging was also linked to increased mental health difficulties. While their search strategy was robust, limitations included inconsistent concept definitions and limited demographic data.

Incidence and gender differences. Several of the studies reported camouflaging behaviours (Anderson et al., 2020; Gaffney, 2020; Halsall et al., 2021; McKinney et al., 2024), with most finding it more prevalent in autistic women and girls (Cook et al., 2021; Wood-Downie et al., 2021). Although a few studies in Cook et al.'s review found no significant gender differences, the overall evidence supported higher camouflaging in women and girls.

McKinney et al. (2024) found that neurodivergent girls scored higher on assimilation than their neurotypical peers, suggesting a distinct form of camouflaging more likely to be used by autistic girls. It is worth noting here that their sample also included girls with ADHD and DCD, limiting direct applicability to the current study.

The absence of qualitative or demographic data also reduces nuance and transferability.

Using quantitative methods, Wood-Downie et al. (2021) found that autistic girls camouflaged more than autistic boys and neurotypical peers, which potentially further contributes to delayed recognition and support. Their inclusion of undiagnosed participants flagged by scores on the Social Communication Disorder Checklist (SCDC) adds strength but also introduces limitations, as these individuals had not undergone formal, robust assessments.

Impact of camouflaging. While some studies noted benefits to camouflaging, such as avoiding bullying or fitting in (Anderson et al., 2020; Halsall et al., 2021), the literature overwhelmingly highlights negative impacts. It is consistently associated with increased anxiety, depression, and emotional exhaustion, particularly among autistic women and girls (Cook et al., 2021; McKinney et al., 2024).

Cook et al.'s (2021) robust review of the evidence outlined above, highlighted that increased self-reports of camouflaging seem to be connected to higher mental health needs, mirroring findings in their adult sample. However, they note that this link was not observed when measured using discrepancy measurement approaches (comparing underlying cognitive differences and observable behaviour), suggesting that there may be a difference between a person's belief that they are camouflaging and their actual ability to do so.

A critical consequence of camouflaging is its impact on recognition and support. When autistic traits are hidden, others may not identify the individual's needs, which creates further barriers to appropriate intervention (Hull et al., 2020; Wood-Downie et al., 2021). Halsall et al. (2021) explored this through semi-

structured interviews with eight autistic girls (aged 12–15), their parents, and school staff. Using a simplified CAT-Q, they found camouflaging was used to hide academic and social difficulties, often ineffectively, with Mothers reporting increased camouflaging during adolescence, linked to rising social complexity. Crucially, camouflaging led to teacher unawareness, missed learning, and a cycle of unmet needs. While the study used a triadic informant design, limitations included a lack of demographic data and male or neurotypical comparison groups and limited consideration of camouflaging by participants during the interview, a common difficulty when researching camouflaging.

Though causality remains unclear (Cook et al., 2021), the literature suggests that camouflaging is a significant contributor to increased mental health needs, which is explored further below.

Internalisation: Anxiety and reduced mental health. Reduced mental health and wellbeing is consistently reported among autistic individuals, with autistic girls particularly vulnerable (Gaffney, 2020; Gray et al., 2021). Studies identify several mental health needs, including depression, anxiety, eating disorders, self-harm, suicidal ideation, exhaustion, isolation, loneliness, and identity struggles (Anderson et al., 2020; Tomlinson et al., 2022; Halsall et al., 2021; O'Hagan et al., 2024). However, as already highlighted, causality is difficult to determine, and it is unlikely that a single factor explains these difficulties; rather, they appear to result from a combination of daily challenges as outlined below.

Potential causes. Multiple factors which may contribute to distress in secondary school is highlighted in the literature including: navigating friendships during adolescence (Halsall et al., 2021; Tomlinson et al., 2022), transitions and unpredictability (O'Hagan et al., 2024; Ayirebi & Thomas, 2024), inconsistent staff

awareness and support (Gray et al., 2021), sensory sensitivities (Tomlinson et al., 2022), camouflaging (Halsall et al., 2021), academic demands and underachievement (Gaffney, 2020), social exclusion and distrust of teachers (O'Hagan et al., 2024), exam stress and perfectionism (O'Hagan et al., 2024), and social media pressures (Ayirebi & Thomas, 2024). Late diagnosis has also been linked to poorer mental health outcomes (Tomlinson et al., 2022; Wood-Downie et al., 2021), which is particularly relevant to the current study. Halsall et al. (2021) emphasise how academic pressures intensify camouflaging, creating a cycle of unmet needs, anxiety, and avoidance.

A further impact on mental health can, for some individuals, come from receiving a diagnosis. Studies report mixed emotional responses to diagnosis. Gaffney (2020), used semi-structured interviews with six autistic women and girls aged 14–20, finding reactions ranging from acceptance and comfort to rejection and ambivalence. Furthermore, Tomlinson et al. (2022) interviewed three autistic girls, their mothers, and a school psychotherapist with similar findings; one participant felt negatively, while two experienced improved self-understanding and mental wellbeing, and reduced masking. However, both findings are limited by the small sample and single-school context, again reducing transferability. Conversely, Halsall et al. (2021) found participants felt validated and proud of their diagnosis, suggesting reduced camouflaging. These mixed findings highlight that while a diagnosis may facilitate access to support, the emotional impact of receiving a diagnosis on the individual can be highly variable, with some feeling positively about it and others potentially experiencing more detrimental impacts on their mental health.

McKinney et al. (2024) found that camouflaging scores significantly predicted anxiety and depression in neurodivergent girls. These increased mental health needs may contribute to reduced school attendance among autistic girls (O'Hagan et al., 2024), which is explored further in the next section. Research at the intersection of autism and EBSNA remains limited, particularly for women and girls, reflecting broader issues of under-identification and exclusion from studies.

EBSNA and autism.

Incidence of EBSNA. As previously highlighted, understanding the true incidence of EBSNA is difficult due to inconsistent recording and categorisation across schools, as well as differing conceptualisations (Totsika et al., 2020). Official figures published by the DfE include all absence types, and so is only a rough indicator of the incidence. However, the below studies have explored its incidence more directly.

Incidence in autism. Studies show that EBSNA is significantly more common among autistic CYP than their neurotypical peers (Totsika et al., 2020; O'Hagan et al., 2024) and recent research further indicates that autistic girls find school progressively more challenging as they grow older, elevating their risk of EBSNA (O'Hagan et al., 2024).

Totsika et al. (2020) surveyed 486 parents of autistic children, exploring incidence and reasons for non-attendance over a month. They found that the risk of an autistic child not attending school increased with age, and 'school refusal' was the most frequently reported reason. Furthermore, persistent absence (over 10%) was observed in 43% of participants, compared to the national rate of 10.8% for the same

year. Based on these findings, Totsika et al. (2020) suggest that EBSNA is ‘common’ among autistic individuals and a matter of concern. While the large sample and use of existing measures strengthen the study, limitations include reliance on parental reports of autism and assumptions about EBSNA classification, which require cautious interpretation.

Risk factors for EBSNA in autism. Totsika et al. (2020) identified four factors associated with increased non-attendance among autistic CYP: attending a mainstream school, age, not living in a two-parent household, and parental unemployment. These factors reflect findings seen in broader populations; however, unlike the wider population, they did not find a link between EBSNA and lower parental education levels. The association between mainstream school attendance and non-attendance for autistic CYP is particularly relevant to this study, although there were some outliers to this finding, requiring further exploration.

A key limitation of Totsika et al.’s study is that sex-based differences were not analysed, despite 69% of participants being male and 31% female. This reduces applicability to the current study.

Hamilton (2024) highlights that autistic girls may be especially susceptible to EBSNA, emphasising the need for deeper investigation. In her narrative review, she examined links between mental health and school attendance post-Covid for autistic CYP in mainstream schools. She argues that bullying, rejection, and daily struggles in what they perceive as a *‘hostile environment’ (P.8)* contribute to situational anxiety and non-attendance. Further research has identified several support strategies for autistic girls, which will be explored below. The limitations of Hamilton’s review,

including lack of search strategy transparency, potential source bias, and exclusion of participant voice, are important to note and mean that these findings should be interpreted cautiously.

3.5.3 Themes relating to review question 2

What does the literature tell us is important for supporting autistic adolescent girls experiencing EBSNA to feel included in school?

Across the literature, several interrelated strategies were found to support autistic adolescent girls in navigating mainstream secondary school and improving attendance. The most consistently evidenced factors relevant to the current study are summarised below.

Eliciting Student voice. Student voice is repeatedly identified as crucial for understanding individual needs and planning effective personalised provision (Ayirebi & Thomas, 2024; Tomlinson et al., 2022), with student-teacher relationships improving when the adult actively asks and listens to their views (Gaffney, 2020). Autistic girls in O'Hagan et al.'s (2024) study described working collaboratively with adults to identify helpful support, which facilitated their reintegration into mainstream schooling. Student voice is also identified as being vital during transitions between settings (Ayirebi & Thomas, 2024).

Fostering positive relationships. Relational factors emerge as particularly crucial and interrelated with other factors considered in this section. O'Hagan et al. (2024) found that feelings of belonging and successful reintegration were strongly influenced by positive teacher relationships, and that they also enabled adults to

recognise camouflaging and respond with sensitive, tailored support. Across the literature, positive relationships with school staff are associated with better outcomes, particularly when adults listen, understand individual needs, and offer flexible, responsive provision (Ayirebi & Thomas, 2024; Halsall et al., 2021; Tomlinson et al., 2022). Supporting positive peer relationships is also important. Autistic girls are often socially motivated, and structured opportunities, such as clubs or girls' groups, can develop their skills in these areas and enhance their sense of belonging (Ayirebi & Thomas, 2024; O'Hagan et al., 2024).

Embedded autism friendly approaches. A whole-school inclusive ethos and consistent autism-friendly approaches were identified as being important to ensure that the needs of autistic women and girls are met (Ayirebi & Thomas, 2024; Halsall et al., 2021; Hamilton, 2024; O'Hagan et al., 2024; Tomlinson et al., 2022). In-line with the wider literature on autism, these included the use of visuals and modelling in lessons, slowing pace of lesson, communicating changes, access to quieter spaces and additional breaks, tailored interventions, managing triggers, use of visuals and other methods to support communication and individual timetables.

However, O'Hagan et al. (2024) emphasise that individualisation is critical. While their participants shared some experiences, their needs varied considerably and effective provision needed to remain flexible and personalised, as discussed in the following section.

Flexible and personalised support. Flexibility across curriculum, exam arrangements, interventions, and daily adaptations is consistently identified as a key factor supporting attendance (Ayirebi & Thomas, 2024; Halsall et al., 2021; Hamilton,

2024; O'Hagan et al., 2024; Tomlinson et al., 2022) and as highlighted above, gathering student voice enables more precise tailoring of support. Tomlinson et al. (2022) found that participants valued flexible provision and felt it helped them use their own initiative to manage anxiety.

Supporting mental health. Mental health support is highlighted as crucial in a number of studies (Ayirebi & Thomas, 2024; Hamilton, 2024; O'Hagan et al., 2024; Tomlinson et al., 2022). Some studies included participants who accessed in-school therapeutic support (e.g., Ayirebi & Thomas, 2024; Tomlinson et al., 2022), which was valued and linked to improved attendance. However, the current researcher wonders about the equity of access to such support both in terms of their availability in most mainstream secondary schools, and the high thresholds and long waits for input from Child and Adolescence Mental Health Services (CAMHS) (British Medical Association [BMA], 2026). Many of the strategies above may indirectly support wellbeing, but access to specialist mental health provision remains a systemic challenge.

Other helpful approaches include enhanced transition planning (Ayirebi & Thomas, 2024) and strong collaboration between home, school, and external agencies (Ayirebi & Thomas, 2024; O'Hagan et al., 2024). These are acknowledged but not explored in depth here due to their lesser relevance to the current study.

Sense of belonging. A sense of belonging is a key protective factor for CYP experiencing EBSNA; those who feel they belong less are more likely to withdraw (Halsall et al., 2021). Autistic CYP tend to report a lower belonging (Ayirebi & Thomas, 2024), which may help explain their increased vulnerability to EBSNA. The supportive factors outlined above are mutually reinforcing and collectively contribute

to fostering belonging (Ayirebi & Thomas, 2024). For example, eliciting student voice and providing a personalised and flexible provision can develop relationships with teachers and peers which can subsequently improve a young person's sense of belonging.

Challenges. However, large secondary environments pose challenges for the effectiveness, consistency and success of adaptations and strategies. Multiple staff and transitions can lead to inconsistency and gaps in understanding (O'Hagan et al., 2024; Tomlinson et al., 2022). Adolescent concerns about appearance and embarrassment may also prevent girls from using access strategies such as break cards (O'Hagan et al., 2024). Consequently, even when needs are identified, support must be highly individualised and so is not without challenges and barriers and could likely be linked to the increase in rates of EBSNA in secondary schools.

Unidentified Autistic Girls. When considering these supportive factors in relation to the relevance for the current study, it is crucial to consider girls whose needs remain unidentified. While there are supportive strategies and approaches that are shown to be effective for autistic adolescent girls, to be provided with these more consistently, their needs must first be identified. Therefore, it would seem appropriate to assume that if they are not identified, they will not receive and benefit from the above. Consequently, their sense of belonging, relationships with adults and peers, and their mental health could decline.

3.6 Response to review questions

This section has outlined the main findings of the literature review and answered the literature review questions.

The main findings related to *question one* identifies a continued male bias within the literature, participant samples, diagnosis and awareness, with their needs being more easily recognised, diagnosed and supported. Research shows that women and girls can present differently to the typical understanding of autism and their male counterparts, with them being more socially motivated, employing camouflaging strategies and showing more age appropriate restricted behaviours. This means that their needs are recognised later (if at all), and thus are less likely to receive support and adaptations. They tend to internalise their needs, causing significant anxiety and autistic women and girls are more likely to experience a range of mental health needs including anxiety, depression, eating disorders and suicidal ideation.

The literature identifies that autistic CYP are more likely to experience EBSNA than their neurotypical peers or those with other types of SEN, with it being 'common' for this group of CYP. Risk factors for EBSNA in autistic CYP was found to be similar to their NT peers, however, a link with parental educational level was not found, which is present in the wider EBSNA research.

Relating to *question two*, several supportive strategies have been identified as being successful to either maintain or re-establish attendance for autistic girls in mainstream school settings. Some of these include increasing positive relationships between student and teachers, eliciting, listening to and acting on student voice, personalised and flexible interventions and support, and support for mental health and well-being. However, these strategies being implemented for an individual, is typically dependent on their needs being identified in the first place, which does not appear to have been covered in depth in the research explored.

The next section considers this and other gaps in the existing literature.

3.6.1 Knowledge Gaps and Research Needs

Theoretical gaps. Despite growing literature on autistic girls and EBSNA, there remains a significant gap at their intersection, particularly from the perspectives of those most affected. This study addresses this by employing a GT approach to explore the experiences of adolescent autistic girls retrospectively, who experienced EBSNA prior to diagnosis. This offers a unique lens on how unidentified autism may relate to EBSNA.

Crucially, no studies have explored the school experiences of autistic girls before diagnosis, nor elicited their views on what might have helped reduce or prevent EBSNA, presenting a significant theoretical and methodological gap.

Relationship between existing theories and the current research. This study draws primarily on the social model and neurodiversity paradigms, questioning whether formal diagnosis is necessary for support and whether earlier recognition of autistic differences could have improved outcomes by adapting the neurotypical world for autistic CYP. The medical model also remains relevant, recognising the biological and neurodevelopmental bases of autism and the importance of diagnosis for some individuals. Systems theory further informs the study by considering the interaction between the young person, their family, school, and wider structures. The current researcher's view is that the link between unidentified autism and EBSNA is complex and individually variable, but that early recognition, whether through diagnosis or attuned adult observation, is essential for inclusion and emotional well-being.

Methodological gaps. This study responds to calls for research that centres the voices of autistic girls and young women (e.g. Gray et al., 2021; Hamilton, 2024; Prosser & Birchwood, 2024), by interviewing participants aged 16–25 who experienced EBSNA during secondary school and were later diagnosed as autistic. It explores how they were supported (or not), the impact of unrecognised needs, and what, with hindsight, they believe could have made a difference.

Methodologically, this study is distinct in its use of GT and its retrospective focus on the voices of autistic girls themselves, a group often excluded from research due to diagnostic gatekeeping. In doing so, it aims to generate new insights into the complex, often hidden, pathways into EBSNA and to inform more responsive, inclusive educational practices.

3.7 Chapter Summary

This review highlights that the needs of autistic women and girls are often missed due to differences in presentation, camouflaging behaviours, and diagnostic tools not aligning with these subtleties. As a result, they are less likely to receive support and face greater mental health challenges compared to autistic males or their neurotypical peers. Autistic girls also appear more vulnerable to EBSNA, which could be attributed to the increased mental health needs. This could suggest that some girls experiencing EBSNA may be autistic, whose unmet needs contribute to their school avoidance; however, this link does not yet appear to have been explored.

This study seeks to explore this gap, explaining how unidentified needs could have impacted school attendance and how earlier recognition and support could

have made a difference. It focuses on their retrospective accounts of what was done for them, what was missed and what could have helped.

While no single factor explains school non-attendance for all autistic CYP, early identification of cognitive differences remains crucial for improving outcomes. By adopting a retrospective GT approach, as outlined in the following chapter, this study aims to centre participant voice, exploring their school experiences prior to their diagnoses, and uncover potential mechanisms for change, thereby explaining the cycle of unrecognised needs, lack of support, increased mental health difficulties, and school non-attendance.

4. Methodology

4.1 Chapter Overview

This chapter outlines the methodological approaches used for this study. It will begin by outlining the purpose and research paradigm of the study, followed by the philosophical stance that influenced the research decisions. The GT method will then be explained, considering how it has evolved to the approach used in this study. The research design and context will be detailed, along with participant recruitment and selection, followed by data collection and analysis.

The way qualitative data is gathered, processed, and analysed will be explained, following an informed, constructivist grounded theory (CGT) approach, which is also discussed (Charmaz, 2014; Thornberg, 2012). Aspects of quality and ethics will be addressed, concluding with reflexive practices to acknowledge and consider potential biases in gathering and interpreting the data.

4.1.1 Research Aims and Questions

The study explores the experiences of autistic young women aged 16–25 whose needs were unidentified during adolescence and experienced EBSNA in secondary school. It examines how their unrecognised autistic needs, including sensory, social-communication, and learning differences, may have influenced their ability to attend school, and investigates the attendance barriers they encountered in relation to these unmet needs. The research also gathers participants' views on what forms of support might have helped them during school and potentially reduced the extent or impact of their EBSNA.

This research explores the following questions:

- What are the experiences of autistic adolescent girls prior to their autistic needs being recognised, and how could this contribute to school non-attendance?
- What are the barriers and supportive factors that influence school attendance for adolescent girls before their autism diagnosis?

Charmaz (2014) highlights a paradox in qualitative studies: often, what you want to discover is not clear until you analyse the data. While there is some awareness of potential themes, what participants consider important remains ambiguous. Although the purpose of this research is outlined above, in line with CGT, the data will be central to the analysis, and the codes and findings will be constructed from it by the researcher and so the actual outcome will be shaped by the data (Charmaz, 2014).

It is important to clarify the concept of need identification, which is central to the first research question. The study will consider ‘identification of need’ at two levels:

- Self, school, or parent identification of differences prior to diagnosis.
- Autism Diagnosis.

This is important because NHS services face high demand for autism assessments, resulting in long wait times (BMA, 2026). The CoP (DoH & DfE, 2014) bases its definition of SEN on needs impacting learning, rather than on the presence of diagnoses. As such, this should not be necessary to meet needs, but it does require that their needs have been identified, which is the focus here, and diagnosis being secondary to this.

4.2 Research Purpose and Paradigm

4.2.1 Research Purpose

This is an abductive study that seeks to provide explanations for the participants' experiences (Charmaz, 2014). Whilst the experiences of autistic CYP and EBSNA have started to be explored, experiences before needs are identified have not. As such, this study will explore this and seek to explain how unadapted mainstream environments and unidentified autistic needs could impact attendance and lead to EBSNA.

A further aim of this study is to promote change through exploring the perspectives of vulnerable members of school communities. It is hoped that this research will deepen our understanding of how autistic girls present, their increased risk of EBSNA, and the importance of early recognition and supporting their needs. In doing so, school staff will be better equipped to identify and support these CYP before they reach crisis.

4.2.2 Philosophical positioning

This section will be written in the first person to reflect my philosophical position and how this has influenced the methodological approaches used.

Ontological position. Ontology concerns the nature of reality, our world, and what we know to exist (Al-Ababneh, 2020; Fox et al., 2007). Various philosophical viewpoints can be adopted to understand this, ranging from realism to relativism. Positioned between these two perspectives is critical realism. A critical realist (CR)

maintains that objects and phenomena exist independently of human experience (Oliver, 2012) but can be experienced differently by individuals.

Epistemological position. Epistemology pertains to how we come to understand phenomena, or how that knowledge is created (Moon & Blackman, 2014), and the relationship between what we know and observe (Lincoln et al., 2024). How a researcher interprets this will greatly influence their approach to studying the phenomenon and the methods employed (Al-Ababneh, 2020; Moon & Blackman, 2014). Like ontology, multiple epistemological positions exist, ranging from objectivism to constructionism and subjectivism, with others falling in between these main positions (Moon & Blackman, 2014).

The CR perspective also exists for epistemology, and it has gained popularity as a framework for research within the social sciences (Fletcher, 2017). Fletcher explains that it has developed from the tensions between positivist and constructivist paradigms, combining aspects of both to bridge the gap and acknowledge a position between them. A key feature of CR is that it rejects the idea that our knowledge is flawless and argues that this ‘epistemic fallacy’, held by positivists, confuses reality with our knowledge of it (Oliver, 2012). Oliver outlines that CR can describe a social world in which there are multiple realities and mechanisms for change, acknowledging that the world is 'theory-laden' rather than 'theory-determined' (Oliver, 2012). Al-Ababneh (2020) summarised this as the belief that ‘what we see is not what we get’, and through CR, we can develop theories that are either closer to or farther from the truth (Oliver, 2012), rather than objective, infallible truths.

CR is a broad methodological framework, but Fletcher (2017) emphasises that it is not associated with any specific research methods and instead directs the use of various methods, such as mixed methods (Oliver, 2012). The methodological approach used in this study, and how it links to CR is explored in the next sections.

4.2.3 Influence on research decisions

This section reflects my research decisions and will therefore be written in the first person. My philosophical stance as outlined above, along with my theoretical approaches to understanding autism and EBSNA, has influenced every stage of this research. It has guided both the methodological choices and the interpretive lens. I start from the premise that autism and EBSNA are real phenomena with individual's experiences and interpretations of them differing depending on their cultural, relational, and contextual perspectives. I adopted a CGT approach that is attentive to participant meaning-making while also aiming to uncover underlying mechanisms and structures. In doing so, I seek to develop a theory grounded in participants' data, connecting lived experience to psychological theories and frameworks.

The methodological approaches used in this study to explore the research aims are discussed next, with the above positionality in mind.

4.3 Methodological Approach

To address the research questions, an exploratory qualitative approach was adopted to explore the participants' experiences.

An informed, CGT approach (Charmaz, 2014; Thornberg, 2012) was employed using a qualitative methodology, with data collected through semi-

structured interviews. This is considered suitable for GT studies when exploring individuals' views and experiences (Charmaz, 2014; Cresswell & Cresswell, 2023; Oliver, 2012), is used in other studies (e.g., Dowd, 2024; Walker, 2019), and is recommended as a method to use when investigating complex social situations (Miller, 1995).

GT was seen as a suitable methodology for this study because it aims to develop a theory based on the participants' views and experiences (Oliver, 2012).

4.3.1 Grounded Theory

Grounded theory was first developed in 1967 by Glaser and Strauss (Corbin & Strauss, 2015) and has since undergone updates from other researchers, including Charmaz (2014) who developed the constructivist grounded theory approach which is used in the current study. An overview of its historical context is included in Appendix 7.

Constructivist grounded theory. In the late 1990s and early 2000s, GT evolved toward a constructivist approach, through the work of Charmaz (2014), retaining the inductive and comparative qualities of the original method while introducing greater flexibility, iterative processes, and an emphasis on meaning and action. CGT also challenges the earlier assumption that researchers can approach data without preconceptions. Researchers inevitably bring prior knowledge, experiences, and theoretical awareness to their work, but rather than attempting to eliminate these influences, CGT encourages researchers to acknowledge and critically reflect on them, using strategies such as memo-writing and reflexivity to

ensure that the theory is constructed from the data (Charmaz, 2014; Rustin, 2016; Thornberg, 2012).

Charmaz (2014) sees CGT as a set of methods guiding qualitative research including the following qualities: Data collection and analysis will be iterative and happen simultaneously; actions and processes will be analysed instead of themes and structures; comparative methods will be employed; data will be used to develop new conceptual categories, and inductive abstract and analytic categories will be created through systematic data analysis. There will be a focus on theory construction rather than mere description or application to existing theories. Theoretical sampling will be used to seek variation within the studied categories and to develop a category rather than simply covering a specific topic (Charmaz, 2014).

For the current study, an informed CGT approach will be employed, as outlined by Charmaz (2014) and Thornberg (2012). It will be called 'informed' because a systematic review was conducted prior to the research. Furthermore, due to the current researcher’s involvement within the field as described in the introduction, she is also highly aware of the existing research and emerging ideas; pretending otherwise would not enhance the trustworthiness of the research. This aligns with this version, as the researcher brings subjectivity to the data in terms of how it might be gathered and interpreted. Therefore, an approach that acknowledges this and supports reflexivity through its process was essential. Elements of an iterative process and constant comparison are also deemed important in this research to refine the understanding of such a heterogeneous group of individuals (Ayirebi & Thomas, 2024; Halsall et al., 2021). Constant comparison and saturation are both aspects of CGT which would support refinement and will be discussed later in the chapter in section 4.5.

Stages in Charmaz's constructivist GT. Charmaz (2014) outlines the stages of CGT but also emphasises that the process is not linear, mainly due to theoretical sampling and saturation, outlined later in this chapter. In her approach, the research question is the starting point, guiding the recruitment and selection of participants and subsequent data collection. Analysis begins alongside further data collection, with initial codes identified to inform the focus of further data gathering, which could lead to a change in questions. This continues with data from new interviews being coded and constantly compared to previous codes, progressing through focused coding and the development of conceptual categories. This process is iterative and forms a 'cycle' until saturation is reached, at which point a theory is developed, signalling the end of the data collection and analysis. Figure 10 represents this process in a simplistic form, with a more detailed representation of the comparative nature of the analysis stages to follow later in this chapter.

Figure 10

Representation Of A Grounded Theory



Adapted from Charmaz (2014).

Comparison of GT with alternative methodologies. Other methodologies were considered when deciding on the most suitable approaches for studying this topic. Initially, interpretive phenomenological analysis (IPA) was considered to explore the experiences of individual participants and the meanings they derived from them (Robson & McCartan, 2016). However, there appears to be an increasing amount of research using IPA to examine participants' experiences (e.g. Browne, 2018; Chian et al., 2024; Cooper, 2019; Gaffney, 2020; Nelson & Lichwa, 2025), and whilst important, these are exploratory studies, and do not explain underlying processes involved unless these can be conceptualised by existing theoretical frameworks (Robson & McCartan, 2016).

In contrast, CGT allows for the identification of causal structures and mechanisms within systems, crucial for understanding complex concepts such as EBSNA, especially in relation to autism. The flexibility to adapt sampling, interview schedules, and coding as new insights develop is also advantageous, particularly when it is unknown what participants might share. Lastly, techniques like layered coding, memo-ing, and constant comparison support the development of a clear and meaningful theory, as they break data into small, nuanced units that better capture emotion and detail.

IPA is idiographic in nature, meaning that individual experiences are analysed and then brought together in the final stages (Eatough & Smith, 2017), whereas in CGT the constant comparative methods used from early in the data analysis and collection stages provide a broader picture of the phenomenon across contexts and participants (Charmaz & Henwood, 2017). Furthermore, the interpretive method of CGT (Charmaz & Henwood, 2017) was more aligned with studying this complex and

currently under-studied phenomenon. As such, the ability to follow where the data was pointing was an important consideration.

Methodological fit with research questions. As outlined by the research questions, this study aimed to explore a connection between EBSNA and unidentified autistic needs, and to explain how this might have contributed to school non-attendance among these participants. Additionally, by examining the barriers and supportive factors affecting attendance, a developed theory could provide recommendations to enhance supportive elements and minimise or address potential barriers.

CGT develops a theory from the data and allows researchers to view phenomena from different perspectives, enabling them to gain new insights (Corbin & Strauss, 2015). Sutcliffe (2016) highlights that it can generate a more substantive theory which shows the 'messiness' of data and uncovers the nuances inherent in experiences. The combination of this approach with a CR perspective means that the theory produced integrates the systematic process of CGT with considerations of the contexts in which the phenomena are embedded, such as the education system, and social and societal contexts.

4.3.2 Critical realism and Constructivist Grounded Theory (CGT)

CGT is described as a systematic method for conducting research, from the early stages of literature reviews to data gathering and analysis (Thornberg, 2012). Its defining characteristic is constructing a theory grounded in the data. Fletcher (2017) states that CR can help researchers explain social events and suggest recommendations to address these issues; with Sutcliffe (2016) arguing that,

together, CR and CGT are particularly relevant for use by EPs, because these concepts are experienced, and are understood differently by individuals. There is an interplay between them that needs further exploration to uncover the underlying processes, leading to potential suggestions about mechanisms of change, which formed a main reason for choosing this approach.

Sutcliffe (2016) links the use of Strauss and Corbin's GT approach with a CR positioning and Oliver (2012) also contends that with some of the more recent developments in CGT discussed above, it can address some of the preconceived ideas and theories valued by CR researchers when conducting research. CGT is frequently adopted within a CR framework (e.g. Daulby, 2017; Grant, 2020, Sutcliffe, 2016), as both approaches share a focus on developing theory from participants' experiences (Oliver, 2012; Robson & McCartan, 2016). Sutcliffe (2016) views that CGT focuses on developing shared understandings, suggesting an acknowledgement of there being many possible truths, held by the CR position in relation to individual experiences. However, Oliver (2012) notes that to align CGT with a CR perspective, adaptations are needed, particularly an emphasis on uncovering underlying structures and mechanisms, and critically examining how participants perceive and communicate their experiences through the process of reflection and constant comparison, which is outlined in section 4.5.2. Given CR's view of knowledge as fallible and shaped by context (Oliver, 2012), the iterative and reflexive nature of GT is well-suited to this paradigm, enabling researchers to explore both what happens and why, through theory grounded in the data.

However, Fletcher (2017) presents counterarguments on the suitability of CR and CGT, including that grounded theorists do not fully engage with pre-existing

literature before analysis, and differences related to a bottom-up (GT) versus top-down (CR) approach. That is, GT is driven by the data; but Fletcher contends that CR is driven by literature and theory. However, Oliver (2012) and Robson & McCartan (2016) both suggest that CGT and CR can be compatible when used flexibly as guidelines, promoting critical reflection on the data, the process, and the researcher's influence at all stages, and addressing both the events themselves and the meanings derived from them. Furthermore, Thornberg (2012) proposed the notion of informed CGT, discussed above, and further adds weight to the appropriate use of CGT in a study with CR positioning.

The next section in this chapter details the design of the current study and the steps followed.

4.4 Research design

The stages in the current study design mostly align with Charmaz's (2014) as outlined above, with the addition of reviewing literature at an earlier stage, making it an informed CGT approach. Much like Charmaz (2014) outlined, some of these stages occurred concurrently and a visual representation of the stages of analysis is presented in section 4.6. The remainder of the chapter roughly follows the order of the research stages outlined in figure 4, from participant recruitment.

4.4.1 Participant Selection and Sampling

This section explains how the five participants were recruited, the challenges encountered, and the strengths and limitations of this sampling approach.

Initial sampling approach and rationale. A national sampling method was used to increase the likelihood of obtaining participants from a wider range of geographical areas, experiences, and demographics. Participation was self-selecting, and individuals needed to respond to a recruitment flyer (see Appendix 8) if they wished to take part in the study.

Inclusion/exclusion criteria. Inclusion and exclusion criteria (see Appendix 9) were applied to ensure that the participants' experiences aligned with the research aims and questions, while minimising potential effects on their emotional well-being.

An additional ethical issue emerged during recruitment, requiring a formal amendment to the ethical approval. The original exclusion criteria included additional mental health conditions such as depression and eating disorders, due to concerns that discussing difficult school experiences might negatively affect wellbeing. However, as recruitment progressed, it became clear that this criterion was unintentionally restrictive. Given the high overlap between autism, ADHD, anxiety, and other mental health needs, it became clear that some potential participants may have assumed they were not eligible due to experiencing anxiety. Two young women made contact to explain that they had experienced eating disorders during secondary school but that their conditions were currently stable. They felt strongly that their difficulties were rooted in unmet autistic needs at school and wished to share their experiences, believing participation would not adversely affect their mental health.

Their accounts prompted careful ethical reflection. Excluding them risked silencing precisely the voices the study sought to understand, and it raised concerns

about how they might feel about being precluded from contributing to research exploring experiences that had shaped their mental health. At the same time, it was essential to ensure that participation did not place them at risk of harm. Following discussion during supervision, an amendment was submitted (see Appendix 10) and approved to relax the exclusion criteria, while introducing additional safeguards (See Appendix 11 for additional procedures).

These steps ensured that participation remained voluntary, informed, and safe, while also enabling the inclusion of individuals whose experiences were central to the study's aims (see Appendix 12 for the email template used for participants with additional mental health needs).

Recruitment strategies and challenges. Participants were recruited via social media platforms such as Facebook, X, and LinkedIn, using support network groups and relevant organisations (e.g., Autistic Girls Network, Not Fine at School, The Autistic/ADHD women's support group). A selection of approximately 80 colleges nationwide were also emailed in July 2025 (see Appendix 13 for email).

The recruitment flyer was posted on social media support networks three times between July and September. Eight potential participants came forward, with five of these consenting to take part. All who made contact did so from the flyer on social media, either referred by a parent or seen directly. No recruitment was obtained via the college route.

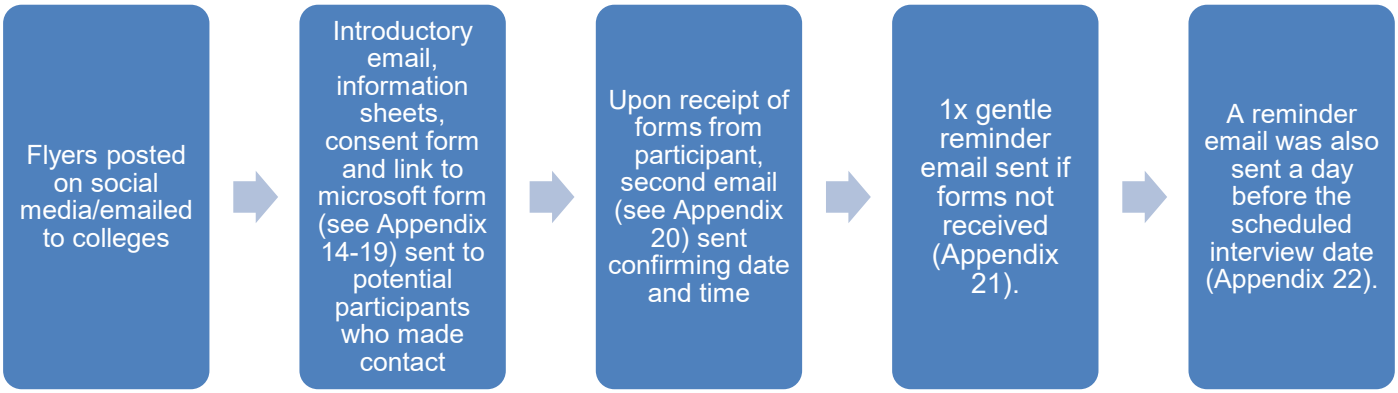
Theoretical sampling was present; however, due to the numbers who came forward, it was not possible to continue this process perhaps as far as Charmaz

(2014) intended, which will be discussed later as a limitation. Figure 11 outlines the recruitment steps taken.

There were challenges with this recruitment approach. The posts also led parents in desperate situations, who knew their daughters did not meet the criteria, to email the researcher and share their stories. This was unexpected, and through supervision, a response email to these types of messages was created, which listened to and acknowledged their stories and directed them to organisations for support (see Appendix 23). Supervision was also used as a support strategy for the researcher in this instance.

Figure 11

Recruitment Steps



There was an over-representation of people living in the South of England and from privileged backgrounds in the participant sample. It is unclear why all participants resided in the South of England and why the sample was not more representative, although it is acknowledged that those involved in support groups are more likely to be accepting of and proactive about their diagnosis. However, it was hoped that the sample would show greater cultural, geographical, and economic diversity. That said, this should not diminish the importance of the stories and experiences shared by this sample. While there are apparent similarities between the participants, there are likely also many varied and hidden experiences that could be relevant to others.

A final challenge with this recruitment strategy was ethical in nature. The social media groups used served as support for the target population, so recruiting through these forums was somewhat uncomfortable. Consequently, the flyers were posted on a limited number of forums, no more than three times over three months to reduce any potential impact on the group members. While continuing recruitment for longer might have yielded more participants or greater diversity, it was agreed during supervision that limiting efforts to three attempts was appropriate given the groups' supportive function.

Power, Positioning, and Researcher–Participant Dynamics. This section reflects on potential power dynamics and so will be written in the first person. A potential power imbalance existed between myself and the participants, shaped by differences in age, professional role, and perceived authority. As a researcher in my mid-40s and a Trainee Educational Psychologist, I may have been viewed as an expert figure, which could have influenced what participants felt comfortable sharing,

or led them to shape their responses in ways they believed were expected. However, during interviews, participants appeared willing to correct my interpretations, offer clarification, and expand on their views when needed. I routinely checked back when hesitation arose, and all participants reported feeling comfortable at the end of the interview, though the possibility of subtle influence cannot be entirely discounted.

Power dynamics may also have shaped who chose to participate. Recruitment was self-selecting, and anyone meeting the inclusion criteria was welcomed and so I was not actively involved in participant selection other than through the inclusion and exclusion criteria. The flyer included my photograph to personalise the study and support informed decision-making, but in hindsight, my identity as a white female researcher may have inadvertently discouraged some individuals from ethnic minority backgrounds, despite the inclusion of diverse imagery elsewhere on the flyer.

I had no prior relationship with any participant, and none attended schools where I currently or have previously worked. Beyond sharing summaries or engaging in member checking, I will have no further contact with them. In terms of positionality, I occupy a space between insider and outsider. Shared elements, such as gender, aspects of my culture (White British) own school experience, and long-standing professional engagement with autistic young people, create some sense of sameness with some of the participants (Burnham, 2012). Yet I remain an outsider in relation to difference in key aspects of their lived experience, including EBSNA, severe anxiety, the contemporary educational context, and cultural background for one participant.

These intersecting dimensions of sameness and difference carry the risk of misinterpretation: I may over-identify with an experience and assume understanding, or conversely, fail to fully grasp contextual factors outside my own experience. Equally, shared elements may have facilitated rapport and enriched the depth of insight. Participant demographics are presented in the following section, and strategies used to surface and mitigate assumptions and biases are outlined.

Demographic information of participants. Demographic information was collected either via the initial questionnaire which served primarily to check eligibility to participant, or during the course of the interviews either directly or through their responses to other questions. The information provides important contextual information which could enable readers to ascertain how transferable the study is to other CYP. As such, it was deemed important to include the demographic information gathered. Data was only received for those who responded to the initial email. One participant withdrew consent having initially provided it, and as consent was withdrawn, her data was not retained. The information detailed in Table 10 was gathered through the initial questionnaire sent to participants prior to the interview.

Educational contexts. Additional information was gathered during the interviews and is presented in table 11, and the subsequent sub-sections on achievement and socio-economic status. This information was not asked directly of the participants but gathered from their answers to other questions.

Table 10

Known Demographic Information

Pseudonym	Age of diagnosis	Age at start of non-attendance	Complete non-attendance or intermittent	If complete non-attendance what yr?	Year attendance improved	Setting in which attendance improved
Lina	16	14	Complete non-attendance	Y10	Y12	College
Sam	21	13	Intermittent	N/A	Never did/has improved	N/A
Becca	23	13	Complete non-attendance	Y9	Y12	College
Esmee	13	6	Reduced timetable from Y9	N/A	Y12	Alternative education package and then College
Emma	13	11	Complete non-attendance	Y11	Y11	Alternative education package

Table 11

Participant's Educational Contexts

Pseudonym	Mainstream school type	Changed schools/ provision?	Alternative package/EHCP	Still in education or year left
Lina	Mainstream mixed	For Post 16	N/A	Still in education (undergrad)
Sam	Private grammar, all girls	For Post 16	N/A	Still in education (Masters)
Becca	Private co-ed but very few girls	Different mainstream for Y10- unsuccessful only attended for ½ a term. Then for Post 16	N/A	Still in education (Masters)
Esmee	Mainstream secondary	N/A	EHCP + alternative package	Still in education (College)
Emma	Grammar mixed	Y- special from Y9 then to EOTAS in Y11	EHCP + alternative package	Y13

Achievement. Four of the participants reported their GCSE grades during the interviews, with the lowest grade being 6, and most being grades 7, 8, and 9. Two of these participants are currently completing Master's degrees, one was about to start a medical sciences degree at university, and one was in the process of applying for medical school to start the following year. The other participant was engaged in various work opportunities and reported to be content, but currently had no desire to pursue further education, despite being capable of doing so.

Economic factors. This was not asked directly; however, all participants reported that their parents worked. The participants not already engaged with mental health services paid for their assessments privately, and two of the participants attended private schools, suggesting that most, if not all, of the participants came from at least a middle socio-economic household.

4.4.2 Research Setting and Context

Description of research environment. Participants were recruited nationally and, consequently, were required to participate online, via Teams. The researcher was in a private room, where the conversation could not be overheard, and the participants were also asked to be in a confidential and comfortable space.

Justification for setting selection. This context was selected to broaden the educational settings experienced by participants, providing a wider range of environments. The focus of the research was not on the performance of a specific institution, but on the shared experiences of the participants, which could influence their attendance within the education system overall. Therefore, including participants from various settings was important.

Access considerations and negotiations. It was acknowledged that participating in an interview as a neurodivergent individual with an unfamiliar person and recounting potentially difficult school experiences could cause anxiety. Procedures were in place with this in mind and are detailed in Appendix 24.

Interviewing neurodivergent individuals can pose challenges due to communication differences (Lewis et al., 2023). Although the inclusion and exclusion criteria likely meant that only those without additional learning or language needs

were included, this remained a consideration and amendments used are included in the Appendix outlined above.

4.5 Data Collection Methods

4.5.1 Data Collection

Microsoft form questionnaire. Data regarding the participants' attendance and autism diagnosis was collected through a brief questionnaire sent via Microsoft Forms with the initial email. Questions included the age their school non-attendance began, duration, and their age of diagnosis. This allowed for verification that they met the inclusion criteria and provided context for their experiences.

Interviews. Semi-structured interviews were selected as the main method for collecting data in this study, which are widely used in qualitative research (Corbin & Strauss, 2015; Robson & McCartan, 2016), giving participants more flexibility to answer questions and allow for follow-up questions based on their responses (Robson & McCartan, 2016).

For CGT studies, unstructured interviews are preferred because they provide the richest data (Corbin & Strauss, 2015). However, some researchers use a semi-structured format to maintain consistency across topics (Corbin & Strauss, 2015). Due to the participants' neurodivergence, it was decided that some structure was necessary, while preserving some depth and flexibility, leading to the adoption of the semi-structured interview approach.

The interview questions were developed specifically for this study and its aims. No existing research explores these experiences retrospectively, and therefore

the resulting questions are necessarily unique. Within qualitative methodologies, particularly unstructured and semi-structured interview approaches, interview guides are understood as flexible, adaptive tools rather than fixed instruments (Charmaz, 2014; Robson & McCartan, 2016). Charmaz (2014) explicitly advocates that grounded theorists construct their own interview questions, particularly in later interviews and in response to the emerging direction of the research, rather than relying on standardised or externally validated question sets.

Imposing predetermined questions risks constraining participants' accounts and forcing data into pre-existing categories, which directly undermines the principles of CGT (Charmaz, 2014). In this context, the interview questions have been developed in alignment with the specific aims and emergent trajectory of the current study, and are expected to evolve as new insights arise. The interview guide for the first two participants included the questions outlined in table 12 below with further information on the question adaptations outlined later in this section.

The interviews lasted between an hour and a quarter and an hour and a half. Questions were presented on a PowerPoint (see Appendix 25), which was shared during the interview to enhance accessibility. Interviews were recorded and transcribed via Teams. After the interviews, the transcripts were reviewed and corrected for accuracy.

Table 12

Initial Interview Questions

Number	Question	Scaling offered?
1	What was your school experience like?	1= very challenging for me; 10= fine
2	Did you have friends?	N/A
3	How did you get on with your teachers, were they supportive?	1= not at all supportive; 10= very supportive and helpful
4	Were there any differences at different stages of schooling e.g. primary versus secondary?	N/A
5	Sorting activities x2	N/A
6	Did you understand at the time why you were finding school so difficult? If so, were you able to explain it to others?	N/A
7	On a scale of 1-10, how well do you think the difficulties you were experiencing with attending school were understood by: Your teachers? Your parents?	1= not at all; 10= very well understood
8	How did they show that, what did they try to do to help?	N/A

Number	Question	Scaling offered?
9	Do you know or remember whether there was any support in place for you at school before your attendance reduced and if so, what?	N/A
10	Sorting activity x 1	N/A
11	Was there anything else that your school did to try and help and did any of it help?	N/A
12	Did anything make things worse for you?	N/A
13	Looking back now, is there anything else that school could have done which you think might have made a difference?	N/A
14	Do you know/ remember whether your family (parents, siblings etc) were supported by school?	N/A
15	If time at end and they are happy for a few more questions: • Was your assessment process quite quick or did it take a long time? • How did the assessment process feel to you? We can scale it if this is easier.	N/A

Number	Question	Scaling offered?
	• Did you notice a difference when you got your diagnosis in terms of the understanding you got from school staff? • Did receiving a diagnosis make a difference to you? • Do you think that receiving one sooner would have been beneficial to you at secondary school?	

Visual sorting activities. Three visual sorting activities were incorporated into the interviews as conversational tools to help participants identify aspects of school they found particularly challenging, and to explore the factors that supported or hindered their attendance. These activities were drawn from *Mapping the Landscape of Fear* (Ripley, 2015) and the *School Wellbeing Cards* (Holder, 2025) (see Appendix 26). Visual mapping tools are widely used by Educational Psychologists to support children and young people in articulating emotions and the contextual factors that shape them, and are particularly advocated for use with autistic CYP and those experiencing reduced school attendance (e.g. Barriers to Education, 2025). Both tools used in this study were developed specifically for work with CYP experiencing EBSNA (Holder, 2025), and in the case of *Mapping the*

Landscape of Fear, for autistic CYP whose experiences of threat and safety may be highly context-dependent (Ripley, 2015).

Furthermore, Lewis et al. (2023) discovered that visual sorting activities could be highly beneficial for neurodivergent participants. They were primarily aimed at supporting and stimulating discussion; however, responses were also compiled into a table (see Appendix 27), providing additional information and cross-checking between responses and for patterns or experiences between participants.

In the Mapping the Landscape of Fear activity, participants were asked to sort commonly experienced school events along a scale from 1 to 5, where 1 indicated an event they avoided entirely and 5 represented something they enjoyed. This tool is designed to help identify which aspects of the school day contribute most to the CYP's distress. The scale was presented visually, as shown in Figure 12. Each event was provided on an individual visual card and read aloud to participants in the appropriate tense. Participants indicated where each card should be placed, and the researcher positioned it in the corresponding column. Examples of events included "talking to teachers or support staff," "receiving results of marked work," and "when something changed that I wasn't warned about."

The School Wellbeing Cards were used to support the identification of each CYP's risk and protective factors. Participants were asked to sort the risk-factor and protective-factor cards into three categories: just like me, a little like me, or not like me. Examples of risk-factor cards included "I worry about being away from my parents," "my parents/carers need me at home," and "I worry about break times." Based on her professional experience, the current researcher added several cards

tailored for autistic CYP, such as “I avoid or worry about specific teachers,” “I often worry I won’t understand the work,” and “I often avoid or worry about specific lessons.” Protective-factor cards included statements such as “my parents/carers are supportive of my education,” “I can make a difference to my life,” “I want to attend school,” and “I feel included at school.” The visual sorting scale is shown in Figure 13.

Figure 12

Mapping the Landscape of Fear Scale

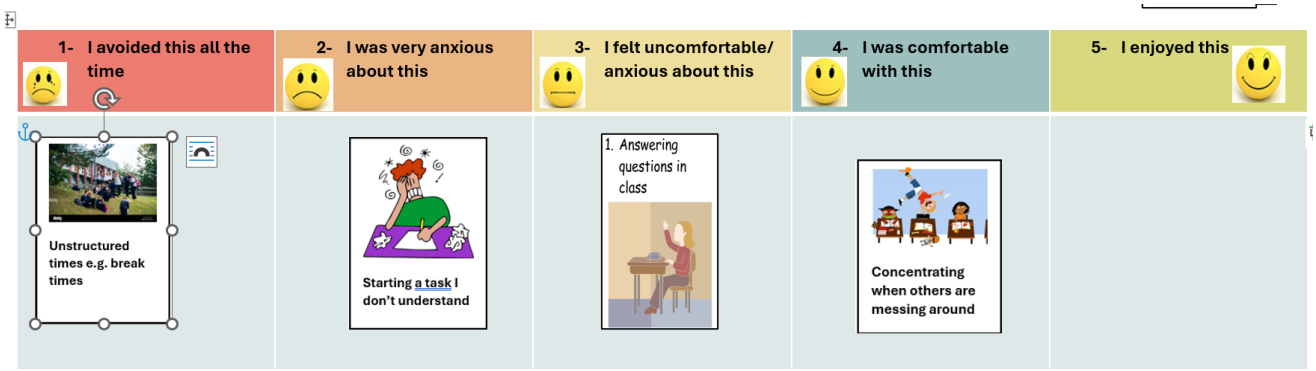


Figure 13

School Wellbeing Sorting Activity



Reflective diary. A reflective diary was maintained throughout each stage of the process to record thoughts during the interview and analysis. During the analysis, emerging concepts, surprises or biases, and changes in thoughts and feelings were documented (see Appendix 28 for examples). Notes on participant presentation were also written either in the reflective diary or within the transcripts when checking and reviewing the recordings.

4.5.2 Timeline and evolution of data collection

Participants were interviewed from the end of July to the beginning of September 2025, allowing data analysis between each interview so that theoretical sampling and saturation could be conducted as required.

Theoretical sampling. Theoretical sampling is a method used in CGT for gathering more specific data (Charmaz, 2014) and is embedded within the iterative process of GT (Hennink & Kaiser, 2019). It allows the researcher to focus on important information (such as recurring themes) to refine categories and develop a theory (Robson & McCartan, 2016). Theoretical sampling involves data collection and analysis co-occurring, where the researcher interviews the initial participants, develops tentative ideas based on analysis, and then explores these ideas further in subsequent interviews until saturation is reached (Charmaz, 2014).

Theoretical Saturation. In CGT, saturation is reached through the iterative processes of theoretical sampling, constant comparison, refinement, and checking. Saturation is defined as the point at which no new properties, categories or relationships between them can be created from additional data (Charmaz, 2014; Thornberg, 2012).

Research has been conducted to determine sample sizes adequate for achieving saturation. Recommendations vary, however Hennick and Kaiser (2021) reviewed studies to identify when saturation was typically reached and found it occurred between 9 and 17 participants for interviews. Essentially, the sample size needed to reach saturation depends on the participant group, study methods, questions asked, and the themes that develop. It is no longer regarded as a ‘fixed point’ at which all information has been extracted from the data (Oliver, 2012), and it is now understood that reaching saturation can only ever be assumed and never definitively 'known’ (Sarfo et al., 2021). Hennick and Kaiser (2019) also highlight that it is argued that saturation does not necessarily refer to all themes having been identified, but when no new information regarding the most important ones have been explored and no new information arises.

Theoretical sampling and saturation in the current study. Data gathering and analysis took place simultaneously to meet the requirements of theoretical sampling and saturation. Data from the first participant was analysed before the second was interviewed, but at this stage, no modifications were made to the interview schedule. The second participant's interview was analysed prior to the third and fourth interviews. This process continued after each interview, and after the fourth participant, despite variations in their experiences and stories, the themes remained consistent within the initial codes that had developed, resulting in a high level of consistency across these key themes. However, for the purpose of achieving saturation, one additional participant was recruited.

Question development. Before starting the study, biases led to an assumption that the schools would not have attempted adaptations due to time and

resource constraints, and that the focus would be on gathering views on what more they could or should have done to support re-engagement. This was not always the case and, based on the responses from participants, questions were added and the focus slightly changed (see Appendix 29). The below represents diary entries made following the first participant's interview to act as a reminder and justification as to why these changes were made.

> Add question 'what more could have been done before your attendance reduced' as well as after to respond to L's reflection that once her non-attendance had begun, it was too late.

A further change to the interview questions was made following discussion during supervision of a surprising reflection made by Sam, and is highlighted in the below diary entry.

> Sam wondered whether receiving a diagnosis earlier have changed her outcomes in a negative way. She was proud of what she had achieved and wondered if she would have had the opportunities if she'd been diagnosed as autistic when younger. This was a surprise to me as there is such a focus on early identification and support. I wonder if this is felt by other participants? I'll discuss in supervision as an interesting piece of data and think about whether to add a question to explore with others.

Memo-writing. Memo-writing was outlined in section 4.3.1 and Table 13 provides some examples, with additional ones in Appendix 30. These were incorporated at all stages of the coding processes and contained information for various purposes including what the code included, whether it was a positive or

Table 13

Memo Examples

Initial Code	Memo example
Resentment	that she had to do the work, and do the thing she found difficult (communicating).
Frustration, worry and distress	Take it personally, dislike of teacher telling off class/other students
Sense of belonging or inclusion	Lack of sense of belonging
Frustration, worry and distress; Fearing failure and not being good enough	Also not being good enough if she does get told off? Teachers seem to feel very threatening and unpredictable to her
Lack of support, nurture and approachability	X made a similar comment about being the one who had to do the work/make the effort
Unhelpful teacher approaches	Seemed to be getting stressed talking about this- voice rising

negative aspect of the code, researcher's thoughts and interpretations and potential links to other codes or participants. This facilitated the comparison of the initial codes for each participant.

The following section outlines the data analysis process.

4.6 Data Analysis Process

In GT data analysis, the researcher creates qualitative codes which describes or defines what is seen in the data- thus they emerge from it (Charmaz, 2014). GT researchers follow the leads found in their data, they are not constrained by pre-conceived themes or categories.

> Coding: the process of taking data apart, defining, and labelling what these data are about (Charmaz, 2014, p. 342).

Excel was used during the analysis stage, and no other software was used for the analysis. Excel's capability to sort and filter by codes was enough for the coding process.

4.6.1 Coding processes

Data was analysed using CGT coding processes to generate categories (referred to as ‘codes’), leading to the development of a conceptual theory (Cresswell & Cresswell, 2023) as previously outlined in figure 10. Four stages of coding were employed to identify the categories, shown in Figure 14. This diagram offers a simplified version of the stages of coding, with a more comprehensive diagram later in this chapter.

The different codes can be visualised as represented in figure 15 below, to form the next set of codes.

Figure 14

Simplified Stages Of Coding

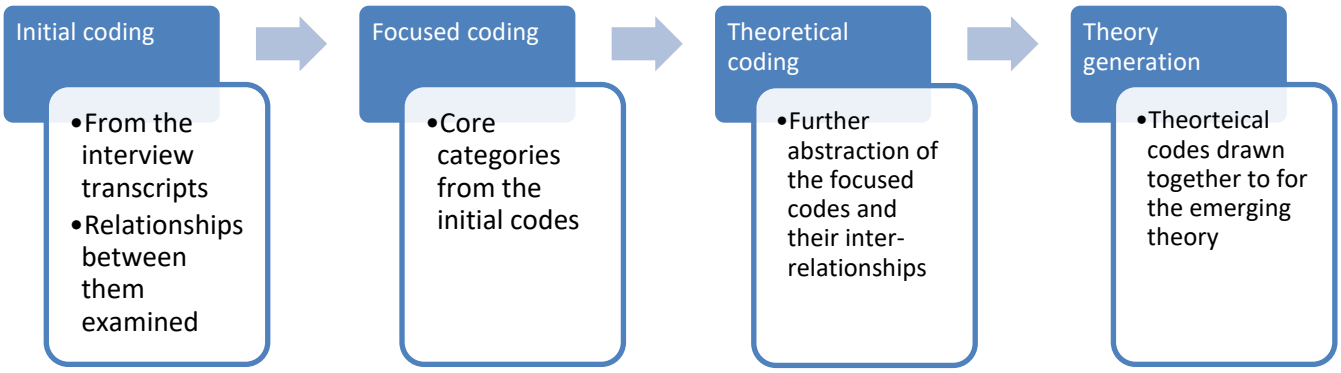
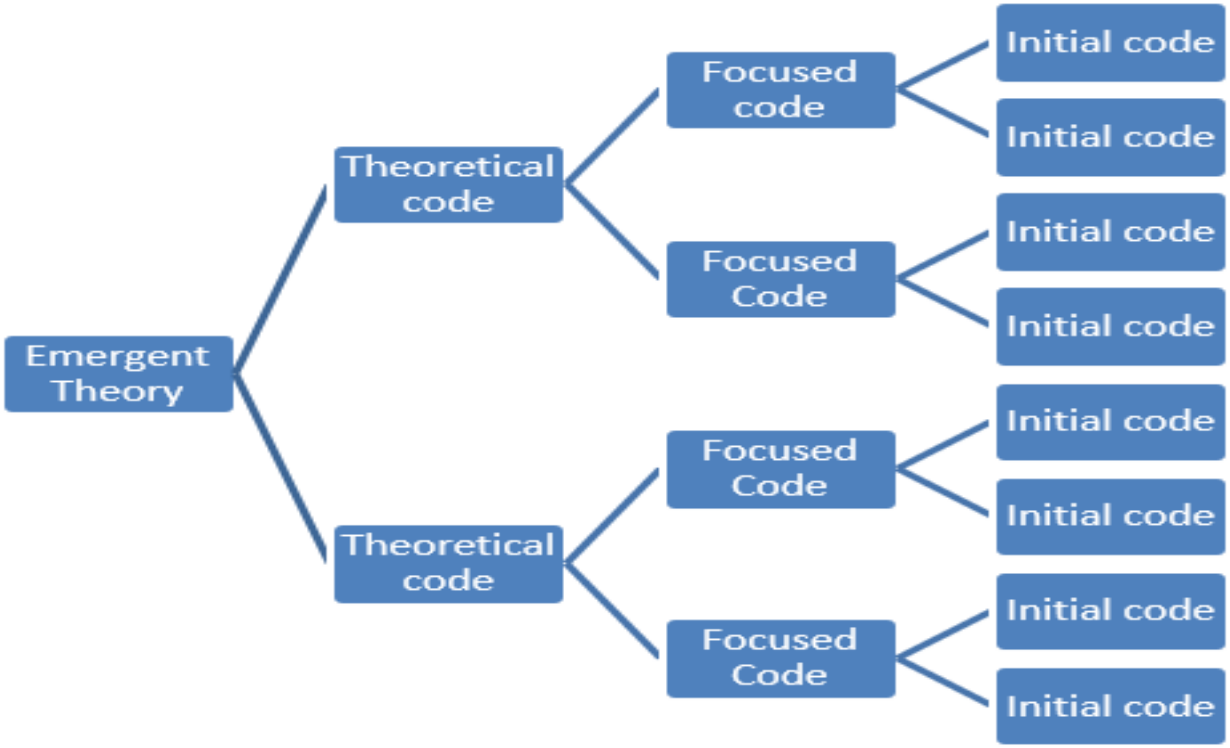


Figure 15

Code Construction



Note. This diagram is for illustrative purposes only to support the readers understanding of how the different codes sit together, moving from initial code to the emergent theory. The number of codes presented here is an example, and each study will have different numbers of codes at each level, including in the current study which has several initial codes per focused code.

These stages will now be described in more detail below.

Initial coding. Initial coding is defined by Charmaz (2014) as:

> The early process of engaging with and defining data. Initial coding forms the link between collecting data and developing and emergent theory to understand and account for these data. (p. 343).

Initial coding is conducted by performing line-by-line coding on each transcript, with each segment (line) of data transferred to an excel spreadsheet. Initial codes were assigned to each line, or sections of the line, and memos were included where thoughts occurred. Table 14 shows an example from one of the participants. See Appendix 31 for further examples of this.

Table 14

Example Of Line By Line Coding

Time stamp	Initial code	Line	Memo
55:11	Concern about perception or judgement from others Not wanting to appear different	I think I was also quite aware of how other people perceive me, so I think if I'd had like a reduced timetable or extra support, I might have been worried about how that would look to other students, I didn't want them to like single me out as weird or, you know, sensitive or that kind of thing.	Would she have been able to accept adaptations? Link to X who could not

The initial codes for participant 1 were transferred to a second spreadsheet to facilitate constant comparison when coding the next transcript. Participant 2's transcript was coded, and where codes from participant 1 were similar or relevant, these were utilised, with new ones added where they did not fit. During the coding of the second transcript, it became clear that there would be a large amount of initial code data, making it very difficult to identify similarities in a list of initial codes arranged 'randomly' on a spreadsheet. Therefore, during the analysis of participant 2's data, they were organised into 'categories' to make them easier to find and compare across participants, such as 'autistic traits' or 'relationships with adults' (See Appendix 32). These then became tentative focused codes.

Once Participant 2's initial coding was completed and her codes added to the other spreadsheet, Participant 1's transcript and codes were reviewed again to determine whether any of the codes identified in the second transcript were relevant or could be combined.

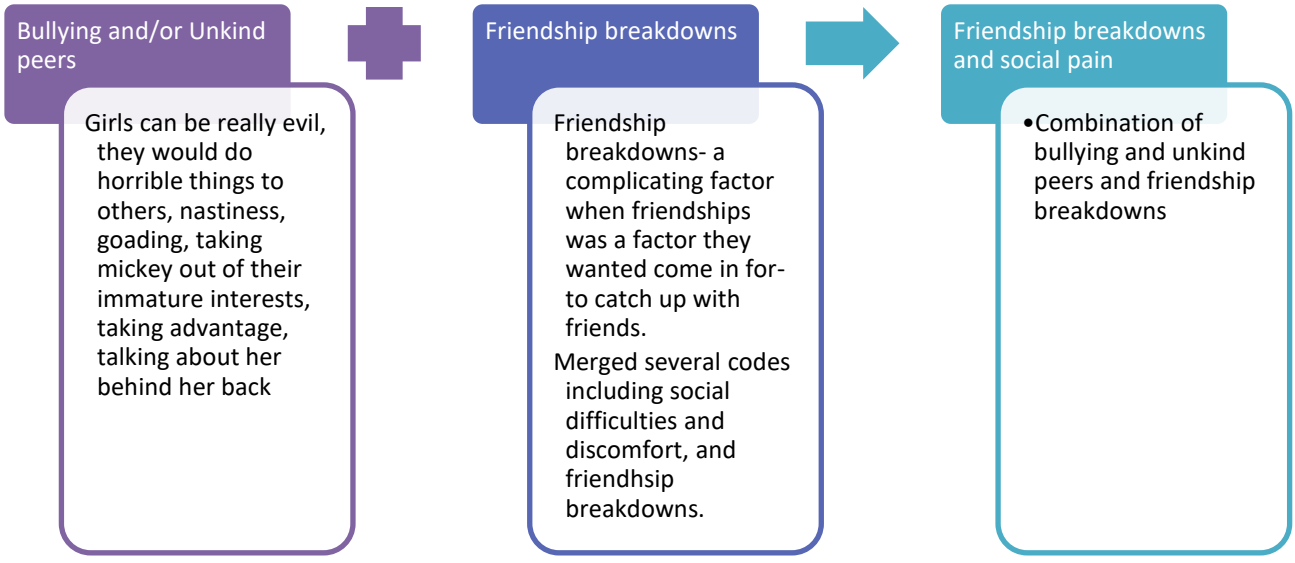
This process continued with the next three participants, with their transcripts being coded individually and relevant codes from the previous data being used or new ones assigned if required. From the first four transcripts, the primary initial codes were identified due to the amount of repetition across participants and the relevance to the research questions. Therefore, the final transcript was reviewed and coded in line with these primary initial codes, with no new initial codes being generated.

Following this, the previous codes and transcripts were reviewed to compare the codes and merge them where they were similar. For example, several initial

codes from different participants were suggestive of the similar experiences. These included ‘difficulties interacting’, ‘social difficulties’, ‘friendship breakdowns’, ‘discomfort with group work’, and ‘social difficulties and discomfort’. Through a couple of changes, these separate initial codes were merged and later formed the ‘*friendship breakdowns and social pain’* initial code. These changes are reflected in the memos assigned to these codes as shown in figure 16.

Figure 16

Memos For Development Of ‘Friendship Breakdowns And Social Pain’



Note. The label in coloured box is the initial code and in the white box contains the memo.

In the second spreadsheet, all the participants' initial codes were listed side by side. Where themes repeated across participants, the cell was coloured green to help compare and quickly identify the most common themes. Figure 17 shows an example of the themes organised during the initial coding phase; each column represents a different participant. Where words are present in the shaded cells, this is to indicate which code is repeated in that line.

In the final stage of initial coding, the focus shifted to comparing the initial codes for similarities and discrepancies, as well as refining them. This was achieved in two ways as outlined in the subsections below.

Figure 17

Example Comparison Of Initial Codes Across Participants

Emotive				
Threats and consequences	Bullying and/or unkind peers	Paralysis	Paralysis	Threats and consequences + Paralysis
Just anxiety	Overwhelming		Just anxiety	
Feeling pressured or forced				
Frustration, worry and distress				
Sense of belonging or inclusion				

At times, the communication styles of some of the participants made the initial coding process tricky. For example, a couple of participants spoke very fast and jumped between thoughts. The below diary entry highlights this and steps taken to aid interpretation.

> Very chatty, but lots of words omitted and tone of voice or expressions used instead so I wonder how this will impact coding. It'll rely on me interpreting her meaning but there's a risk I might not interpret it correctly. Will need to replay video a few times and watch her expressions carefully.

Comparison across participants. Where the code arose for each participant, the data was reviewed to check for any discrepancies. If any differences in meaning were found, a different code was created, or a more relevant one was applied. For example, a 'sense of belonging' initial code existed, but for some participants, this referred to a positive sense of belonging, while for others it related to a lack of sense of belonging. As such, this was split into two codes: 'Feeling a sense of belonging and inclusion' and 'lack of belonging and inclusion'. A lack of belonging and inclusion was later merged with 'fear of perception from others' as often these two themes came hand in hand. As such, these codes became: 'Lacking a sense of belonging and fearing judgement'. On further analysis of sense of belonging and inclusion, it became clear that this related to when they re-engaged with education in college or alternative provision, and so this was highlighted within the memo for consideration at the focused code stage. The memos for both are shown in table 15.

Table 15

Memos For ‘Lacking A Sense Of Belonging And Fearing Judgement’ *And* ‘Feeling A Sense Of Belonging Or Inclusion’.

Initial Code	Memo
Lacking a sense of belonging and fearing judgement	Before, during and after non-attendance, as a result of non-attendance for L and not before. 'Just anxiety', rejection sensitivity ('hate me forever'), not drawing attention to self/wanting to appear different, of capability, being looked down on, people knowing, justifying absence, being perceived as lazy, being watched and judged, what people might think, lack of sense of belonging and concern around perception or judgement from others combined.
Feeling a sense of belonging or inclusion’	In 6th form or EOTAS provision where attended and succeeded.

Comparing memos. The memos for each initial code were also compared. Where these memos could be combined to form one, the code was kept. If the memos were significantly different in meaning, a new code was created to

distinguish them. For example, there were multiple initial codes such as shutdown and paralysis, sudden crisis, burn out, and incapable of attending school. The memos for these labels were similar and hinted at mental health crises- as such, the codes were combined and formed one initial code labelled ‘shutting down, feelings of paralysis and mental health crisis’. The memos from each original initial code were also combined and information was included to show this merge process as shown below.

> *Merged paralysis, burn out, complete shutdown and incapable of attending school. Couldn't get out of bed, out the car, couldn't explain, freeze, incapable of attending, not being able to go through school gates, can't not won't, incapability not choice, absolutely exhausted and burnt out, too unwell to do anything, wasn't well emotionally, literally couldn't walk, therapy non-attendance, Also added not seeing a future and hospital admission to escape from school.*

While the initial codes were divided into categories to aid the initial step as outlined above, forming some early focused codes, the most relevant ones were copied to a third spreadsheet (See Appendix 33), along with their initial codes and memos and a selection of data segments for each participant. These were codes that recurred across multiple participants or had several critical initial codes relevant to the research questions. This also allowed for the easier comparison of the initial codes and for additional initial codes to be collapsed into a single initial code. For example, codes hinting at school anxiety being linked to their autistic differences such as environmental overload, ambiguity, and unpredictability, were collapsed into ‘autism traits making school, unpredictable and overwhelming’.

Focused coding.

> [Focused coding is] a sequel to initial coding in which researchers concentrate on the most frequent and/or significant among their initial codes and test these codes against large batches of data…when the researcher's initial codes are concrete, the researcher can code them by asking what analytic story these codes indicate, and this arrive at a set of focused codes. (Charmaz, 2014. p. 343).

Focused codes were developed by comparing the initial codes and their memos to identify similarities, differences and actions between them. To do this, each initial code was printed separately with their memo, so that they could be viewed, compared and moved around into different groupings (see Table 16 for examples). As these groupings formed, other initial codes that were not included in the early focused codes were also checked for relevance to the new focused code groupings and five more were added.

These codes, memos and quotes were then transferred to a fourth spreadsheet in their new focused code groupings as shown in table 17.

Table 16

Examples Of Initial Codes And Memos

Initial Code	Memo
Avoidance of specific lessons or events	Skips particular lessons (e.g. drama or PE), teachers, days of tests/assessments she felt unprepared for, canteen,
Emotional consequences at home	Taking it out on parents, cry for hours after school, emotional meltdowns
Increased absence	Attending but avoiding lessons, lower attendance compared to peers, missing days sporadically, reported as illness, refusing
Early physiological symptoms	Headaches, stomach aches, feeling sick, feeling of not being able to walk/get out of car, 'frozen in place', sleep difficulties, nightmares, irritability

This led to further refinement of the initial codes through the process of constant comparison when it became evident that some aspects of an initial code did not fit the focused code. For example, the initial code of ‘relationships with adults’ included both positive and less helpful aspects of teacher relationships, so this initial code was split, with one renamed to ‘the difference made by positive relationships with adults’ and another created as ‘lack of support, nurture and approachability from school adults’. These were then placed in two different focused codes; ‘moments of visibility and recognition’, and ‘cumulative stressors and overwhelm in the school environment and system’ respectively.

Appendix 34 shows the final focused codes, initial codes, and sample quotes, and a simpler version excluding the quotes. Frequency counts were added to each

initial code and focused code. Urquhart (2017) highlights that, for those adopting a critical realist position, frequency counts might help add a ‘factual’ basis to what occurs in the transcripts.

Table 17

Focused Code, Initial Code, Memos And Quotes

Focused code: Invisible path of distress to absence		**Memo**: School as overwhelming and threatening, home is safe. Retreating for self-protection and cumulative stress.				
Initial code	**Memo**	Lina	Sam	Becca	Esmee	Emma
Increased absence	Attending but avoiding lessons, lower attendance compared to peers, missing days sporadically, reported as illness, refusing	'my attendance … was usually in, like the 85 range. And then I stopped to get or maybe like 80 range. And then I stopped going, and it felt like 30 and then zero.'	‘I'd be forced by I forced myself to go in and I would like not attend [lessons].'	‘It was, yeah, it was year nine when I started missing like a couple of days here and there.'	'So I guess in primary school there was absence, but I think it was more that I said I was sick, but…looking back now, it wasn’t illness';	N/A

Initial code	**Memo**	Lina	Sam	Becca	Esmee	Emma
Early physiological symptoms	Headaches, stomach aches, feeling sick, feeling of not being able to walk/get out of car, 'frozen in place', sleep difficulties, nightmares, irritability	N/A	N/A	'I remember in, that's another one in primary school where I went through a phase where I felt sick at every lunchtime	my sleep anyway, but sleep got much worse. I'd wake up a lot in the night with bad dreams or I don't really know what it was, but I think anxiety is like waking up with quite a lot of anxiety.	' But I just was like, frozen in place by fear and anxiety of like, I don't want to go in.'

Theoretical coding. According to Charmaz (2014), theoretical codes are:

> Codes that researchers draw on from prior theories or analytic schemes and use to integrate the categories of their analyses. (p. 345)

To develop the theoretical codes, once the focused code groupings appeared coherent, these were then written onto Post-it notes along with their constituent initial codes, compared with each other and moved around. From this, early theoretical codes were generated, and in discussion with the research supervisor, these were tweaked and adapted. The first two early versions of one of the theoretical codes are shown in Appendix 35. Theoretical codes provided a description of the relationships between the focused codes and hinted to underlying theoretical concepts. By example, table 18 shows two focused codes, the theoretical code they form, and its memo.

Through this process and during supervision to explore the codes, further amendments were made to focused and initial codes, such as the focused code of ‘unrecognised needs at different levels’ being disbanded, and its initial codes moved to the ‘barriers to earlier recognition and effective response’ focused code. This conceptualisation was then amended slightly to version 2.

Table 18

Theoretical Code Formation + Memo Example

Focused codes	Theoretical code	Memo
Cumulative stressors and overwhelm in the school environment and system Impact of prolonged exposure to stressors on their mental health and ability to attend school	Activated threat response and consequences of being unable to act	Relationship between systems factors (external/environmental/ system stressors/lack of autonomy), and within child factors- distress and mental health consequences

The label for this theoretical code was later changed to ‘emotional response to unnoticed distress and lack of autonomy’.

This process was completed for all focused codes with constant comparison throughout of initial and focused codes, with some initial codes being refined further or moved at even the later stages. For example, ‘I got lucky’ was also moved from ‘resilience, achievement and hope’ to ‘participant hindsight’.

The labels of the theoretical codes continued to adapt and change throughout the process and during/following the second literature review, which will be outlined in the discussion chapter.

Theoretical framework development. As for the focused code process, the theoretical codes were written on Post-it notes with their constituent focused codes to support the understanding of the meaning of the codes. As before, some refinement of the codes and their placements continued during supervision. Diagrams of versions 1 and 2 are shown in Appendix 36.

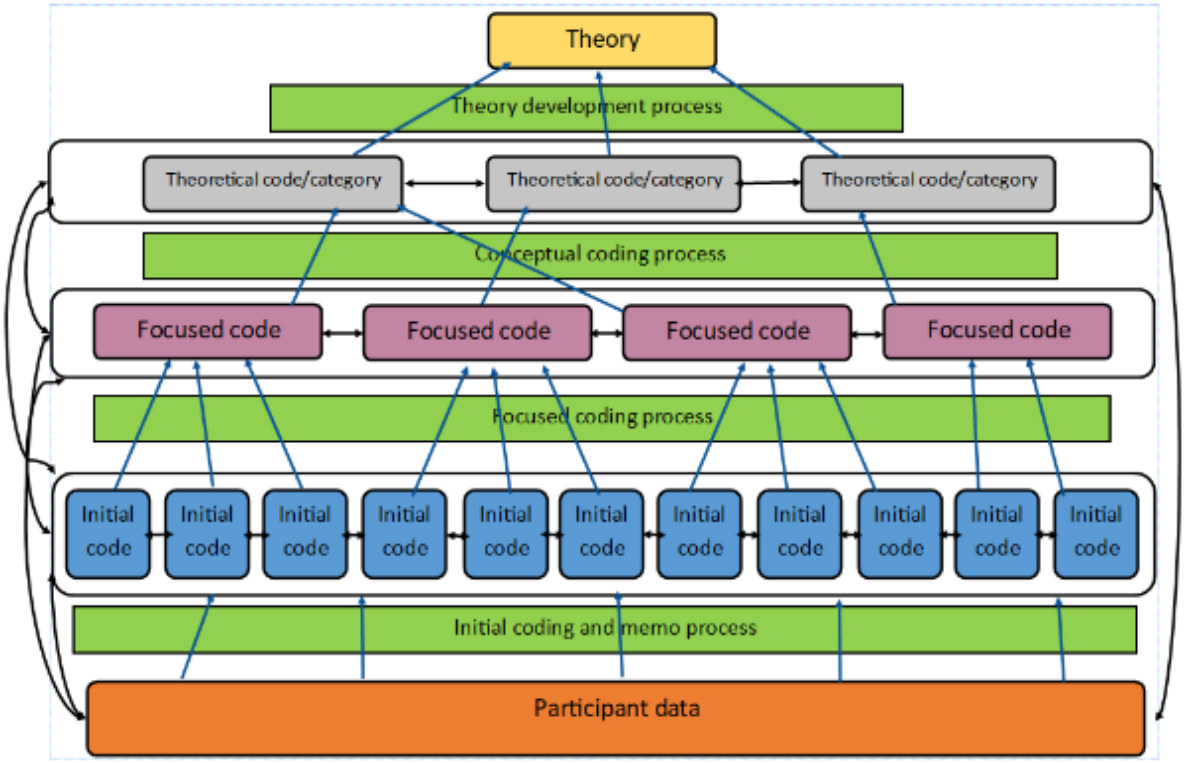
The headings given in each of these early diagrams were descriptive of the process which was occurring; some became the code, others were further refined. Sutcliffe (2016) highlights that the researcher develops the theory through demonstrating the pattern and relationships between the codes and this process of trying out different combinations of conceptual codes and interactions between them supported this. Discussions with the supervisor continued, until the final versions were established. Final digital versions of the diagrams are presented in the Findings Chapter.

4.6.2 Visual representations of analysis process

In line with the GT methodology, Figure 18 shows the visual representation of the analysis process.

Figure 18

Visual Representation Of The Analysis Process



The blue arrows indicate the information that was used to create the step above. The black arrows represent the process of constant comparison. While this diagram is presented in a bottom-up fashion, it is not a linear process, and all stages were tweaked and compared at every stage.

From the early stages of coding the participants data, emerging ideas were developing which were captured in the researcher's reflective diary as things to test out with subsequent participants or to look back at when coding. Many of these early

ideas formed initial codes. Some examples of diary entries of these emerging ideas are included below.

> Importance of understanding and having key staff to talk to; gaps due to missed school and unable to catch up, placed pressure on herself to do so- non-attendance and missed learning exacerbated the problem; didn't understand herself why she was finding school so have and couldn't explain it to others- entries made after first participant's interview.
>
> Didn't learn that way and learnt more teaching herself; success, resilience and pride were a strong theme coming across from Sam. She achieved it despite her struggles and did it all herself- entries after second interview.
>
> Isolation, loneliness and feelings of invisibility; not wanting to be seen as different; Becca reflected that 100% attendance does not mean that everything is ok; 'it depends' has already been stated a lot by all three participants and suggestive of why difficulties might be missed by adults or perceived as a choice?- diary entries after interview 3.
>
> Feelings of paralysis; 'just anxiety' is coming up again; benefits of a later diagnosis 'would I have had the same experiences if my parents knew I was autistic, would I have still gone to parties or to the theatre in London?'; her responsibility to find ways to communicate with the teachers- Reflections after Interview 4.

The following section addresses the quality of the study, including its strengths and limitations.

4.7 Assessing Quality

Assessing quality in a qualitative study has long been debated and remains unresolved (Thornberg, 2012). The reliability and validity of qualitative studies have been criticised for many years by positivist researchers seeking objective truths. However, qualitative research (including CGT) does not conform to the usual quality criteria applied to quantitative studies, and therefore, requires different indicators (Thornberg, 2012). Researchers have proposed various markers of quality, and Corbin and Strauss (2015) explain that qualitative researchers agree on the importance of evaluating quality in qualitative research, however, there is little consensus on the most suitable framework to adopt.

Since a CGT method was used, it was deemed most appropriate to follow Charmaz's (2014) criteria; credibility, originality, resonance, and usefulness. Credibility was considered in the research design and so will be discussed here. Originality, resonance and usefulness will be considered in the Discussion Chapter.

4.7.1 Credibility

Credibility can be considered as the 'trustworthiness' or 'believability' of a study's research findings (Corbin & Strauss, 2015). Markers of this include prolonged engagement with the data, triangulation, peer review or debriefing, clarity of researcher bias, member checking, and rich descriptions. Charmaz (2014) also highlights that systematic comparison within and between data and categories, and strong, logical links are indicators of credibility.

In this study, different data sources (participants) were interviewed, and their accounts were compared to enhance credibility (Corbin & Strauss, 2015). Member checking was offered to participants to confirm the accuracy of interpretations,

though this was optional given the time they had already contributed; two participants chose to engage with this but did not respond. Codes which did not support the main interpretations were also presented. Peers, colleagues, and research tutors were consulted at various stages of analysis to reflect on the findings and offer neutral or alternative perspectives.

The researcher's positionality and potential biases have been discussed in this and previous chapters. Reflexive approaches, including memos and a reflective diary were used throughout to document thoughts, reactions, and surprises in the data . One diary entry demonstrates this, while a second shows my reflection on H's reporting of experiences, both are included below.

> Am I challenging what they participants are saying or is my experience, position and assumptions leading me to not do so? I challenged B and she considered the alternative scenario. Continue this if situations arise in subsequent interviews.

> L was very realistic and rational about her experiences in terms of recognising that adults tried but lacked capacity and resources.

Line-by-line coding and constant comparison supported prolonged engagement with the data; transcripts were read in full at least twice, and initial codes were reviewed continuously during early coding phases.

Cresswell and Cresswell (2023) suggest that trustworthiness can be enhanced by clearly outlining the research and analysis process to support replication. While the steps and documents in the appendices would allow others to repeat the study, replicability must be considered in light of the unique participant

experiences and narratives. Some excerpts from interviews and coding will be included in the analysis section and appendices, allowing readers to trace how conclusions were drawn and refer directly to participants' views.

Negative case analysis. Negative case analysis involves identifying and reporting cases that do not fit the emerging theory or developing patterns, thereby helping to mitigate researcher bias (Charmaz, 2014; Robson & McCartan, 2016). Throughout the analysis, attention will be paid to locating negative cases within the data, and these will be presented to enhance transparency, strengthen credibility, and support ongoing theory refinement.

4.7.2 Limitations and methodological challenges

Data collection methods. Although measures were implemented to minimise the impact of communication differences on participants' responses (as outlined in the sections above), it cannot be assumed that all potential effects have been mitigated, and some discrepancies between intent and interpretation may still exist. Additionally, the visual sorting activity, used to support communication, appeared to occasionally cause some conflict for the participants. They reported that certain concepts within the activity were unclear and felt uncomfortable presenting an inaccurate view. For instance, one participant explained that initially, reading aloud in class caused her some anxiety, but she still did it. However, as her anxiety increased, she began to avoid it entirely. As a result, she was unsure and anxious about where to place it. For two participants, increased anxiety was perceived by the researcher, and in one case, one of the sorting activities was not used to reduce further discomfort.

Sample size. Sample size is often reported as a limitation of qualitative approaches, limiting the generalisation of findings to wider populations. However, as noted in the quality indicators above, this is not necessarily a marker of quality in qualitative studies.

The sample size in this study is small for a grounded theory approach and may not fully meet the standards for saturation outlined by Charmaz (2012), who cautions that too few participants may generate conceptual themes but struggle to refine them into a theory. Nonetheless, saturation appeared to have been reached for the primary concepts, though the researcher adopts the view of Sarfo et al. (2021) that saturation can only be assumed, never definitively known.

Hennick and Kaiser (2019) reported a study that reached saturation with five participants, and Sutcliffe's (2016) research also included five participants. Both papers stress that that saturation should relate to the depth of particular concepts rather than the number of them. Therefore, while the small sample size is acknowledged as a limitation, it may not compromise the quality of the data, or the importance of the findings.

Lack of demographic information. Although some demographic information was collected during the interview, this was not done consistently for all participants and was not specifically consented to be used in the study, especially regarding ethnic or cultural background and so has not been presented in detail. Consequently, this affects transferability, as it becomes more challenging for others to determine whether these findings are relevant to their own aspects of identity.

Limited range of backgrounds. Linked to the previous limitation and as already discussed, location and socio-economic (SE) background of the participants appeared similar, although this is assumed from their other responses (e.g. school type, parental careers). As such, this may also limit its applicability to a broader range of backgrounds, especially those from ethnic minority groups, deprived areas and lower SE groups. It would be important to explore the experiences of individuals from these backgrounds, as their experiences and outcomes could differ.

Summary. Whilst there are limitations to this study, particularly regarding its applicability to a broader range of backgrounds and identities, the social constructivist orientation of the grounded theory approach, and the markers of quality in this type of research more generally, mean that generalisability is not a primary aim. As Charmaz (2014) notes, data are situated within a particular social context and participant group and therefore cannot be reliably generalised beyond it. These boundaries are inherent to the methodology itself and reflect its epistemological position, rather than constituting additional limitations specific to this study. Nonetheless, the limited diversity of the sample is acknowledged as a contextual limitation.

4.8 Ethical Considerations

Ethical approval was obtained from the Tavistock and Portman NHS Trust's ethics committee on 17th April 2025 (please see Appendix 37). The participants in the current study are regarded as vulnerable due to their neurodiversity and age, especially those aged 16-18.

4.8.1 Informed consent procedures for vulnerable participants

As outlined in the participant recruitment section, email responses and additional information was sent to the participants before obtaining consent to ensure this was informed. Participants were asked to indicate any signs of distress and how they would like the researcher to respond in such cases, and were reminded that they did not have to answer any questions they did not want to. Throughout the interview, they were monitored for signs of distress or assent in case they did not feel comfortable communicating that they wished to end the interview. No signs were noted, and so the distress protocol (see Appendix 38) was not required.

At the beginning of each interview, participants were reminded of the key aspects concerning consent, confidentiality, recording, and the right to withdraw. Consent was verbally confirmed, prior to starting the interview, and they were asked to repeat their understanding of the study. Participants were informed when recording commenced.

At the end of each interview, they were asked how they experienced the session and how they felt. All participants reported feeling fine, with some expressing feelings of closure or satisfaction with the idea of potentially helping others. No participants described feelings of upset or distress, and they said they felt comfortable throughout the process.

Participants were directed to professional support services, such as The Samaritans and the National Autistic Society, in the initial contact email and in the follow-up thank-you email sent to them the following day (see Appendix 39).

4.8.2 Anonymity, data protection and storage protocols

Interviews were conducted and recorded online via Teams, with the transcription function utilised. The transcript was downloaded to a secure University OneDrive account and anonymised. Only the researcher is aware of the data's ownership and pseudonyms assigned by the researcher are used in the write-up. After the data was processed into initial codes, the transcripts and recordings were deleted from the server.

Once the programme has been completed, the findings from the study may be used for publication or future research. If this is considered, the anonymised data will be transferred from the secure OneDrive account to a password-protected personal computer. No personal details will be stored, and references to any specific events that could identify participants will be removed. The anonymised data will be stored and handled appropriately for 6-10 years in accordance with the Tavistock and Portman NHS Trust Data Protection and Handling Policies.

4.8.3 Ethical challenges specific to grounded theory

An ethical challenge of the CGT method, particularly during data collection and analysis, is that the line between the role of participant and researcher can blur due to how embedded the researcher becomes within the data (Corbin & Strauss, 2015). It may become difficult to distinguish the researcher’s interpretation from the participant’s intended message. Additionally, conducting such intensive interviews and immersing oneself in data that includes emotive, and, at times, distressing stories is challenging for the researcher, who may experience some of the participants’ feelings being projected onto her. Corbin and Strauss (2015) acknowledge this ethical challenge, emphasising the importance of the researcher

recognising this, setting the data aside, and engaging in self-care. A risk assessment for the researcher was completed for the ethics approval in this regard (see appendix 40). In the current study, general self-care was necessary after all interviews, and supervision was sought to debrief after the researcher experienced one of the interviews as particularly upsetting.

Another ethical challenge encountered is that of the research outcome. In CGT, the themes from participants' stories are combined to form a higher-level analytical theory that may not closely resemble their original stories. Even during member checking, their initial codes are merged with those of others, so they are not solely theirs. This was explained to the participants who requested a feedback session, but it raises questions about what their expectations might be and whether these differ from the actual outcome. Furthermore, the theory generated will be based on the researcher’s interpretation of the data and could be viewed as ambiguous or biased. However, by including examples of the data in the appendices, readers can verify interpretations and draw their own conclusions, thereby increasing transparency.

Finally, although not specific to CGT, a key ethical consideration for this type of research is understanding what benefit it offers to participants. While they may not receive a tangible change or outcome, participants expressed experiencing emotional relief and closure, feeling empowered and validated, knowing their stories were important and valued. They also felt their participation might help others, and some reported increased awareness of their experiences. Some reported that it helped them process these experiences and seemed to offer a therapeutic element.

4.8.4 Reflexive discussion on ethical dilemmas encountered

This will be written in the first person in line with other reflective sections. A central motivation for this research was to safeguard the well-being of the participants involved. This was reflected in the inclusion and exclusion criteria, concerns about the study's impact on them, the tools used, how the interviews were conducted, their duration, and the care taken with the types of questions asked, especially regarding signs of distress and how I could respond.

However, in the early stages of the research, I found it difficult to balance this with the requirements for ethical approval. Specifically, the amount of information needed in the participant information documents and consent forms was challenging. Managing this alongside their potential communication differences and age was quite demanding.

In the final interview, the participant provided very detailed answers, and the session exceeded the estimated time. Once again, I had to balance between cutting her off or moving her on, and allowing her to explain the nuances of her answers and provide examples. She was very aware and apologised repeatedly for talking too much; I was quick to reassure her and felt sad that she felt the need to apologise. I shortened the interview by removing one of the sorting activities (which she found difficult) and did not explore the final questions in as much depth as I would have liked. However, another balance was needed. Despite her saying she was happy to continue, I felt that having gone 15 minutes over the scheduled time and considering the time she had already spent, it was more than enough to ask of her.

Throughout the study, the overarching ethical dilemma seems to be balancing participant needs, ethical considerations, and what I needed to gather to achieve the study's aims and purpose. I believe I achieved this balance and that no ethical issues arose, and I am very relieved that not only did I gather important data, but the participants also gained something from the process.

The next section will reflect on the methodological choices made.

4.9 Methodological Reflexivity

4.9.1 Critical reflection on methodological choices

Grounded theory was entirely new to me. I had not anticipated the complexity of iterative processes such as theoretical sampling, saturation, and constant comparison. The time, focus, and attention to detail required during analysis far exceeded my expectations, and at times, the volume of data felt overwhelming whilst also managing placement and university demands.

Semi-structured interviews were always the intended method, as I wanted to explore lived experiences and hear participants' voices. While I've acknowledged the challenges of interviewing neurodivergent individuals above, interviews more broadly are not without critique, particularly regarding identity, diversity, and potential power imbalances (Charmaz, 2014). I was mindful of this. It cannot be assumed that interviews automatically foster the depth of relationship needed for participants to share their experiences fully. I was also conscious of, what was shared is not an objective truth, but a subjective account of how events were experienced. For example, a participant's view that school staff were unapproachable may contrast

with the staff's own intentions. However, what matters is how the participant experienced the situation, as this shaped the outcomes that followed, in keeping with my critical realist ontology and epistemology.

Ultimately, to explore a phenomenon as nuanced and individual as the experiences of autistic women and girls, interviews seemed the most appropriate method. Through the CGT lens, with an emphasis on reflexivity and constant comparison, their accounts are not treated as objective truths, but are examined for complexity, contradiction, and meaning. An example of this was evident during an interview where I asked whether teachers could have been doing things for her in the background without her knowledge. She considered this briefly but then explained that as nothing changed, she felt this was unlikely.

Communication styles did pose challenges. While participants were highly engaged and reflective, many admitted to overthinking their responses to avoid misrepresentation. This often led to complex trains of thought and detailed examples, making it difficult to identify their core answers. To overcome this, I asked for clarification or summarised their responses to check understanding, or during analysis, I replayed video and transcript segments multiple times to interpret their intended meaning better.

Their engagement in the process and the detailed response they provided yielded interesting and, on occasion, surprising findings which are discussed the next chapter.

5 Findings

5.1 Chapter Overview

The previous chapters have outlined the existing literature and research findings, and the methodological approaches and design used in the current study. This chapter will outline the study's findings.

This study aimed to centre participants' voices, exploring their school experiences prior to their diagnoses. The research questions for this study were:

- What are the experiences of autistic adolescent girls prior to their autistic needs being recognised, and how could this contribute to school non-attendance?
- What are the barriers and supportive factors that influence school attendance for adolescent girls before their autism diagnosis?

There is considerable overlap with the RQs being addressed across multiple codes. As a result, they are answered directly in the discussion section, with a visual representation of where they are answered.

This chapter outlines the findings, beginning with an overview of the findings, a summary of findings from the visual sorting activities, before an explanation of the emerging theoretical framework. A summary table will then be presented, highlighting the theoretical codes along with their focused codes and memos. The theoretical codes will subsequently be introduced in the same order as in the summary table. The main findings for each theoretical code will be summarised, and its conceptual diagram will be introduced, including the primary focused codes and their initial codes. A table displaying the labels and frequencies of these initial codes

will be shown before exploring each one, with examples of participant quotes and some of the memos to support the reader to understand the researcher's interpretations.

In presenting participant quotes, those used are direct quotes unless an ellipsis or square brackets are inserted to add omitted words for context. The language remains the participant's voice, and no alterations have been made (other than to shorten the quote by omitting irrelevant words or repetition), including to grammar. This also applies to a few quotes containing language that might be considered offensive. The researcher has intentionally retained these words to preserve the participant's voice, to reflect both the extent of their feelings regarding what they are describing, and the evolving standards of what is considered 'appropriate' language.

In detailing each focused code, not all initial codes will be discussed. The initial codes selected for inclusion in this section include those that most frequently occurred, or those that represent exceptions to the code, such as those that occur less frequently or contradict the formulation (Charmaz, 2014). When reviewing the included quotes, it is helpful to be aware that some answers were direct responses to questions using the 'Mapping the Landscape of Fear' and 'School Wellbeing' card sorting activities. These answers contain either numbers or responses such as 'just like me', 'a little like me', or 'not like me'. Where numbers are mentioned, they represent a scale, from 1 = highly anxious and avoiding the scenario to 5 = I enjoy it.

5.2 Overview of findings

This research has produced a considerable number of findings which are presented in this chapter. These can, however, be summarised into three primary findings.

5.2.1 Finding 1- Early needs remained invisible

Participants' emerging difficulties, sometimes present for years before their non-attendance, were largely unnoticed or missed by school staff and, to a lesser extent, parents. Their distinct autistic presentation, strong academic performance, camouflaging, limited self-awareness, and desire to fit in contributed to this invisibility. As a result, they remained in stressful, unadapted environments without appropriate support. The barriers to education significantly outweighed the few protective factors they described.

5.2.2 Finding 2- Chronic stress led to escalating anxiety and withdrawal

Ongoing exposure to an un-adapted mainstream secondary environment intensified their anxiety. Previously manageable aspects of school became additional stressors, activating sustained threat responses and undermining their mental well-being. This culminated in within-child mental health needs and school non-attendance as self-protective coping strategies. Participants consistently reported that by this stage, intervention felt "too late." Some participants experienced prolonged periods out of education, up to two years; while others accessed alternative provisions after a slightly shorter period of absence.

5.2.3 Finding 3- Re-engagement was possible under the right conditions

All participants were able to re-engage with education when provided with environments that offered greater autonomy, flexibility, and relational safety. This typically involved alternative or hybrid learning arrangements, or Sixth Form settings where they could choose subjects and exercise more control over their learning. Across cases, autonomy, belonging, and approachable adults were the key factors enabling successful re-engagement.

5.3 Findings from the visual sorting activities

As highlighted, the visual sorting tools were used to aid conversation and recollection. As such, the findings from these tools are incorporated within the codes and in the appendices, however some of the main qualitative trends are highlighted in the following section.

5.3.1 Mapping the Landscape of Fear

Participants most frequently reported avoiding, or feeling most anxious about, class tests and assessments, answering questions or reading aloud in class, working in a group, beginning work they did not understand, and sitting in the canteen. In contrast, they most often reported enjoying situations where the teacher wrote instructions down, working independently, and activities that required quiet or stillness in class. Although these represent the most commonly reported patterns, there were individual variations across participants. CYP also routinely explained that their responses to these events depended on several contextual factors, including the stage of their education they were considering (with things getting

harder to manage as their non-attendance increased) and who was involved (for example, whether they were able to choose the person they worked with).

Interestingly, four of the participants reported that they were fine or happy to follow instructions given to them, the below entry from the researcher's reflective diary highlights initial thoughts about this.

> All have so far reported feeling fine or enjoying following instructions from adults (when they are clear). I wonder if this speaks to some level of compliance and masking- doing what they're told to not get into trouble or stand out?

5.3.2 School Wellbeing Cards

Risk factors: All participants reported hiding themselves or their difficulties from others (camouflaging) while at school, worrying about going to school, feeling worried while at school, and feeling physically unwell when thinking about school. None reported that their parents needed them to remain at home. Other risk factors were mentioned only infrequently, including more general difficulties with leaving the house and worrying about being away from parents.

Protective factors: The least frequently stated protective factors included being able to show their true feelings at school, feeling included, and experiencing a sense of belonging. For some participants, these factors improved once they moved to college. The most common protective factors were that their parents were supportive of their education and that they enjoyed learning.

5.4 Developing theoretical framework- Accumulating Barriers to Education

Figure 19 illustrates the theoretical framework constructed from the findings and outlines how the theoretical and focus codes interrelate and interact with each other. This process model shows how their experiences leads to EBSNA and mental health needs, and also highlights an interaction between educational systems and within child factors, which culminated in their school non-attendance and increased mental health needs.

This constructed theory will be discussed in more detail in the discussion section, where it will be linked to existing psychological theories and literature. Its inclusion and summary here provides an overview of the parts of the model and the relationships between them.

Figure 19

Current Theoretical Framework

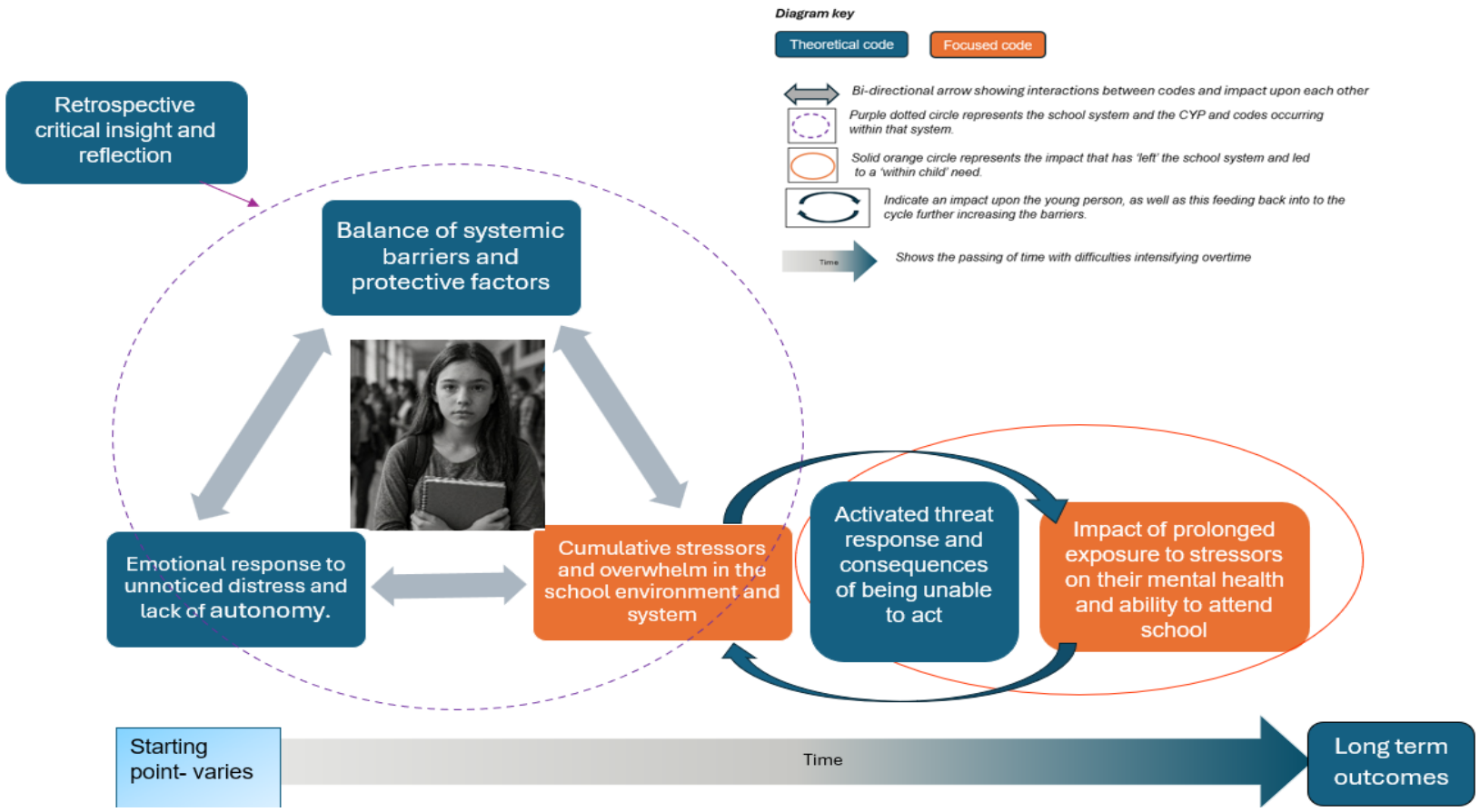


Image of CYP generated by Co-Pilot.

The larger dotted circle represents the school system, highlighting that this process occurred within it and begins with the participants starting to experience stress in this system. The arrow along the bottom shows the passage of time and that the starting point varied for participants. This cycle began in primary school for all participants, but for some this was evident earlier than for others.

Balance of barriers and protective factors- This theoretical code represents that, due to several barriers, their needs are not recognised, or, when they are, factors prevent the strategies from being effective. These barriers outweigh the supportive or protective factors.

Emotional response to unnoticed distress and lack of autonomy- This theoretical code represents how, as stress accumulates, so too do their emotional responses, which then feeds back into the balance of barriers and protective factors by adding further 'barriers' and preventing an increase in protective ones.

Activated threat response and consequences of being unable to act- This theoretical code is presented in the model by its constituent focused codes. Cumulative stressors and overwhelm in the school environment and system represent the causes of their distress and overwhelm in relation to their autistic differences and the systemic factors involved. This feeds into the within-school cycle of balance of barriers and protective factors, emotional responses, and the hidden or continued invisible nature of their needs in a multi-directional fashion, with all of these impacting each other. The bidirectional arrows within the school system highlight that each of these codes influence each other and increase the impact of each. For example, the balance of barriers and systemic barriers become more outweighed towards the barriers as the CYPs emotional responses increase as the cumulative nature of the overwhelm caused by the stressors. As a result, the barriers

become greater as their tolerance reduces and they become less resilient and accepting of support, which continues as an accumulating cycle of increased overwhelm, distress and barriers.

The model then steps outside the school system to highlight the impact on the individual's attendance and mental health as part of the second phase of the activated threat response and the consequences of being unable to act. This is viewed not only as a consequence of their unrecognised and unsupported needs within the mainstream environment, but also as feeding back into the system through their school non-attendance and mental health needs, now acting as an additional barrier, including affecting their tolerance of events and preventing the school from implementing additional supportive processes.

Long term outcomes and retrospective critical insight and reflection-The two further arrows represent the participants' outcomes and potential supportive factors enabling this, and their critical insights into what they believe needed to occur at the earlier stages, which could have changed their trajectories. For the participants in the current study, their long term outcomes were re-engagement, autonomy and resilience. However, on the theoretical model, to retain theoretical transferability, this is referred to as ‘long term outcomes’ because these will be varied.

5.5 Presentation of Theoretical Codes

The theoretical categories are presented as in Table 19, to represent the journey of the participants’ secondary school experiences, from the very early stages of school-based anxiety, through to their outcomes and critical retrospective reflections.

Table 19

Theoretical Code Order (See Appendix 41 For Table With Memos)

Theoretical code	Focused code
Balance of systemic barriers and early protective factors	Barriers to earlier recognition and effective response
	Moments of visibility and recognition
Emotional response to unnoticed distress and lack of autonomy.	Invisible path of distress to absence
	Emotional landscape of distress, and a lack of belonging and autonomy
Activated threat response and consequences of being unable to act	Cumulative stressors and overwhelm in the school environment and system
	Impact of prolonged exposure to stressors on their mental health and ability to attend school
Long term outcomes- Re-engagement, autonomy and resilience	Conditions enabling re-engagement and fostered feelings of safety and belonging
	Resilience, achievement and hope
Retrospective critical insight and reflection	Participant hindsight on missed opportunities
	Diagnostic journey and its impact on identity, acceptance, and support

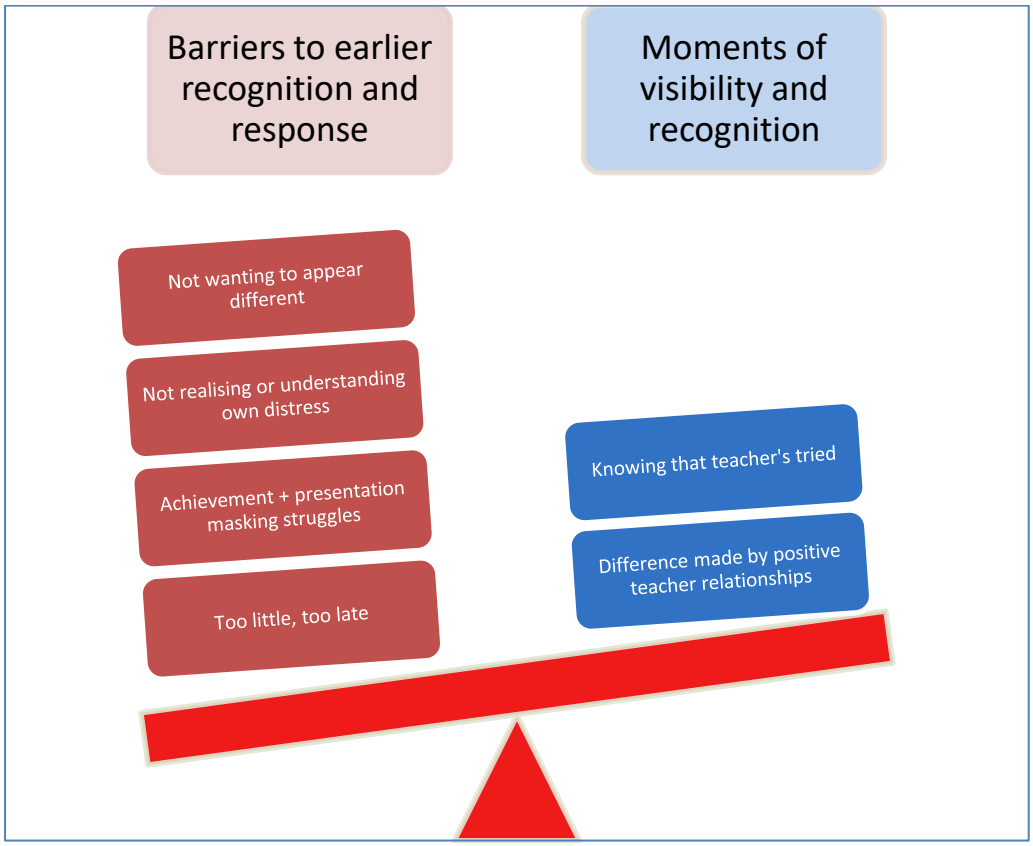
5.5.1 Balance of systemic barriers and early protective factors

This theoretical code describes the relationship between two focused codes relating to participants' experiences of secondary school in the lead-up to their non-

attendance. They identify some of the barriers and protective factors the participants reported experiencing and while some protective factors were reported, they were significantly outweighed by the number of barriers and were not sufficient to overcome or manage these barriers. The frequency of occurrence of these codes reflected this, with barrier-related codes occurring 126 times and moments of visibility 99 times. Figure 20 visually represents this imbalance. The items on the scale represent the initial codes outlined in the section which follows.

Figure 20

Conceptual Diagram Of Balance Of Systemic Barriers And Early Protective Factors



This section will now consider the focused codes and some of their primary initial codes.

Barriers to earlier recognition and effective response. This focused code highlights some of the barriers present, which may have prevented earlier recognition, the effectiveness, or acceptance of interventions when their difficulties were beginning to be recognised. The barriers originate in both systemic factors (the education system, staff training and understanding, the timing of interventions and the degree of impact) and in the individual and their capacity to accept and adopt these adaptations at that time and are shown in Table 20. Other themes that appeared included teachers ignoring agreed adaptations, and those offered being unhelpful.

Table 20

Constituent Initial Codes For 'Barriers To Earlier Recognition And Effective Response'

Initial code	Frequency
Not realising or understanding own distress	28
Achievement, diligence and presentation masking extreme struggles	25
Early parental concerns dismissed	3
Too little, too late	17
It depends	17
Not wanting to appear different	7
All or nothing, no grey area	1
Total frequency for focused code (including initial codes not shown)	126

Not realising or understanding own distress. This initial code developed very early in the first participant's interview, when reflecting on whether others understood her difficulties with attending school. It continued across the other participants, occurring for all five, a total of 28 times, making it a significant code.

Table 21

Participant Quotes Highlighting 'Not Realising Or Understanding Own Distress'

Participant	Quote	Memos
Lina	'I didn't even understand them myself, so when they would then ask me why I'm struggling, I wouldn't be able to give them an answer'	Not understanding herself Unaware of her struggle
Sam	'I just didn't know why…But like, because I didn't know, I just needed a quiet space'	
Becca	'I didn't really know what it was that I was feeling'	Just didn't know- didn't know what anxiety was and that it was what she was feeling
Esmee	'But I would say I don't think I really understood why I was finding school so difficult.'	Didn't understand why finding school so difficult- in line with other participants.
Emma	'and there were definitely times before then that was like I'm not, I'm not realising it yet, but I'm not OK with going to school and I am struggling.'	

A related initial code developed in that participants were unable to communicate their difficulties, even when they had a better understanding of them. These two factors represent very early barriers to others recognising what was going on for them; they did not know and/or could not tell someone that they were struggling.

Achievement, diligence and presentation masking extreme struggles. All five participants expressed that the difficulties they were experiencing were hidden from others due to their presentation, camouflaging and academic achievement.

Table 22

Participant Quotes Highlighting 'Achievement, Diligence And Presentation Masking Extreme Struggles'

Participant	Quote	Memo
Lina	'I hated it. And then I got my report back for that term, and the teacher was like; yeah, X excels in economics. She, like, seems to really enjoy the subject, she's really engaged. And I was reading it thinking like, does he really think that? There's no way I'm ok, I'm shaking in this lesson, how does he think that? But that was before the autism diagnosis.'	Masking/camouflaging Teacher's unaware of how much she was struggling Appearing to cope
Sam	'I guess maybe because I was more adaptable even in those scenarios, they didn't suggest it	Masking? Conforming? She also said she'd just copy everyone else.

Participant	Quote	Memo
	[autism as a possibility]. They just thought it's just like general.'	
Becca	'Yeah, like quiet, diligent. This is all the stuff that would come up in my school report, like 'conscientious student'. Like I won the form prize for the year quite a few times and like I suppose they saw my academic success, as it were like almost as a catchall for my overall success, yeah.'	Compliance? Camouflaging? Academic ability, engagement and silence confused with being fine?
Esmee	'Because I was masking, it wasn't obvious. And I've I've never, like, hurt anyone or insulted anyone.'	Camouflaging/masking Signs not as obvious
Emma	'…my year six teacher was all like, "oh, no, she's not autistic, she can't be autistic"; because that was obviously a bad thing, a negative thing. And like, "well, she's really smart. Like, she's she's functioning in school"'	

Early parental concerns dismissed. Both Esmee and Emma reported that their parents had raised concerns with the school, either about the possibility of autism or about their additional mental health needs, which were dismissed or not acted upon. All participants were asked whether their parents raised concerns with their school. The other three said they were not sure whether this had occurred or what the outcome was. As such, this initial code appeared only three times across these two participants but is included as a key barrier to recognition of need and

relates to the initial code above. It is also possible that parents of the other three participants expressed concern, but did not tell their daughters; none of the participants said that their parents did not speak to the school about any concerns.

Too little, too late. This initial code refers to both the type of intervention being insufficient to change things for them and that, by the time it was offered, it was too late. This question was added for the third participant onward, following the analysis of the first participant's data.

Table 23

Participant Quotes Highlighting 'Too Little, Too Late'

Participant	Quote	Memo
Lina	'…at that point I'd already been out for for too long and struggling too much and too burnt out that everything that was realistic, that they were proposing to me, I could not consider handling. It was so too little, too late.'	Couldn't consider anything Nothing would have been enough, too burnt out.
Becca	'And then when I came back… when they, I tried to go back to the new school, I do think they tried a lot of things. They had a key support person, they tried to do like a phased return, they said that, I could like, I don't know, go home at lunch and stuff like that; but it was just too overwhelming. I had no desire to go back to that school whatsoever, so.'	Too late when she came back- already too overwhelmed.

Participant	Quote	Memo
Esmee	‘I think I had a timeout card, but again that wasn't very helpful because by the time I got to the point that I was so overwhelmed, the idea of getting a timeout card out of my bag and going to the front of class and showing it to a teacher…[wasn’t feasible]’	Already overwhelmed, adaptation not useful as too late by then.
Emma	‘Maybe there are things that other people have put in place for them that are really helpful and that would have benefited me…But I think it felt so like point of no return of like I'm one foot out the door already. '	Past the point of no return, one foot out the door already

In Esmee’s case, she referred to this concept in relation to an intervention she was given, which she could use once she had become overwhelmed, linking to the idea that the intervention was not enough. By the time she was overwhelmed, it was too late and she was unable to access it. Esmee was also asked directly whether she felt that by the time she stopped attending, it was too late, to which she replied ‘yeah, definitely’. This code occurred 17 times across the four participants, making it common among them.

It depends. This code occurred across all five participants, and highlights the nuances of the participants’ experiences; many of their answers were caveated with ‘it depends’. This suggests that, at times, they can manage a particular event or situation, but at other times they cannot. This could add further complications to their

needs being recognised, as there are times when they can talk to teachers or a group of friends, possibly making their anxiety and difficulties less obvious.

Table 24

Participant Quotes Highlighting 'It Depends'

Participant	Quote	Memos
Lina	'I'd put that in three [interacting with classmates]. The same sort of. It would depend very much on the classmates.'	Degree of anxiety dependent on context e.g. the peers involved
Sam	'I think it depended on the person [adult supporting in class] on the on the person. Like I'm just thinking about like, yeah, it just depends on the person.'	Depends on the peer- could manage it with some?
Becca	'Again, probably would depend on the teacher, but I'd say again, like between 2 and 3. [talking to teachers/adults]'	Depends on who
Esmee	'[working with a partner] I'd say it depends on the person, so I'd probably say three because I'd say even people I knew I'd probably feel uncomfortable about it.'	It depends
Emma	[how did you find it when others messed around] '… it would, depending what lessons and what teachers were ... But I think I think I did all right with it in the sense that I just sort of like tuned it out. But at times … it would get to a point where	Some difficulties with others messing around

	it was over stimulating…and sometimes like that would then just lead me to, like, leave lessons.'	

Not wanting to appear different. This was not a question that was directly asked, but arose naturally from their answers to other questions, most frequently about specific adaptations such as an adult supporting them.

Table 25

Participant Quotes Highlighting 'Not Wanting To Appear Different'

Participant	Quote	Memos
Lina	'No, and I wouldn't wanted to [have TA support] because it would have brought attention to myself. I would have found that even more distressing than not having one.'	Not wanting to appear different- barrier to adaptations
Becca	'I think I was also quite aware of how other people perceive me, so I think if I'd had like a reduced timetable or extra support, I might have been worried about how that would look to other students, I didn't want them to like single me out as weird or, you know, sensitive or that kind of thing.'	Would she have been able to accept adaptations? Link to L who could not and did not want to appear different.
Esmee	'So it wasn't, I didn't really utilise that because first of all, I'd be drawing attention to myself if I'd leave the class early, which I didn't want to do.'	Not wanting to appear different.

Their answers reflected the early stage of their non-attendance and increasing anxiety as school adults began to become aware of their difficulties and offering a little support. Not wanting to appear different was a barrier to accepting some of the strategies and adaptations, which could have been a barrier for them even if their needs had been identified before they reached overwhelm.

All or nothing, no grey area. This code only arose for one participant, but it has been included because it is an interesting point to consider.

Table 26

Participant Quotes Highlighting 'All Or Nothing, No Grey Area'

Participant	Quote
Lina	'They offered me half days, that I could have then continued up until GCSE. But because I viewed it as all or nothing, even if they then told me that it's not all or nothing like you didn't have to do it all…and to be fair, they did let me drop some subjects'.

Lina was offered a reduced timetable and for work to be sent home, however, she viewed school as either 'all or nothing'. She could not consider less than full attendance or alternatives such as learning from home, which could relate to her autistic differences in flexibility.

A similar point was made by Emma, when reflecting on the difference an alternative package made for her. She also described some inflexibility, with her view of education as attending school. Anything different she viewed as 'strange', which she explained that, along with already being anxious and depressed, meant it was not an easy transition.

Table 27

Participant Quote Highlighting 'All Or Nothing, No Grey Area'

Participant	Quote
Emma	And even then, that wasn't perfect because I had also started from a point of being anxious and depressed. If it had been from the get go, with my perception being that it wasn't a strange thing to be doing. Like, if that was the norm…it probably would've been very different.

Moments of visibility and recognition. This code represents the moments of visibility and the supportive factors that were in place either before or at the early stages of their school non-attendance. These factors are all located outside the individual and rely on the support and approachability of friends and school-based adults; meaning there was very little within their control.

Table 28

Constituent Initial Codes For 'Moments Of Visibility And Recognition'

Initial code	Frequency
Knowing that teachers tried and expression of empathy for the adults	20
Difference made by positive teacher relationships	50
Relying on and catching up with friends	18
Total frequency for focused code (including initial codes not shown)	99

Knowing that teachers tried and expression of empathy for the adults. Even for some of the participants who recounted the most difficult circumstances,

this initial code developed as they recognised that some of the adults around them did what they could and acknowledged that the systems and large class sizes hindered efforts.

Table 29

Participant Quotes Highlighting 'Knowing That Teachers Tried And Expression Of Empathy For The Adults'

Participant	Quote	Memos
Lina	'They didn't have the resources to to help me as much as I know they wish they did, and neither did the school… They did try and it just wasn't enough'	Seems to understand there was only so much they could do Consequences of lack of resources and funding
Sam	'But like again they would try, they would show support when they could, but they never really understood it.'	Supportive but understanding
Becca	'And I remember one teacher came down because I'd got upset about one of the exams and he, I can't really remember what he said, but it was along the lines of like, oh, you know, you're like really smart and capable. And you just need to get back to school and…but I think he was trying to be helpful or like inspirational or something'	She sounded quite critical of him as it made her feel very uncomfortable at the time. But did then acknowledge that he might have been trying to help.
Emma	'And also kids also like social factors, were a big factor and like everybody's so preoccupied with managing their own stuff until that stress is relieved, they won't have any capacity to help each other, which means that the teacher has to help all of them. Which one person cannot do. Especially when they're dealing with their own shit.'	

Emma highlighted the significant pressure placed on teachers within the current education system. She noted that many pupils in a class are likely managing their own challenges, making it difficult for a single teacher to support everyone effectively while also coping with their own lives.

Despite the difficulties they were facing, four of the participants recognised that the adults around them were trying, within their capabilities. This also links to the following initial code, which showed some interesting nuances.

Difference made by positive teacher relationships. All five participants recounted helpful teachers, some of whom they trusted and who appeared to go out of their way to support them. The number of occurrences for each participant is also included here, as this yielded some interesting differences.

Table 30

Participant Quotes Highlighting 'Difference Made By Positive Teacher Relationships'

Participant	Frequency	Quote	Memo
Lina	1	[asking for help if I haven't understood something] 'I would put that in three because in some with some teachers it would be two and with some it would be 4 so...'	
Sam	19	'…I was like first, first in line to ask them for help for stuff. And they were really, really supportive in terms of, like, academic, academically….Like I'd give them probably a 10 on that, on that scale, yeah'	Would go in to get help from teachers. Supportive factor.

Participant	Frequency	Quote	Memo
Becca	3	‘Most of the teachers I liked, I think I always used to get the comment in my school reports that like I was a joy to teach and all that kind of thing. But then there were others that were quite friendly that I wouldn't mind talking to.’	She liked, or teachers enjoyed teaching her because she was quiet and diligent? Was able to talk to some teachers more than others.
Esmee	13	‘I had one really good teacher who was absolutely amazing…And like if there was like sensitive topics for me like in relation to eating or stuff like that, she'd always send me the PowerPoint in advance’	Difference made by positive teacher relationships- this was one lesson she could consistently attend.
Emma	14	'I had a few key teachers that I found were like almost safe people and were really, really good, really nice that I really clicked with that sort of gave me motivation to…try and try and attend and engage with the help that was being given.'	Supportive factor

Lina and Becca talked very little about teachers they felt were good and responsive, except when asked directly about them. Interestingly, out of the participants, they experienced the most significant non-attendance through years 9-

11. When they did talk about staff, the comments made were quite general, e.g. they were friendly, or they tried.

Conversely, Sam reported the most supportive relationships with most adults at her school, mentioning how supportive they were 19 times, referring to them as *'besties for life, actually'*. She was the only participant who remained in the same secondary school throughout, although her attendance was inconsistent and below 90%.

Esmee and Emma reported positive teacher relationships more frequently than Lina and Becca. However, crucially, they spoke only about the same one or two members of staff.

Relying on and catching up with friends. Four of the participants reported that friendships in the early secondary stages were important factors supporting their attendance.

Table 31

Participant Quotes Highlighting 'Relying On And Catching Up With Friends'

Participant	Quote	Memos
Lina	'I was probably a bit reliant on my friends in social situations. I used them sort of as a crutch while I was in school...pretty much the entire time'	
Sam	'When I was going through the really rough times where like that one friend that I had during the period was like not in or like it [breaktimes/unstructured times] was busy, yeah, I'd hate that basically. But	Reliant on friends to manage unstructured times.

Participant	Quote	Memos
	then when they were in, it was absolutely fine.’	
Becca	'And that aside from the work, that was like one of the only other things that would kind of get me in; was like you know, wanting to catch up with my friends and stuff'	Friends a supportive factor.
Emma	'I mean in year seven I probably would just ask my friends and just ask like, what are we doing?'	Friends a helpful and supportive factor.

Reliance on friends included helping them to understand the work they needed to do, to navigate unstructured times or provided motivation which outweighed the discomfort of particular scenarios or lessons; or they went in to school so that they could catch up with their friends. Friendships appeared as either a supportive role to help them understand the ‘system’ or just a feeling of belonging and connection, or a combination of both.

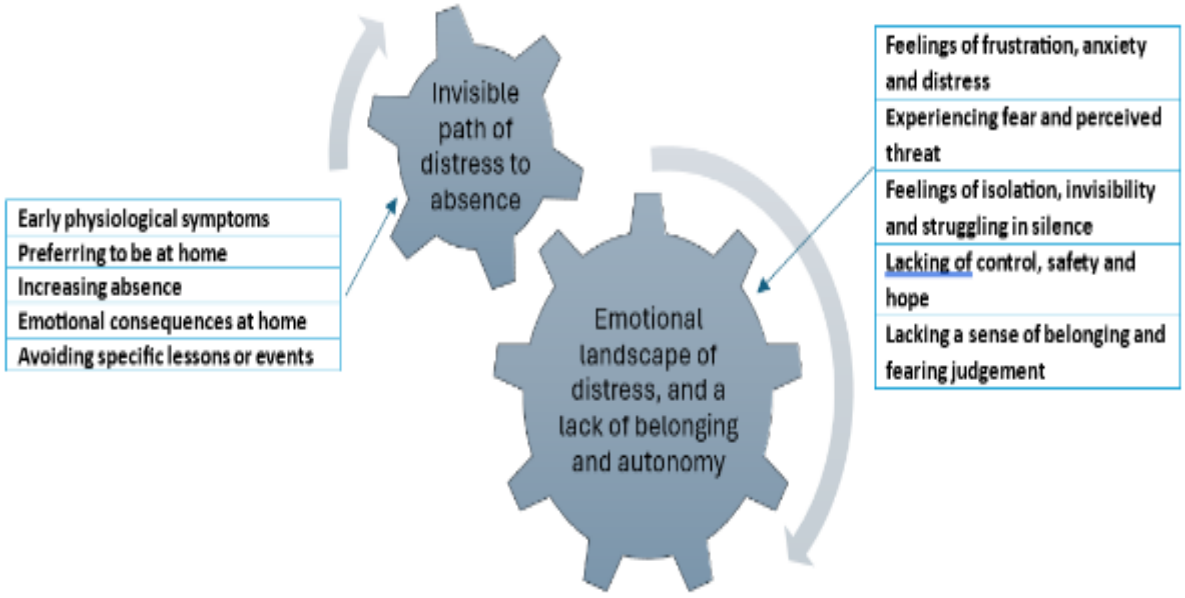
5.5.2 Unnoticed distress, lack of autonomy and defence mechanisms

This theoretical code outlines the interaction between the signs that the participants were not coping, which were invisible, not taken seriously, or not frequent enough to raise concern, as well as the distressing feelings and emotions they experienced. It demonstrates a two-way process between these factors. The signs that the participants were not managing in school were missed. As a result, they experienced continued negative emotional responses.

Figure 21 shows this interaction between the two focused codes.

Figure 21

Conceptual Diagram Of Unnoticed Distress, Lack Of Autonomy And Defence Mechanisms



It is worth noting that some of the quotes and codes that follow in this and the following theoretical code could be distressing to readers, as they relate to the participants' emotional experiences and mental health outcomes, and were experienced by the current researcher as very powerful.

Invisible path of distress to absence. This focused code describes some of the events and signs present, which school adults did not notice. They know this because none of them had additional support or interventions in place at the time they experienced them. The inclusion of Covid in this focused code sits slightly outside the nature of the other codes. However, for the participants who mentioned this, it was a trigger point for realising how difficult they were finding school and that

they could learn and feel better at home. In combination with the others, this is also considered an early warning sign.

Table 32

Constituent Initial Codes For 'Invisible Path Of Distress To Absence'

Initial code	Frequency
Avoiding specific lessons or events	15
Early physiological symptoms	12
Leaving	6
Preferring to be at home and difficulties separating from parents	13
Covid made me realise	7
Total frequency for focused code (including initial codes not shown)	**65**

Avoiding specific lessons or events. Four of the participants reported that skipping specific lessons or events was a key feature of their non-attendance, present from the early stages, before they became overwhelmed. For all participants, the reasons for avoiding a particular lesson included difficulties with the teacher (relationship or teaching style), dislike of the lesson (e.g. drama or P.E), or, as for Lina, something that they did not feel prepared for.

Table 33

Participant Quotes Highlighting 'Avoiding Specific Lessons Or Events'

Participant	Quote	Memos
Lina	'I was very anxious about it [tests and assessments in class], but I'd probably even put it in one because a lot of the time, even	First signs of school anxiety Skipping school on specific days E.g. tests/assessment, P.E., specific lessons/teachers

	before I'd stopped, you know, before I'd sort of burn out and stop completely attending, I would skip days where I had tests I felt unprepared for'	
Sam	[avoiding specific lessons] ‘I did. Yeah. That's just like me.’	Early signs of anxiety
Becca	‘And…I know that often when I first started to not attend, it would be the days that I had lessons that I didn't like the thing that we were doing. So like if it was a day that had drama or PE, then I was probably more likely to not attend.'	Early warning signs of anxiety and non-attendance
Emma	'when I didn't attend lessons because I couldn't predominantly, I think in my head at the time was linked to the the the lesson and the teacher.'	Can’t not won’t.

Early physiological symptoms. This question was asked directly of the final three participants based on data from the first two participants, changing the focus to earlier recognition. This code appeared for these three participants and were present *before* their absence became more chronic. The first two participants did express physiological symptoms, but these were related to their non-attendance once it had peaked.

Physiological symptoms reported included headaches, stomach aches and nausea, often resulting in increased illness absences, sleep difficulties, irritability, and feelings of paralysis and not being able to get their legs to work.

Table 34

Participant Quotes Highlighting 'Early Physiological Symptoms'

Participant	Quote	Memos
Becca	'I remember in… primary school where I went through a phase where I felt sick at every lunchtime and I remember telling the teachers that and being like, oh, I can't go to lunch because I feel really sick and them just being like, "oh, it seems to be that this only happens at lunchtime", like sort of accusing me of…I don't really. '	Early physiological symptoms prior to non-attendance.
Esmee	'I mean, I've always. I always struggle with my sleep anyway, but sleep got much worse. I'd wake up a lot in the night with bad dreams or I don't really know what it was, but I think anxiety is like waking up with quite a lot of anxiety'	Early warning signs- bad dreams, waking in night, struggling to get to sleep
Emma	'But I just was like, frozen in place by fear and anxiety of like, I don't want to go in.'	Early signs of anxiety and fear response

Leaving. Three of the participants reported early warning signs of leaving either the school site or the lesson, due to fear or overwhelm.

Table 35

Participant Quotes Highlighting 'Leaving'

Participant	Quote	Memos
Sam	'There were times, but before I had this card, I would just disappear. Like I would just, like, leave the classroom…there were maybe like two or three times they had to send out search parties for me.'	Leaving the classroom, needing space
Esmee	'And there was times like Mum would drop me off at school and then I'd run off the school playground because I didn't want to go to school'	Early signs of school based anxiety
Emma	'…in secondary school it got just that I just hated it so much, then felt so anxious about being there. It overruled the anxiety of, like leaving, and I was like, no, I'm leaving now because I I hate this so much'	Dislike of school now outweighed the fear of leaving and being told off.

Emma explained that the desire to leave had been present earlier in primary school, but that her fear of being told off outweighed the stress of attending. However, once she started at secondary school, this balance shifted: the thought of staying caused her more distress than the fear of being told off, so she began to leave the site. Surprisingly, these events did not raise earlier alarms. The frequency of these occurrences was not ascertained, and it could be that they were too infrequent to be noticed or deemed a concern at the time.

Preferring to be at home and difficulties separating from parents. This code was interesting and nuanced, and it involved additional questioning to

understand their response. For all participants, when asked the question ‘preferred being at home’, they unequivocally answered ‘yes’. This raised questions that needed further clarification—did they just want to be at home where they could do what they wanted, or was it something else not captured by the question?

Table 36

Participant Quotes Highlighting ‘Preferring To Be At Home And Difficulties Separating From Parents’

Participant	Quote	Memos
Lina	‘Yeah, yeah, that would definitely just like me [preferred to be at home]. And that was proved during COVID when I flourished.’	
Sam	‘Yeah, a little like me. A little like me, just because I knew I was going to do better work at home than I was going to do at school.’	Better learning at home
Becca	[Would you rather have been at home than at school?] Yes. [Asked whether it was due to not wanting to go to school, or not wanting to deal with the environment] Yeah, yeah. So maybe a little like me. And I think that was sort of a gut reaction because I was like, oh, no, I don't want to go to school, but I wanted to be at school if it was completely empty…and I just did my own thing.	Because of academic and social demands.
Esmee	‘I did so well academically when I was at home and it was just a	Happier being at home and learnt better

Participant	Quote	Memos
	much better environment. I was really happy during that period'	

With this deeper questioning, all participants recognised that their difficulty was not with school or learning itself, but with the school environment, and its many demands and expectations. They generally wanted to attend and learn, but found the environment unmanageable or the learning methods unhelpful. Only one participant also described separation anxiety, which further affected her ability to be at school.

Covid made me realise. Until this point, the Covid-19 pandemic and associated lockdowns have not featured prominently in the participants' accounts. They referred to it only to situate their school experiences in time, which was unexpected given how significant the period was for many people. Notably, none of the participants connected their anxiety to health or infection concerns, either during or after the pandemic. Although Covid was not a meaningful factor in their narratives, it is included here because of the wider discourse that positions the pandemic as a key driver of increased non-attendance.

Lina, Esmee and Emma were attending secondary school during this time and would have been in Years 7-9. Sam was at college in Year 13, and Becca was attending university, so their experiences of education during Covid are not relevant to the secondary education phase.

Table 37

Participant Quotes Highlighting 'Covid Made Me Realise'

Participant	Quote	Memo
Lina	'And then I flourished in COVID. I felt so happy. And then I went back, and it was just like everything hit me at once. So I realised I was not happy. I realised I was so anxious at everything. My nails. I started biting them again. I would fidget loads. I would struggle. I'd cry lots and I just realised that that wasn't normal…But it wasn't because of COVID that I didn't go. It was because I was struggling and I didn't realise it until COVID.'	Being at home during the COVID lockdowns enabled her to see how anxious and stressed school made her.
Esmee	'But I think also year seven we had COVID, so some of year seven, I was at home and I really loved being at home.'	Happier being at home and learnt better

Lina spoke about Covid the most and explained that whilst her attendance difficulties started at this time, they were not because of Covid, but that it made her realise how much better she felt at home and that there was another way of 'being'. The tone and intonation with which she described the first quote above were quite powerful in themselves and represented feelings of disappointment and resentment about having to go back and experience the overwhelm.

Emma only mentioned Covid once during her interview, and this was in relation to difficulties maintaining school friendships during this time, noting that

some of these friendships were lost because of lockdowns. She did not link this directly to then finding it difficult to attend.

Emotional landscape of distress and a lack of belonging and autonomy. This code highlights the participants' feelings associated with attending school and the struggles they faced, as well as their emotions during their non-attendance. Some of their accounts are powerful, littered with strong feelings of isolation, invisibility, fear and anxiety, and a perception of threat from the demands and unpredictability of the school environment. A lack of belonging and autonomy is also consistently experienced by all participants in some form. However, interestingly, for Lina, she felt she belonged before her non-attendance began, and so this, by itself, was not strong enough to counter the other things she was experiencing.

There was a significant increase in the occurrence of these codes across all participants' transcripts, and all but one of these initial codes occurred for every participant, indicating a high level of saturation for this focused code and its initial codes.

Table 38

Constituent Initial Codes For 'Emotional Landscape Of Distress And A Lack Of Belonging And Autonomy'

Initial code	Frequency
Feelings of frustration, anxiety and distress	110
Experiencing fear and perceived threat	44
Feelings of isolation, invisibility and struggling in silence	31
Lacking control, safety and hope	14
Lacking a sense of belonging and fearing judgement	29
Total frequency for focused code (including initial codes not shown)	**275**

Feelings of frustration, anxiety and distress. This initial code was the most frequently occurring across all code categories and relates to how the participants experienced the school environment and the feelings it engendered. As per a previous code, participant frequencies here are also included for context to aid the description of the code.

Table 39

Participant Quotes Highlighting 'Feelings Of Frustration, Anxiety And Distress'

Participant	Frequency	Quote	Memos
Lina	15	'I didn't have any room for anxiety because it was just complete despair.' 'cause I was like they'd, you know, logically they're doing everything they can, and I still can't go to school.'	Strong negative emotions- complete dispair
Sam	18	'Cause even during sixth form, even though I wasn't as worried about it, like there was always a dread of like fuck sake, like, no, not another day.'	Worry about school- strong negative emotions (dread)
Becca	15	'And I didn't like going places on my own, so if I had a lesson that was different to my friends then, like, walking there on my own was quite difficult.'	

Participant	Frequency	Quote	Memos
Esmee	36	'I was I got very, very anxious erm worrying about what people think and just like the idea of going back into that busy environment really.'	What others thought and going into the environment caused feelings of anxiety.
Emma	26	'I I I would feel so anxious about it because it felt like every time, even if I put, even if I put loads and loads of effort into something and really tried, I would still get corrections back.'	Could never get it right? Frustration.

Whilst the frequency of the occurrences is helpful, it is also worth noting that this does not account for the gravity of those feelings. For example, in Lina's interview, the intensity of the despair she recounted was felt by the researcher, projected through the screen; yet the frequency was lower. However, the frequency does provide some interesting information in that for both Esmee and Emma, whose transcripts included higher frequencies, they both ended up with alternative school packages and experiences of more significant mental health difficulties.

Experiencing fear and perceived threat. Slightly linked to the above is the participant's experience of fear and perception of threat. This code again occurred for all five participants.

Table 40

Participant Quotes Highlighting 'Experiencing Fear And Perceived Threat'

Participant	Quote	Memo
Lina	'Yeah, yeah, that's just like me very much [worried about school work].' 'Like, in year 8 I had this maths homework that was like just typical maths homework and I spent the entire evening crying over not knowing how to solve one of the questions.'	Worry about getting it wrong, not being good enough?
Sam	'That'd be terrifying, basically [going to breaktime alone]'	
	'Yeah. Just like, yeah, getting worried that I just wasn't gonna pass basically.'	Negative self-concept, fear of failing and not being good enough.
Becca	'There were quite a few that I found quite…authoritarian, I guess is the word and I was petrified of them.'	Strong emotional reaction- 'petrified'- fear.
Esmee	'I don't really know what the word was, but I guess I was kind of scared of it and feeling a bit overwhelmed.'	
	'[when the teacher told of other students?] Err two. I think because…I'd take it personally as well, especially because a lot of telling off was done to the class in general. So even if I knew that it wasn't necessarily me that did something or that they were telling	Take it personally, dislike of teacher telling off class/other students

Participant	Quote	Memo
	off about, it would still feel quite intimidating.'	
Emma	'I don't know whether I if I leave, am I going to get yelled at by these pastoral people? I I can't. I don't want to interrupt because they were still teachers'	Unpredictability of teachers responses and this feeling threatening to her?

For Lina, this fear was mostly about not being good enough and fearing failure. But for some, this experience of fear was more extensive, involving a sense of 'threat' arising from typical secondary school experiences, such as being told off, doing the wrong thing, stricter teachers, and something generally bad happening.

Isolation, invisibility and struggling in silence. This was another very powerful code, and these parts of the interview were incredibly emotive for the researcher. Even writing this section of the findings invokes the feelings experienced during the interviews.

Table 41

Participant Quotes Highlighting 'Isolation, Invisibility And Struggling In Silence'

Participant	Quote	Memo
Lina	'They were there [signs of autism]. They just weren't as obvious as my brother's. But I wasn't throwing chairs in nursery or refusing to do things. I was just struggling in silence.'	'Just anxiety'
	'I don't think anyone really properly understood the struggles I was	

Participant	Quote	Memo
	having…they just thought I was, you know, a little bit anxious about school and just skipping …out of misbehaviour'	
Sam	[feeling that people didn't believe you] ‘Oh, 100%, yeah. Just like me 100%.'	Perception from others as to the reason for her non-attendance. Others don’t understand. Feeling isolated as a result?
	'Yeah, they thought I was just avoiding it because of because it's just easier that way, which in some ways is true,'	
Becca	‘I just felt lost in the system I guess…Sometimes I look back and I think like was I literally invisible.'	I experienced very strong feelings of isolation and invisibility from Becca here.
	'[At least one adult you could talk to at school?] No.'; '[Or there were people to help you at school.] Not really.'	They felt all consuming, particularly when she then went on to answer no to the following questions.
Esmee	'And I think a lot of it was dismissed as just anxiety as well.'	‘Just anxiety’
	'[they didn't believe me] Yeah, I would say just like me.'	Not feeling believed by others
Emma	'Yeah. And in some ways, I think also I maybe sometimes thought like there's no point in explaining it because no, nobody gives a shit. Sorry if I shouldn't swear.'	The way she said this was very blunt and 'matter of fact'

For Becca, the feeling of invisibility she spoke of seemed to represent an abyss of isolation. Despite having a couple of teachers she felt a little more supported by, she reported having no adults she felt safe enough with to talk to.

While reporting staff were mostly friendly and enjoyed teaching her (because she was quiet and diligent), there was no support or connection, and even friendships were superficial.

For most participants, this code also related to the feeling that others did not believe their difficulties. A phrase used repeatedly by the participants was that others thought or might think that their experience was ‘just anxiety’, as though this felt less validating than being autistic.

Lacking control, safety and hope. This code represents the participants’ feelings of not feeling safe (emotionally rather than physically) and not feeling a sense of control. Due to the inclusion of information which could make the participants identifiable to a familiar reader, the pseudonyms are not included in this initial code, and the order of the quotes has been changed.

Table 42

Participant Quotes Highlighting ‘Lacking Control, Safety And Hope’

Quote	Memo
'[did the eating disorder come after the autism diagnosis or before?] No before, which I think that is what I got to crisis point because I wasn't coping in school and that was a coping mechanism to make me feel in control.'	Eating disorder as a mechanism to cope with school.
[did you feel you had any control in your life?] 'I don't think I fully felt like I had control and could make a difference, and I still feel like I think a little bit now’	

'I can't go into school. There's no point doing half days. There's no point doing the work they send me because either way, I'm just hopeless and I can't do it.' 'But at that point I think I was using my eating disorder to kind of as a crutch to cope with the massive challenge of changing schools after 12 years so'	Feeling of hopelessness and no being any point. I felt these emotions in myself, they were very strong and powerful. Eating disorder as a coping strategy.

Four participants reported a lack of sense of control, with one also recounting feelings of hopelessness and said that her anxiety was very much in control of her life at the time. Two participants developed eating disorders, which they viewed as coping strategies to gain some level of control. The participants' mental health needs are discussed in the ‘activated threat response and consequences of being unable to act’ theoretical code.

Lacking a sense of belonging and fearing judgement. All five participants reported feelings of not belonging and fear of what others thought of them. This made it difficult for them to accept adaptations because they did not want to look different, as highlighted above in the barriers, but this stemmed from a fear of how they were perceived by others.

Table 43

Participant Quotes Highlighting ‘Lacking A Sense Of Belonging And Fearing Judgement’

Participant	Quote	Memo
Lina	'it was more of, I'd worry like everyone would think I was stupid' 'but when I did [think about attending], I worried that I would	Impact of non-attendance of feeling of belonging and what others would think of her.

Participant	Quote	Memo
	feel really out of place going back, not understanding the work'	
Sam	'[did you sometimes feel like you didn't belong there] Oh yeah. Like 100%, just like, yes. 100% and good for good reason, for good reason.'	Lacking a sense of belonging
	'they were like, yeah, but like, you're also just being lazy kind of thing. And that would really suck, the lazy card…'	Judgement and perception from others
Becca	'I think I as also quite aware of how other people perceive me, so I think if I'd had like a reduced timetable or extra support, I might have been worried about how that would look to other students, I didn't want them to like single me out as weird or, you know, sensitive or that kind of thing.'	Fearing judgement and negative perception
Esmee	'It's not an accurate recall, but there was definitely me being left out, but I don't really know why, but perhaps it was due to communication, perhaps it was because I was a bit different, but no one really knew. Then yeah, I don't. I don't really know why, but yeah.'	Feeling excluded because of her differences.
Emma	'[At main in mainstream, did you have that sense of belonging at all]	Not being good enough if she does get told off?

Participant	Quote	Memo
	No, I no, I don't think I did. I think I I had moments where I was like, oh my God, my friends are really, really great and really helpful. But I didn't feel. I never felt like at peace or like, just calm.' '…And oh, I've been out of lessons for loads like people are going to think like, oh, people are, I don't know what people are going to think'	Lack of sense of belonging at mainstream

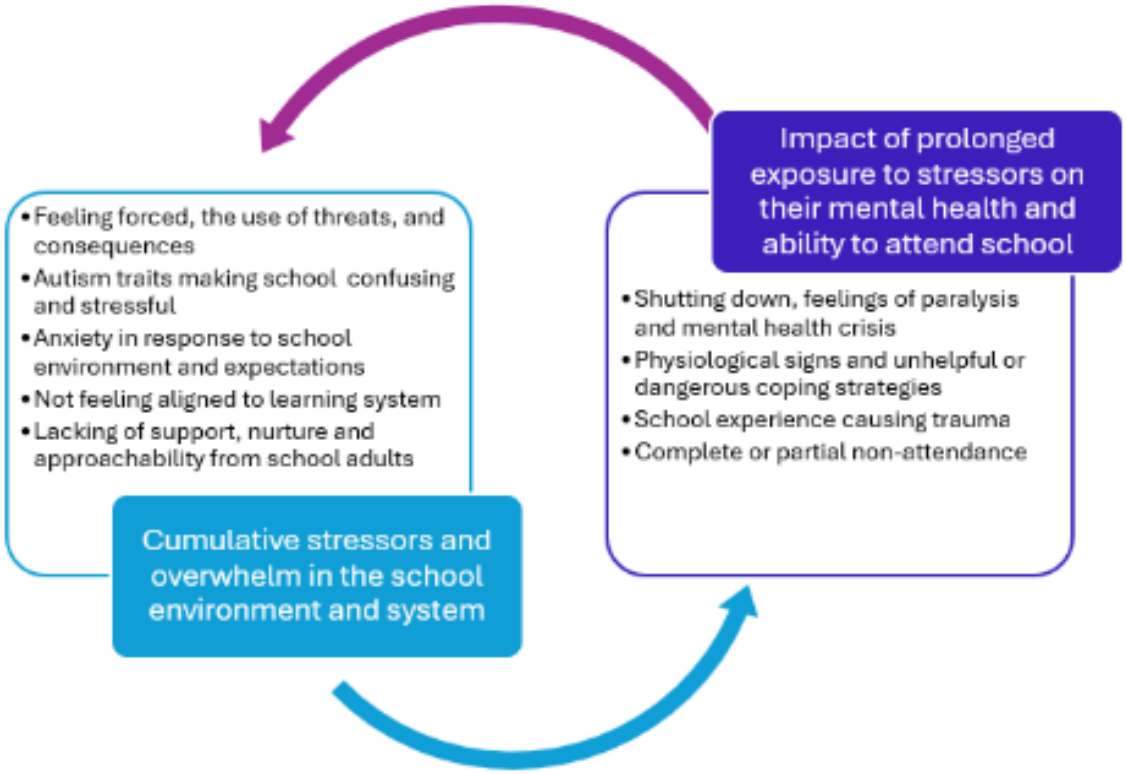
In the main, participants reported that they never had a sense of belonging at secondary school, both before and during their non-attendance, and that this worsened as their attendance reduced. Lina, though, reported a good sense of belonging at school until she realised how overwhelmed she was. For her, this sense of belonging only reduced as her attendance did, and she realised she was not able to keep up with the work because of what she had missed, and that she felt out of place with her previous friendships.

5.5.3 Activated threat response and consequences of being unable to act

This theoretical code highlights the cumulative nature of exposure to stressors and their impact on the participant's mental health. It's a two-way process because as their mental health and wellbeing reduced, their tolerance for events reduced and experiences they could previously manage became more anxiety-provoking for them over the years. Hence, this could be visualised as a spiral with their non-attendance and more substantial mental health needs appearing at the top as the 'culmination'.

Figure 22

Conceptual Diagram Of Activated Threat Response And Consequences Of Being Unable To Act



Cumulative stressors and overwhelm in the school environment and system. This focused code outlines some of the key stressors experienced by the girls, and, for most, these gradually accumulated over time. Other themes not discussed included friendship breakdowns and social pain, as well as a lack of alignment with the learning system, which caused frustration and made their time in school feel wasted. Sam explained that she would skip lessons, tell her peers she was off to do something fun and defiant, but actually go to the library to study by herself. This focused code has the highest frequency, with occurrences across all five participants, indicating a high degree of saturation.

Table 44

Constituent Initial Codes For 'Cumulative Stressors And Overwhelm In The School Environment And System'

Initial code	Frequency
Feeling forced, the use of threats, and consequences	27
Autism traits making school confusing and stressful	83
Anxiety in response to school environment and expectations	50
Lack of support, nurture and approachability from school adults	73
Total frequency for focused code (including initial codes not shown)	**333**

Feeling forced, the use of threats, and consequences. Participants discussed this initial code at different levels. Some felt pressured to attend school by others, or from themselves, and some recounted times when they sat in the car at school, crying, unable to get out.

Table 45

Participant Quotes Highlighting 'Feeling Forced, The Use Of Threats, And Consequences'

Participant	Quote	Memos
Lina	'They [school] tried with therapy with the kind of threat that they'd fine my parents otherwise, because I can't just not be in school for no reason'	Push factor (away from school). Helpfulness of this when difficulties are so significant
	'When I wasn't going at all, she [head of year] came [to the house] and pretty much ordered me to get up out of bed and come to school, and I was I completely shut down in that moment.'	Wondered if this made things worse?

Participant	Quote	Memos
	‘They [parents] were like trying to sort of force me and they were driving me to school in tears.’	
Sam	'I definitely had pressure [to attend] from my parents. Yeah.'	I wonder what this entailed e.g. you need to go to school to do well. Could this be viewed as a threat or consequence?
Becca	'Well, there was sort of never a doubt in my mind that I had to go to school, but I knew, obviously it's the law'	Placed the pressure on herself to attend.
	'So for me to not attend, it felt like a bit of a like…me being ungrateful or something, not that they said that, but that's how I felt.'	
Esmee	‘But I would do it [answer a question in class] because I think I would have felt more anxious about what people would think if I didn't respond.’	Consequences of not conforming led to her anxiety so had to weight up which level of anxiety was greater?
	I'd say probably from school [pressure to attend], yes. So I guess a little bit.	
Emma	‘to begin with like like my mum would sort of like yell at me to like you've got to. You've got to get up’	

Lina spoke of being ‘sent’ to therapy, which she also struggled to attend. She recalled being threatened with discharge if she did not attend; unsurprisingly, she was discharged. She also recounted a teacher coming to the house and going up to her bedroom to try to get her out of bed, but because of the distress this caused, the teacher backed down.

For other participants, the pressure came from themselves, either because they knew they should be attending school or because they still wanted to do well. Becca felt added pressure because she attended a private school paid for by her parents. Esmee also felt that the pressure was on her to make the adjustments, rather than on adults. She was forced to make the effort to communicate her difficulties after realising that nothing would change if she did not. Despite finding this incredibly challenging and communication differences being inherent to her needs, *she* was able to find ways to make this a bit easier.

Autism traits making school confusing and stressful. This code developed from combining several initial codes that captured experiences participants found stressful, which can be seen as relating to their autistic differences. It appeared across all five transcripts and was the most frequent initial code in this category. The sorting activities were particularly valuable in clarifying the specific types of difficulties involved. As noted in an earlier code, many responses were qualified with “it depends,” highlighting the contextual nature of these stressors.

Table 46

Participant Quotes Highlighting 'Autism Traits Making School Confusing And Stressful'

Participant	Quote	Memo
Lina	'It [canteen] was really packed really loud. The benches were extremely close together to the point where I'm like, wow, I really should not be that hard, like, I shouldn't have to climb over 16 people to get to the end of the bench. There was no space to walk down the like the aisle was between benches. A lot of the time, the food would really distress me, tables weren't cleaned like after every person that ate in them... It stressed me out.'	Source of high anxiety- Noise, busyness, people staring/judging, social expectations/demands, crowds/lack of space, smells/food, cleanliness
Sam	'I hate that [working as part of a group]. I hate that I would put that like like, yeah, like, avoided all the time yeah, to be honest.'	Source of high anxiety
Becca	'I know that I did find it really difficult being in that social space [lunchtimes/breaktimes].'	Autistic differences
Esmee	'…because it was art and it was quite ambiguous. Some of the tasks and I was struggling with the fact that there was a lack of structure and the teacher wasn't very good and the teacher would just sit at the front of the class and just let the class be talking really loud the entire time.'	Ambiguity a difficult experience for her.
	'Or if it was like 3 pieces got set on one day, even if the pieces were set… like	Changes in expectations and overwhelm.

Participant	Quote	Memo
	one was due in next week, another one due in… two weeks time. Just that amount would overwhelm me.'	
Emma	'[starting a task you hadn't understood] I I really struggled. I I open-ended tasks where I didn't know what was like wanted from me was a really really difficult. '	Source of high anxiety and potential avoidance. Also not being good enough if she does get told off/gets something wrong? Teachers seem to feel very threatening and unpredictable to her.
	‘I wouldn't necessarily understand…because some of the teachers like you have to be quiet, but it's like, but if you don't understand what's going on, surely you have to be able to ask somebody and you don't want to anger the teacher who's already been kind of angry and saying you have to be quiet. So you want to ask a friend. But then it's like your teacher will get more annoyed that you’re asking a friend because they'll think you're talking’.	Very literal thinking

Participants reported many stressful experiences that could be linked to their autism, including environmental overload, social aspects of school and learning, unstructured times, ambiguous language, difficulty understanding tasks, and other students ‘messing around’, to name a few. Emma found unstructured times particularly challenging and spoke about putting her own structure in place to better manage them, such as going to different places at different times (e.g., the library, a classroom), either with others or by herself. These difficulties caused anxiety, and

the following initial code describes some of this in more detail. The participants' responses during the Mapping the Landscape of Fear activity provide interesting additional information about the type of experiences they avoided the most.

Anxiety in response to school environment and expectations. This code is slightly different from the previous one; however, it is still linked to the participant's autistic processing differences. This code highlights *how* and *why* the school environment and 'normal' expectations caused them stress.

Table 47

Participant Quotes Highlighting 'Anxiety In Response To School Environment And Expectations'

Participant	Quote	Memos
Lina	'In a in a lot of scenarios erm where people would say stuff, it would give me quite a lot of anxiety to not know what they meant or to feel like people interpreted it differently than I did.'	Understanding of language, the task, expectations, rules and norms- autism related too
Sam	'It's it's like with when you have a worry, I think with autism and you have ADHD as well, you're look, you're always looking for the next thing that can happen...So yeah'	Hypervigilance?
Becca	'[avoid specific teachers?] Yeah, I'd say any that shouted. I didn't like that. And any, I mean, there were some that had been at the school for quite a while. It tended to be them that were more sort of strict and not very approachable.'	Teachers shouting a source of anxiety.

Participant	Quote	Memos
Esmee	'I think…even if I have one piece of homework I'm worrying about it not necessarily to do with the content of the homework but say I've planned out to do something in a day and then I get told I've got homework to do. That would be quite anxiety producing.'	Changes to expectations cause of anxiety
Emma	'Sometimes I did find that anxiety provoking because some teachers are like, yeah, go in, sit down, be prepared. Like other times teachers would get annoyed at you for not going in and doing that, whereas some teachers would be like, you can't enter my classroom like you have to wait outside. Like, what are you doing? So there was a bit of anxiety of like, especially with new teachers or at the beginning of terms or whatever when also or at the start of a term where, you know, they changed the seating plan. So you can't…and then being told off for something you didn't know, had no way of knowing and different teachers do it different ways. And the expectations are completely different.'	Unpredictability and fear of being told off for doing what she thinks is the right thing

Sam spoke a lot about how her brain worked differently and how she viewed things differently from others, which made group work particularly difficult. She learnt that she needed to weigh up how important it was for her to express her view against the possible repercussions of doing so. Becca spoke several times about teachers who shouted and the anxiety this caused her. For most participants, the unpredictability of school and the teacher's responses was difficult, and Emma, in particular, felt fearful of inadvertently doing the wrong thing. Esmee spoke quite clearly about why homework was a challenge for her, as it changed her expectations and routine for the evening or the next few days, and she was overwhelmed when she received multiple pieces in one day.

Lack of support, nurture and approachability from school adults. This initial code also appeared for all five participants, though to a much lesser extent for one. This code was concerning, although four participants also acknowledged that the teachers often tried their best and understood the challenges they faced, as already identified.

Table 48

Participant Quotes Highlighting 'Lack Of Support, Nurture And Approachability From School Adults'

Participant	Quote	Memo
Lina	'especially with um teachers, that sort of punish you for, for not listening, when [they] knew damn well that I was paying attention and that there was just one bit I missed in their list of five instructions.' [did you feel that teachers understood] 'I would put it at a 2, only because I know	Feeling punished for not 'making an effort' or 'paying attention'

Participant	Quote	Memo
	they tried otherwise they would be a zero.'	
Sam	‘[anything that they tried that made things worse for you?] They did do this thing once where they thought it'd be helpful to put me in a room with all my bullies and they were like, I think you should, like, tell them, like, how you've been feeling.’	
Becca	'Erm, no, I don't think they really did anything. I don't know, maybe they did, but I can't remember. But I don't can't remember anything. [or perhaps it was happening behind the scenes?] Yeah, maybe, but then I didn't feel like anything had changed though.'	Didn’t feel teachers did anything to try and support her.
Esmee	'…but I'd say I got very much underestimated. My ability was very much underestimated. Like I got told drop a GCSE. It'll be, you know, more relaxed, you’ll cope better if you drop a GCSE. Well, I got six 9s, a 6, a 7 and an 8. So I don’t really think I needed to drop a GCSE.'	Underestimated suggestive they aren’t supportive or setting high expectations for her?
	‘I'd say it was all on me…I think I started to use quite a lot of emails because that was an easier way to like if I'd come out of class and I was upset about something, I'd e-mail about it rather than wait till the end of class and talk to someone at the end.'	She made the effort to find adaptations that worked for her and initiate this. Didn’t feel effort from teachers in helping her to communicate.

Participant	Quote	Memo
Emma	'There were things like like they teachers were supposed to and had been emailed by like the pastoral team that I have to be sat either at the back or by the door with somebody, like with one of my friends. But some teachers would just disregard that, some teachers would specifically would put me at the front ' ‘Some, it would be a sort of ego thing of thinking, oh, I'm like I'm a teacher and you're a student, so I must be doing... Must be helping because you know I'm an adult, ‘	Lack of teacher reflection and flexibility, arrogance?

Participants discussed aspects of this code extensively in different forms. A recurring issue was the language adults used and the inconsistency of their responses, which left them unsure of where they stood and often afraid to seek clarification. Emma, for example, described the stress she felt when a teacher, frustrated by classroom chatter, instructed the class to “be quiet” or said, “don’t say a word.” She then became highly anxious about asking for help, fearing she would be shouted at simply for speaking. This uncertainty extended to not knowing whether a teacher would respond supportively or with irritation. Becca similarly expressed disappointment that her teachers were not more nurturing, describing feeling ignored and invisible. Another participant recounted entering a room to hear her teaching assistant speak unkindly about her and her family, which led to a complete breakdown in that relationship and necessitated a change of TA. In contrast, as noted earlier, Sam’s experience was markedly different; she described her teachers

as consistently helpful and supportive, and this code appeared only four times in her data compared with twenty for Esmee.

Overall, within the mainstream secondary environments, four of the participants experienced most of the teachers and other adults at school negatively and described some of them as accusatory, unhelpful, arrogant, unapproachable, authoritarian, unresponsive, inconsistent, inflexible and underestimating of their potential. There were, of course, exceptions among all participants, and this reflects a general view.

Impact of prolonged exposure to stressors on their mental health and ability to attend school. This focused code describes the impact of their secondary school attendance and unmet needs on their mental health. The participants are very clear that their mental health suffered because of the stressful experiences outlined in previous codes, and that they saw an improvement in their mental health when they did not attend school. One participant explained that she had also experienced an earlier trauma, which contributed to her mental health crisis and its severity, but following a significant amount of therapy, she was also clear that her school experiences contributed considerably to this.

For this code, pseudonyms are omitted, and the quotes are presented in a different order to prevent readers from identifying an individual to their pseudonym.

Table 49

Constituent Initial Codes For 'Impact Of Prolonged Exposure To Stressors On Their Mental Health And Ability To Attend School'

Initial code	Frequency
Mental health crisis, shut down and feelings of paralysis	45

Physiological signs and unhelpful or dangerous coping strategies	21
Impact on identity	3
School experience causing trauma	8
Total frequency for focused code (including initial codes not shown)	80

Mental health crisis, shut down and feelings of paralysis. Four participants experienced significant mental health 'breakdowns', characterised by shutting down and being unable to attend school. They highlighted this as different from not wanting to attend; the difference between can't and won't.

Table 50

Participant Quotes Highlighting 'Mental Health Crisis, Shut Down And Feelings Of Paralysis'

Quote	Memos
'I'd sort of describe it as being like in a state of paralysis like I just… Either I wouldn't get out of bed or I wouldn't get out of the car when we got there; but I couldn't explain what it was that was the problem.'	Link to X's codes of complete shutdown, incapability, shutdown for self-protection
'Because I think my parents were so pleased that suddenly I'd gone to a new school and it was all fine. And then I don't know if, like, subconsciously going to hospital was a way of being like…escaping from it in a way. So 'Oh, I'm too ill to go to school, What a shame' 'Which was yeah, which was a dangerous coping mechanism [eating disorder],	Eating disorder as a dangerous coping strategy and hospital admission better than attending school

Quote	Memos
which I know now. But at the time it helped me.'	
'I'd say physically the feeling of going to school like some days mum would drive me to school and my legs, I just literally, I couldn't walk.'	Feeling of paralysis? Link to B?
'But I think the mental health was because I wasn't coping and that the mental health condition that I had [eating disorder] was kind of a way of me controlling things.'	Eating disorder as a coping mechanism for school?
'…I was exhausting myself from completely. I I'm like, I mean, I'm definitely completely burnt out. I definitely burnt myself out. And that was definitely what was happening.';	Burnout, exhaustion
'At that point, like my mental health had taken such hit my anxiety was so bad I was getting really depressed.'	Feeling depressed and mental health decline.
'I was laying in bed, not really seeing my friends. I wasn't eating well. I wasn't well that emotionally.'	Poor mental well-being impacting whole life not just ability to attend school
'And I was just sat there crying saying that I can't do it. I can't go in, stop trying to make me. I'm just so anxious. I can't do it.'	

All participants reported anxiety, with some receiving diagnoses of anxiety disorders and depression, and two developing eating disorders, which they reported enabled a sense of control and ability cope with the pressure of school. Both participants received support from specialist services, with one being hospitalised for

several months. A third participant also reported not eating well, but did not report that this developed further.

Sam was the only participant who did not experience a substantial mental health need; however, she did report experiencing significant anxiety and burnout. The possible reasons for this will be considered in the discussion section.

Interestingly, when comparing the participants' sorting activities, the three participants who experienced the most significant mental health needs, reported that school-based experiences caused them more anxiety during the mapping of the landscape of fear activity. They reported more frequently that they avoided certain things ‘all of the time’ or were ‘very’ anxious about them. All participants reported similar risk factors in the school well-being card sorting activity; however, the same three participants reported the fewest protective factors.

Physiological signs of distress and anxiety. During their increasing non-attendance, four of the five participants reported physiological symptoms. This question was not asked from the fifth participant and so it should not be assumed to have not been present; she did experience physiological symptoms prior to her non-attendance. Pseudonyms are again removed from this section, and the order of the quotes are random.

Table 51

Participant Quotes Highlighting ‘Physiological Signs Of Distress And Anxiety’

Quote	Memos
'But at that point I think I was using my eating disorder to kind of as a crutch to cope with the massive challenge of changing schools after 12 years so…And	Eating disorder as a coping strategy

that was already around at my last school [ED], but it got much worse.'	
'Oh, for sure. Yeah, for sure [felt unwell when thinking about school]. Just like me. Oh, my God.'	Physiological symptoms in response to school
'[I felt unwell when I thought about school.] Oh, just like me'	Sleep difficulties as a result of anxiety.
'I'd wake up a lot in the night with bad dreams or I don't really know what it was, but I think anxiety is like waking up with quite a lot of anxiety. '	
'…quite consistently I would get stomach aches all the time. I would get headaches, I'd feel nauseous. It would feel like an ache in my chest.'	Watching TV, YouTube etc as distraction techniques to quell some of the unpleasant feelings. Not a reinforcing factor but a coping strategy.
‘[I’d] just use any distraction method I could get my hands on... to sort of not have to think about it [school], because that every time I did, I would feel ill and distressed.’	

A previous code considered early physiological symptoms before the peak of their non-attendance. This code relates to those symptoms at the time when their non-attendance and anxiety were at their worst. For most, just the thought of school would trigger their physiological symptoms, and for one this would lead them to shut down.

Impact on identity. The impact of school attendance on identity did not feature prominently in the transcripts, possibly because the question was not asked directly. However, it was raised by one participant who is female and identifies as such, but explained that she is exploring her femininity. This participant was also the

only participant who reported being from a minority ethnic group and a first-generation immigrant.

'It's actually…had some major effects like because I went to an all girls school, and my mother was autistic, she wasn't incredibly feminine either. So then it also even had an effect on my identity as like a woman I was like, am I?... I wasn't like the other girls and I wasn't liked by them either…. So now I was just looking at myself being like…What the, what the heck?'

Whether this initial code truly fits within this focused code is open to debate. It's been included here because the combination of the stress of a secondary school environment, attending an all-girls school, and her autistic needs could be contributing to her questioning her identity, causing some level of confusion for her.

School experience causing trauma. This code developed from the final three participants' accounts. It was not a question asked of them directly, but appeared in their answers to other questions.

Table 52

Participant Quotes Highlighting 'School Experience Causing Trauma'

Participant	Quotes	Memos
Becca	'But now that I've got the awareness, I am autistic, I think…that has also caused some trauma, I think, particularly in my school experience…Erm…I think…Yeah, I'd say that probably contributed.'	Experiencing school as traumatic and contributing to her mental health needs.
Esmee	'No..well...In primary school, there was a friendship group, but it was very rocky, very toxic friendship	

Participant	Quotes	Memos
	group, which I think I do have a bit of, perhaps trauma there.'	
	'Like I often have, like flashbacks or dreams about that, and I think after that I never really had a stable group of friends.'	Trauma like symptoms
	'…I would say there's quite a lot of perhaps trauma there from primary school that is still there and will need to eventually be explored.	Feeling of school causing some level of trauma for her.
Emma	'So I'd say more on the not like me in the sense that if if somebody were to go, oh, do you want to go to school again? I'd be like absolutely not never again. But more from a fear place than I. I don't know. It's a weird one.'	Ability to trust adults eroded away
	'I let myself think I could trust this teacher to be a bit more caring and then they're not. And then… I'd just be like it just I just lost. Slowly lost all trust in the system completely.'	

Esmee also explained a situation when attending open days at local colleges. At one college, they were asked to wear their school uniform to the open day. She was not attending but was still on role and found it very difficult to put on her old school uniform, suggesting a possible link between the uniform and feelings of stress.

The following theoretical code moves away from the distressing and serious nature of the participants' school experiences and highlights their re-engagement and achievement, as well as the factors that supported this.

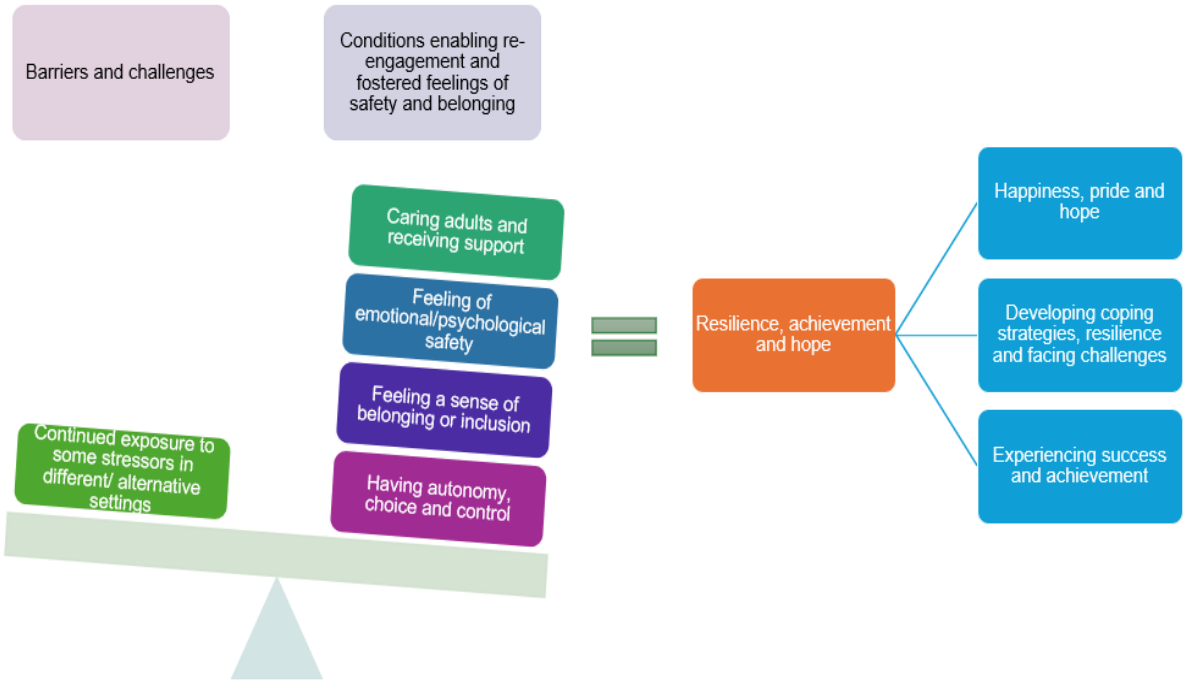
5.5.4 Long term outcomes- Re-engagement, autonomy and resilience

This theoretical code considers the outcomes achieved by these participants and the relationship between these outcomes and the conditions which supported them. It is important to recognise that the participants are still autistic and continue to have differences which make the neurotypical world difficult for them to negotiate, as such, barriers still exist. But through being in a more supportive environment, the ‘balance’ was in favour of the supportive factors, which now outweigh the barriers. It has been presented in a similar way to the initial theoretical code to highlight this shift.

For all participants, positive outcomes were experienced despite chronic non-attendance at critical stages of Key Stage 3 and 4. As positive outcomes became evident, the factors present for them that enabled this success were explored.

Figure 23

Conceptual Diagram Of Long Term Outcomes- Re-Engagement, Autonomy And Resilience



Resilience, achievement and hope. This focused code explores the outcomes achieved by the participants, both academically and in terms of life skills such as resilience and the development of their own coping strategies. They all felt a sense of pride and happiness in what they have achieved and where they are now. The factors that supported these outcomes and their re-engagement are considered in the next focused code.

Table 53

Constituent Initial Codes For 'Resilience, Achievement And Hope'

Initial code	Frequency
Experiencing success and achievement	17
Developing coping strategies, resilience and facing challenges	34
Total frequency for focused code (including initial codes not shown)	64

Experiencing success and achievement. This code reflects the participants' achievements despite their low attendance. As a reminder, Lina and Becca did not attend school for the majority of Year 10 and 11, and Esmee and Emma were accessing education through alternative packages.

Table 54

Participant Quotes Highlighting 'Experiencing Success And Achievement'

Participant	Quote	Memos
Lina	'out the seven that I sat, I got two sixes, 2 sevens and three eights which was complete like I opened my results and I like my jaw dropped…and then then I went into sixth form not feeling so useless because I got the grades and I came out of sixth form with A*, A*, A.'	Seeing she could achieve was a pull factor back towards education.
	'I'm going uni in September now.'	Made it through, new beginnings
Sam	'I still left with a great a brilliant set of friends, and I got a brilliant set of grades and I've got a really good degree and a really good job, so I	Success and achievement-sense of pride?

Participant	Quote	Memos
	was just kind of like, wow, and I did that all on my own, like all'	
Becca	'I did XX for undergrad and I'm doing a master's in XX.'	
Esmee	'Well, I got six 9s, a 6, a 7 and an 8.' 'And I have, yeah, I have to sit entrance exam (for university) this summer for it so.'	High achievement despite non-attendance, alternative education package and MH needs
Emma	'I I know what I'm doing now and that I'm enjoying what I'm doing now'	Content, employed and exploring interests.

All five participants reported being in a much better position and being happy and proud of what they have achieved. For four of the participants, this has or is due to include continuing education at university, at undergraduate and master's level, for Sam and Becca.

Lina and Sam both expressed pride and happiness in what they had been able to achieve and for being able to improve their attendance. A quote from Sam feels quite pertinent to include here:

> 'I got it [my diagnosis] after I've survived school and basically that I still achieved everything I wanted to achieve.'

Developing coping strategies, resilience and facing challenges. The participants reflected on what they did, which enabled them to cope better when they were attending, whether they knew at the time that this was what they were doing or not. They often faced their challenges, though rarely through choice, and have still achieved well, achieved good outcomes, and perhaps are more resilient as a result.

Table 55

Participant Quotes Highlighting 'Developing Coping Strategies, Resilience And Facing Challenges'

Participant	Quote	Memos
Lina	'I sort of went in [to school] with the mentality that, you know, the days aren't going to be completely the same and that I had to cope with it [changes]'	Unpredictability of school which she had to accept and cope
Sam	'Yeah. I was comfortable with doing it... I think when you have autism, when you have those experiences, you constantly have to do things that you find difficult, don't you';	Pushing herself to face challenges
Becca	'probably finish it like at home or something.'	Coping strategy for if she couldn't finish a piece of work at school.
Esmee	'But then I think I've I learned that if I don't ask for things then things will never get sorted out. So I think I gained a bit more confidence in the fact that I needed to speak up.'	
Emma	'I think without realising it, especially in year seven, I built a routine of like, well, me and my friends will go do this and then we'll go do that and then if I've got a club this day, I'll go to like the lunch hall really quickly and then I'll like go to my club'	Put in place own structure to manage unstructured social times. Overwhelm of having to plan and think ahead to that detail

Becca explained that she was comfortable with not being able to finish a piece of work, explaining that she'd take it home to finish it on these occasions. This

suggests that she had developed a way to cope with something she found tricky without realising. Emma also spoke of her challenges with speaking up and felt that it was all on her to do so, which, for someone with a communication difference, was hard. But she has come to appreciate that this has enabled her to understand the need to advocate for herself.

Conditions enabling re-engagement and fostered feelings of safety and belonging. This focused code explores the participants' accounts of their experiences after re-engaging in education, and the differences they felt between this and their secondary school experience. The factors they reported as important were individual, so there is less saturation across these focused codes across participants. However, they were an important mechanism of change for the individuals and may be for others as well, so they are included. Additionally, this line of questioning developed toward the final interviews and was not consistently and explicitly asked of all participants, which may have affected how frequently these themes arose.

Other themes emerging from their more successful settings included calmer environments and more structure, better feelings of safety, belonging and inclusion, flexible schooling, and experiencing adults who cared and offered support.

Table 56

Constituent Initial Codes For 'Conditions Enabling Re-Engagement And Fostered Feelings Of Safety And Belonging'

Initial code	Frequency
Having autonomy and choice and taking control of their learning	13
Fresh start	6
Caring adults and receiving support	8
Parental support and fight	24
Total frequency for focused code (including initial codes not shown)	75

Having autonomy and choice and taking control of their learning.

Comments from four participants highlighted the importance of being able to take control of their learning and having more choice.

Table 57

Participant Quotes Highlighting 'Having Autonomy And Choice And Taking Control Of Their Learning'

Participant	Quote	Memos
Lina	'In sixth form, yes, because … I picked subjects I was interested in. So it's no longer being forced to study things I didn't want to.'	Supportive factor- having choice over what to study and where.
Sam	'And also I did have a year out of school after I left education... But of my own way of teaching and I was like, oh, wow, OK, guys, I'm actually not that…[stupid-inferred]'	Interpretation of her non-verbal cues; she appeared to be referring to being able to learn better by herself and realised she was clever/capable.
Esmee	'So we got, the Council gave us funding for tutoring and then we	Autonomy over learning.

Participant	Quote	Memos
	chose what tutors we wanted or I wanted.'	
	'but I think by doing stuff at home it made me feel in control and yeah, '	
Emma	‘And there's definitely a teething period of realising like, oh, your education doesn't need to be the same as everybody else because actually it is not…There is not just one track for education. This is different and it is like and life is not about education. It's about being OK and enjoying it.’	

Lina explained that being able to study subjects she was genuinely interested in at sixth form, and having choice over where she attended, made a meaningful difference to her experience. Similarly, Sam felt that taking a year out and directing her own learning helped her recognise her capability, which enabled her return to education. For Emma, taking control involved realising that an alternative pathway existed and that it suited her needs. She also reflected that the strong pressure to remain within the mainstream system delayed this realisation, and by the time she began to explore alternatives, her mental health had already deteriorated.

Fresh start. Two participants reported that the fresh start they experienced at college/sixth form was a significant factor in their success.

Table 58

Participant Quote Highlighting 'Fresh Start'

Lina	[Was your Post 16 provision attached to your secondary provision?] 'No, and thank God not because I think if it was, I wouldn't have gone…I went to one that was sort of down the road. It was brilliant. They were amazing…Complete fresh, thank God, because I needed it. I needed the fresh start.'

During her interview, Lina spoke frequently about her strong desire for a fresh start and felt that if she'd been able to start Year 9 again, things might have been different. However, being a year younger would have caused her a lot of anxiety, and the fear of standing out and judgment would have prevented this, even if it had been possible.

Esmee also reported that having a fresh start in her current setting was important. Her trust in adults had been damaged in her previous school, but when asked whether this continued to impact her, she explained:

Table 59

Participant Quote Highlighting 'Fresh Start'

Esmee	'I'd say not my new school, but I don't know if that's just because I associate that with a fresh start and different'

However, fresh starts were not helpful for all. One participant changed schools after being in the same one for 12 years, which she links to the deterioration of her mental health:

> "But at that point I think I was using my eating disorder to kind of as a crutch to cope with the massive challenge of changing schools after 12

years”

She felt resentment about having to change schools, which affected her sense of belonging and her ability to consider returning to the new school after her hospital discharge.

Parental support and fight. Consistent across all five participants was the support they received from their parents and their ability to advocate for their children. It has been included within this focused code because of the key role they played in getting their children the support they needed; however, it sits slightly differently to the others in that this support was in place before they re-engaged in learning and was not unique to their successful placements, but it was still a crucial factor in enabling their re-engagement and in securing their successful provision.

Table 60

Participant Quotes Highlighting ‘Parental Support And Fight’

Participant	Quote	Memos
Lina	'And she [Mum] pretty much immediately like dropped everything. She booked me a private appointment because she didn't want to go through the NHS again for the third time, knowing how annoying and long it is to get those.'	
	'They couldn't have done much more than they did without, you know, me really shutting down completely'	Parents did try, it was frustrating for them too.
Sam	‘my parents were on my first line of defence because obviously I'd be like God I think, I think I'm getting bullied or they they would be like guys. I think she's getting bullied	

Participant	Quote	Memos
	and my parents would 100% swoop in and be like, let me talk to a teacher.'	
Becca	'I think they knew it was a lot more than I just didn't like school because I'd always loved school, so… and I had no problem sitting at home doing all the work that the school sent home.'	Parents knew it was more than just her not liking school- had seen a change.
Esmee	'But then Mum pushed and I ended up getting a TA in that class.'	Parents had knowledge and capacity to fight- what about those who don't, could this be a reason for the above average outcomes?
Emma	'So to begin with, we took a bit of a risk [getting home tutors] because we didn't know if we were going to get funding from the Council.' 'my mum…like would join Facebook groups, would join all sorts. She's the one who … would talk to the school and … eventually … did all the sort of groundwork to get my EHCP and … like, grew her understanding that joined loads of Facebook groups and and that group.'	

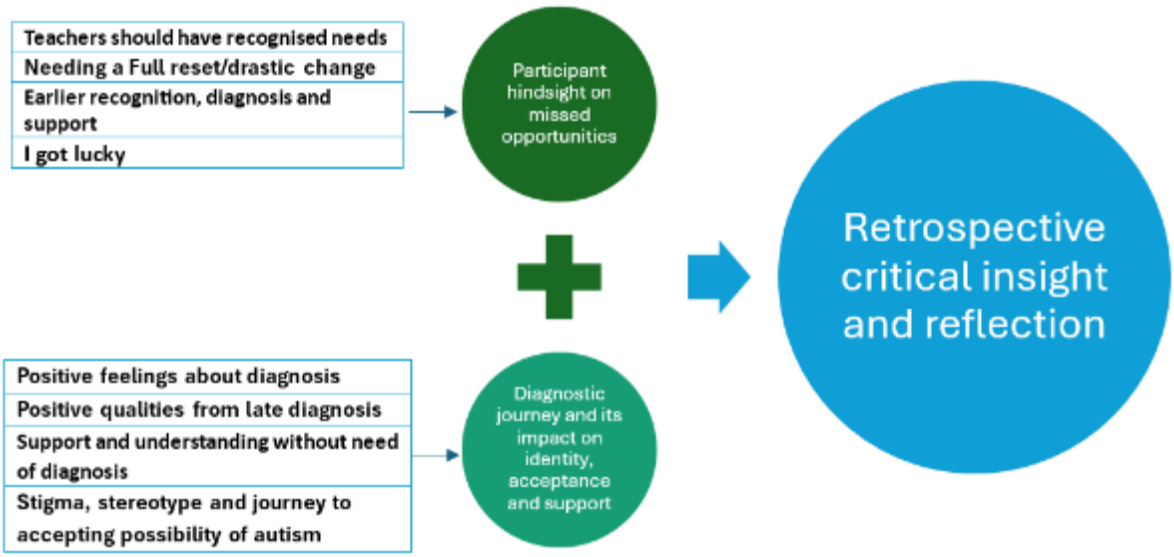
From liaising with the school about their daughter's attendance to obtaining autism assessments and pushing for additional support, including Education Health Care Plans (EHCPs), fighting for alternative provisions, the participants' parents were all supportive and proactive in their education and well-being. Esmee's mother even suggested that Esmee take two of her exams earlier to help her prepare for what they would entail in a more controlled manner, which the school agreed to and was very successful for her.

5.5.5 Retrospective critical insight and reflection

This theoretical code reflects the participants' views on missed opportunities and the impact of receiving a diagnosis. It stands alone in the emerging theoretical framework and adds information to the potential mechanisms for change that could prevent other individuals from experiencing similar difficulties and consequences at school. Overall, their critical reflections lean heavily towards a focus on earlier recognition of needs and subsequent support, but most participants argue that this should not necessarily require a diagnosis.

Figure 24

Conceptual Diagram Of Retrospective Critical Insight And Reflection



Participant hindsight on missed opportunities. This focused code highlights the participants' thoughts on what more could have been done to support them. Teachers recognising needs and receiving an earlier diagnosis and support were generally viewed as the main things that could have helped. Still, Lina felt she needed a full reset, and Emma also said that a drastic change would have been needed to make things more manageable for her, which links to previous codes around learning differently. It’s important here to link this to a previous code in which all participants also expressed that, by the time they had stopped attending, it was too late. By that point, they felt nothing more could have been done, again emphasising the importance of earlier recognition and intervention.

Table 61

Constituent Initial Codes For ‘Participant Hindsight On Missed Opportunities’

Initial code	Frequency
Teachers should have recognised needs	10
Earlier recognition, diagnosis and support	9
I got lucky	8
Total frequency for focused code (including initial codes not shown)	**32**

Teachers should have recognised needs. Four of the participants said that they felt their teachers should have recognised their needs, or that, in hindsight, the signs were present.

Table 62

Participant Quotes Highlighting 'Teachers Should Have Recognised Needs'

Participant	Quote	Memos
Lina	'They were there [signs]. They just weren't as obvious as my brother's'	
Sam	'They should to be fair, I do think maybe they should have been like, why don't you go for an ADHD diagnosis or something like that or go for a diagnosis? Because I was trying like I was talking to these teachers like, yeah, like I this is quite this. This is quite a loud experience kind of like that they could have [noticed]'	Teacher's should have recognised, it was quite obvious looking back.
Becca	'Because now looking back knowing that I am autistic, it seems blaringly obvious, especially to like, you know, teachers who are supposed to kind of have a bit of awareness of these things, but again, times have changed, but…erm' '…why didn't anyone notice sooner? But there you go.'	Feeling of frustration and resentment for not noticing?
Emma	'So I think there were things that I did that just you would in some context be normal and wouldn't be early warning signs…But looking back were signs.'	

Participants said the signs were there, but Lina and Emma acknowledged that those signs were not as obvious. Becca and Sam were quite surprised that their teachers had not recognised their needs and felt that their teachers should have been more aware of difference.

Earlier recognition, diagnosis and support. Related to this, all five participants felt that having their needs recognised and supported earlier would have made a difference to them. However, this is not straightforward, and their views on their diagnosis will be discussed in the next focused code. It is also important to acknowledge that all participants viewed that earlier recognition should not require a diagnosis.

Table 63

Participant Quotes Highlighting 'Earlier Recognition, Diagnosis And Support'

Participant	Quote	Memos
Lina	'an earlier diagnosis and earlier support would have changed a lot.' 'Without a doubt [receiving the diagnosis sooner would have helped]'	Earlier diagnosis would have helped
Sam	'[would receiving a diagnosis earlier been helpful to you at school?] Oh, a hundred. A hundred percent, 100% '	
Becca	'[what might have made a difference at the early stages?] Someone noticing that I wasn't OK, I guess.'	Felt that an earlier recognition that she wasn't ok would have made a difference.

Participant	Quote	Memos
	'if it was me now, but in this current climate, definitely 100%, I would have wanted to have the diagnosis because it it just as I say, opens up doors to support that you didn't even know existed so'	Feels earlier diagnosis would have been helpful and enables access to more support.
Esmee	'[would an earlier diagnosis have been beneficial?] I think it would have been.'	Earlier recognition could have meant she didn't get as unwell?
	'But I feel like it would have made a difference in the fact that perhaps you would have been a bit more aware of how anxious I get and when things aren't coping then maybe I wouldn't have got as ill maybe.'	
Emma	'And even then, that [alternative education] wasn't perfect because I had also started from a point of being anxious and depressed. If it had been from the get go, with my perception being that it wasn't a strange thing to be doing. Like, if that was the norm…it probably would've been very different.'	If she had had this earlier, it would have been an easier transition for her to manage.

Participants were asked directly whether they believed that receiving a diagnosis earlier would have made a difference to them. This was a cautious question, as it was important not to lead participants to answer in a way they felt was

wanted or expected. However, participants did think about this question quite carefully, and whilst they agreed that it would have made a difference, they were also able to identify costs and benefits, as outlined in the focused code that follows.

I got lucky. Three of the participants expressed feelings of luck that the missed opportunities and school non-attendance had not impacted their 'life chances'. This was not a prompted question and arose naturally in their discussions about where they are now and the support they received.

Table 64

Participant Quotes Highlighting 'I Got Lucky'

Participant	Quote	Memos
Lina	'I got lucky that I had enough, I had enough baseline intelligence that my attendance didn't completely cripple me in terms of life, but I understand that there's people that probably weren't so lucky. '	Reflection on her outcomes and that this is not the case for many others. She seemed to put this down to her underlying cognitive ability.
Sam	'I was very, very supported and also I never…felt disabled by it as such like, even though I had those struggles with school,'	Feeling lucky?
Emma	'Yeah…I got very lucky. It's weird to say, but I got very lucky in the way things went for me.'	
	'I feel so like rare in the sense that I know other people who you would maybe like who are maybe in a better place than they were,	

Participant	Quote	Memos
	but are still so heavily impacted by it and still don't realise themselves'	

Lina and Emma both expressed luck in how things turned out for them and acknowledged that this is not the case for everyone with similar experiences. Sam acknowledges that she was very well supported at school, to the point that she did not feel that her differences held her back.

Diagnostic journey and its impact on identity, acceptance, and support. This focused code outlines the participants' views on their diagnosis.

Table 65

Constituent Initial Codes For 'Diagnostic Journey And Its Impact On Identity, Acceptance, And Support'

Initial code	Frequency
Positive feelings about diagnosis	12
Positive qualities from late diagnosis	15
Stigma, stereotype and journey of acceptance	20
Impact of the diagnosis	18
Total frequency for focused code (including initial codes not shown)	**79**

Positive feelings about diagnosis. All five participants expressed positive views about their diagnosis. However, it is important to acknowledge that for some, this was a journey, and for others, they identified positive aspects of receiving this diagnosis slightly later, as highlighted below.

Table 66

Participant Quotes Highlighting 'Positive Feelings About Diagnosis'

Participant	Quote	Memos
Lina	'Things changed immensely…Massively. Like, really significantly,' 'I think the diagnosis was one of the best things that could have happened to me in school and in life.'	Strong powerful positive feelings associated to her diagnosis. Marked a point where things changed for her.
Sam	'Yeah, it was a huge amount of relief on my end. And also just a big sense of pride, to be honest, because, well, I got it so late.'	Relief, but also pride.
Becca	'[How did receiving a diagnosis feel for you?] I'd say it's like probably one of the most significant things that's ever happened in my life'	'Significant'- positive impact
Esmee	'And it it, it made me feel a little bit better as well, 'cause, I didn't feel like I was….I think I always knew there was something different, but I didn't really know what it was.'	
Emma	'[did getting the diagnosis make a difference to you?] …it has been helpful in that for me personally, it's been helpful in my understanding of things later down the track when I've been able to think about things.'	Helpful to understand previous experiences.

Participants used strong words to describe the extent of their feelings about receiving the diagnosis, such as this being ‘significant’ and a ‘huge relief’. However, a couple of the participants also explained that receiving the diagnosis has not changed their experiences of anxiety and challenges, only how they understand and communicate them to others. For Lina, getting the diagnosis enabled her to accept the adaptations offered and validated her difficulties, making her realise that she was not just ‘milking it’ and that she was deserving of and able to accept the adaptations she had previously declined.

Positive qualities from late diagnosis. However, from the second interview, an interesting concept was constructed. When asked whether an earlier diagnosis would have been helpful, Sam’s immediate response was to say yes, but then she paused and added to this.

Table 67

Participant Quote Highlighting ‘Positive Qualities From Late Diagnosis’

Participant	Quote	Memos
Sam	‘I'm really proud of the qualities that I've gained with my diagnosis. Like I've become… I'm a lot… I'm a fast learner and I'm more resilient. Like, I kind of just don't care and I'll just do it anyway. If if I had that diagnosis [earlier], would I have been? Would I have been more like would I have been more? would I be too comfortable and I wouldn't have had gained these experiences like not not	Proud of what she achieved without a diagnosis and adaptations. Would she still have been given the same opportunities and achieved was she has had she known? Counters the idea of earlier intervention and support being better.

Participant	Quote	Memos
	again, not not saying like, not judging anybody else's experiences who have had support. It's just like me personally. Like, would I have been?'	

Sam was wondering whether she would be the same person she is now if she had received a diagnosis earlier. She is proud of who she is and what she has achieved, and wondered whether she would have done so if she had received her diagnosis earlier.

As a result, this was asked of subsequent participants. Becca and Esmee were asked directly whether there were any positive aspects to their later diagnosis.

Table 68

Participant Quotes Highlighting 'Positive Qualities From Late Diagnosis'

Participant	Quote	Memos
Becca	'Erm, I suppose I didn't stigmatise myself kind of thing…And I also I don't know if I would have had a different treatment in like therapy … and stuff.' '…I don't know whether I would have received treatment for the things that I needed treatment for, if they'd sort of said, oh, well, that	Not taking on negative societal assumptions about autism/assume she wouldn't be able to achieve?

Participant	Quote	Memos
	must be due to autism or something.'	
Esmee	'but also I wonder if we would have done things differently like I wonder if like if I was younger, whether my parents would have been like, oh, I don't know if she should go to a birthday party or stuff like that. I wonder if we would have perhaps maybe not done as much things as I did. Like we love going to the theatre and I wonder if we perhaps wouldn't have done that.'	Could have missed out on things if she'd been diagnosed sooner?

Similarly, they wondered whether they would have been 'held back' by an earlier diagnosis and not experienced the things they enjoy. Esmee, however, qualified this by saying that, for her, these positive aspects of a later diagnosis do not outweigh the benefits of an earlier one, and that an earlier diagnosis would still have been preferable. Becca was concerned about whether she would have received the treatment she did, which helped her, or whether her mental health needs would have been attributed to her autism instead, and treatment would have differed. She reported that autism can sometimes be a 'catchall', where everything is attributed to the autism instead of considering the possibility of both autism and additional mental health needs, with a similar type or level of treatment being required.

Stigma, stereotype and journey of acceptance. Despite now being happy about their autistic diagnosis and the difference it has made for them, Sam and

Becca described this as a journey from initial dismissal of the possibility to their current relief and acceptance.

Table 69

Participant Quotes Highlighting 'Stigma, Stereotype And Journey Of Acceptance'

Participant	Quote	Memos
Sam	'I think my parents were actually they were more, they were more pushing. They like, when I said I had ADHD, were like no you don't, you're definitely autistic. I said absolutely not. Go away.'	Acceptance of autism took longer than ADHD. Wonder if she felt there was more stigma around autism?
Becca	'Well, I don't know because as I say at the time when I was having these difficulties, I would have been highly offended if somebody suggested that I was autistic. And I think that is kind of the reaction that was had when … they [first] suggested it.' '…And then when I went to university, suddenly I was exposed to people who were, like, quite comfortable saying, oh, I'm autistic and…I think it became a bit destigmatised in my head. So I think that was important for me to get to that point before I got the diagnosis, because then when I got it, it was like, OK, that makes sense. '	Internal conflict- knows it would have helped but also knows she might not have responded to it terribly well because of the stigma and perception of what autism was.

Becca felt that in the current climate, and through high-profile autistic individuals disclosing their diagnoses, there is slightly less stigma and more awareness, which may have enabled her to be more accepting at an earlier stage.

Impact of the diagnosis. All five participants spoke of the impact that the diagnosis had had for them in more tangible terms, in addition to how they 'felt' about it.

Table 70

Participant Quotes Highlighting 'Impact Of The Diagnosis'

Participant	Quote	Memos
Lina	'I think teachers and staff and everyone's generally a lot more understanding when I struggle in a way they weren't when it was just anxiety.'	'Just anxiety'- is this less validating??
	'I'm a lot more understanding of my struggles. I used to be really, really quite harsh on myself and I still am, but. Well, a lot of my struggles and actions can be explained.'	Greater understanding of her own 'struggles' which enabled her to have explanations
Sam	'But then I gained that [confidence] later on. Not with the adjustments, but just with the diagnosis and then the adjustments just made that confidence, it didn't. It just, you know, I don't know.'	

Participant	Quote	Memos
Becca	‘Because, finally I had some kind of explanation as to why I felt completely different to everyone else.’	Understanding and explanation
Esmee	‘Err and I think I remember afterwards I did a lot on a lot of reading about autism and like books and stuff, and it made me feel a lot better. I think not knowing and not understanding yourself doesn't help I mean for anyone.’	Greater understanding of herself.
Emma	‘It gave more arguments to, like it gave other people more reason to listen to me, and to have to help me’	Made others listen more

All participants reported a greater understanding of themselves and their identity. Lina, Sam, and Emma also discussed others gaining more insight and the consequent increased support. Emma mentioned this several times and felt that her diagnosis strengthened their EHCP request, which she expressed frustration about, saying she had to ‘collect diagnoses’ and ‘exhaust all options’ before securing the support she needed.

5.5.6 Section summary

This section has presented the findings of the study, which has yielded some interesting, insightful and unexpected findings which are explored in more detail in

the Discussion Chapter. The findings have both supported and challenged some assumptions and biases, which are also considered in the next chapter.

5.6 Chapter Summary

This chapter has outlined the emerging theoretical framework, its five theoretical codes, and descriptions of their focused codes and primary initial codes.

Within the theoretical codes, this section has indirectly answered the following research questions:

- What are the experiences of autistic adolescent girls prior to their autistic needs being recognised, and how could this contribute to school non-attendance?
- What are the barriers and supportive factors that influence school attendance for adolescent girls before their autism diagnosis?

They will be answered directly in the Discussion Chapter, along with a third research question which emerged from the participant data.

Overall, the theory shows how the educational and school system and within-child autistic differences interact, culminating in high levels of stress and anxiety, leading to increasingly significant mental health needs and chronic school absence. The current researcher views that the current participants' outcomes is a testament to the resilience of the participants and their parents, rather than to the education system. This supports the strengths-based model of disability but also highlights within-child differences and the need to develop inclusive practice, particularly in relation to educational flexibility, teacher training, awareness, predictability, and the importance of home-school collaboration.

These factors will be discussed in the discussion chapter which follows, with links to psychological theories and the current literature.

6. Discussion

In this chapter, the research questions are responded to, and new lines of enquiry revealed by the participants are followed. The study's findings are discussed and compared with existing research and theoretical frameworks. While there are several existing ones relevant to the current theoretical framework, these do not account for the findings of this study by themselves. As such, a new theoretical framework is presented to explain the processes which occurred for the participants.

In the first instance, the key findings are presented to directly answer the research questions.

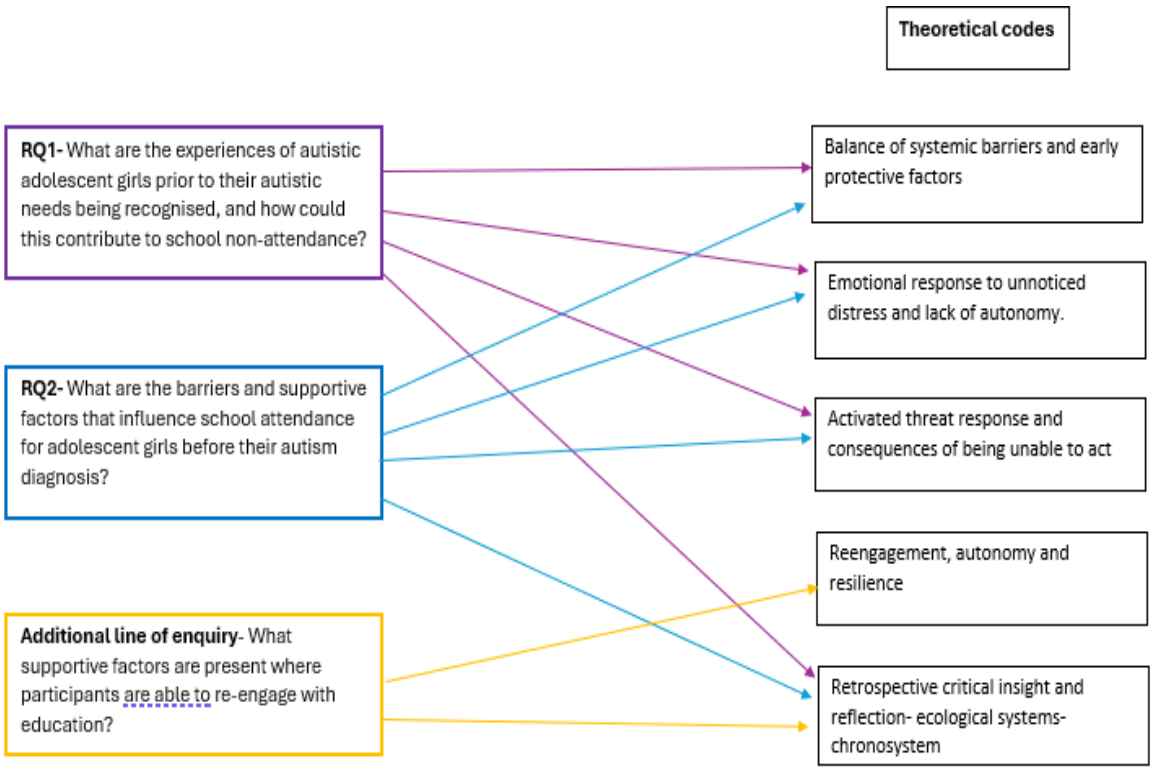
6.1 Summary of key findings

As outlined in the findings section, the research questions are answered across different theoretical codes. The diagram below outlines where the questions are answered to guide the reader to link the findings to the research questions.

One of the strengths and benefits of CGT is the ability to follow the data and explore what arises from the participants (Charmaz, 2014). During the analysis of the first transcript, differences in experiences between secondary school and participants' re-engagement in education in a different form were created. This was not adequately addressed by the research questions but was considered an important line of enquiry to follow, which could add to possible explanations and mechanisms for change. As such, this has been added to address this line of enquiry.

Figure 25

Illustration Of Where Research Questions Are Addressed



Research question 1- What are the experiences of autistic adolescent girls prior to their autistic needs being recognised, and how could this contribute to school non-attendance?

Before their needs were recognised, participants described feeling overwhelmed in the school environment but were unable to recognise, understand or communicate this. As a result, adults were unaware, and the girls continued to be exposed to the same stressors. These stressors related to the nature of mainstream secondary schools and their autistic differences, including sensory and environmental overload, ambiguity and unpredictability, academic demands, and the

social and communicative expectations of large secondary settings. This led to escalating anxiety, stress, and frustration that remained largely hidden from school staff.

Participants described limited autonomy, control, and feelings of belonging, as well as predominantly negative or unhelpful relationships with teachers. Over time, repeated exposure to these stressors contributed to significant mental health difficulties, burnout, and ultimately school non-attendance.

Research question 2- What are the barriers and supportive factors that influence school attendance for adolescent girls before their autism diagnosis?

The barriers to attendance were complex and stemmed from the gap between the mainstream environment and their autistic differences, and the emotional overwhelm this caused them. Without identification, no adaptations were put in place, and anxiety and overwhelm continued to build. Earlier recognition was impacted by their differential presentation, strong academic performance, difficulty communicating distress, and limited staff approachability and understanding, with early parental concerns often dismissed. By the time support was offered, participants felt it was “too late,” as their distress and avoidance were already entrenched. While earlier identification may have mitigated some barriers, others would likely have persisted, and so reducing barriers by itself would likely not suffice.

A small number of supportive factors were noted. Participants identified one or two adults with whom they felt safer, and some expressed empathy for staff who were trying within systemic constraints. The participant who experienced the most consistent support from adults also had the least disrupted attendance, suggesting that widespread relational support may be more protective than one or two key

adults. Friends also provided some support, though these positive influences were outweighed by the number and intensity of barriers and broke down as attendance reduced, further contributing both to non-attendance and to deteriorating mental health.

Additional line of enquiry which developed from the data- What supportive factors are present where participants are able to re-engage with education?

All participants were able to re-engage with education when they moved to a different provision. For two, this occurred through college or post-16 settings; for two others, through alternative packages, followed by college for one. One participant maintained school attendance but experienced greater success through self-study and later in college. Across all cases, increased autonomy, control, and belonging were central to their renewed engagement.

Having their needs recognised, whether through a diagnosis or not, meant staff understood them better and could offer more appropriate support. Choice over what and how they studied, alongside the opportunity for a “fresh start,” were also key facilitators. Although challenges remained, participants felt safer with adults in these new settings and were more able to seek support when needed.

This chapter will now consider how the findings link to existing theories and literature. The remainder is organised into three parts. In the first part, the emerging theoretical framework will be presented, and the psychological theories and frameworks relevant to this will be discussed and critiqued. In the second part, the theoretical codes outlined in the findings section will be explored further, drawing on

the existing literature. Part three will consider the value of the research and offer a critical evaluation of the study.

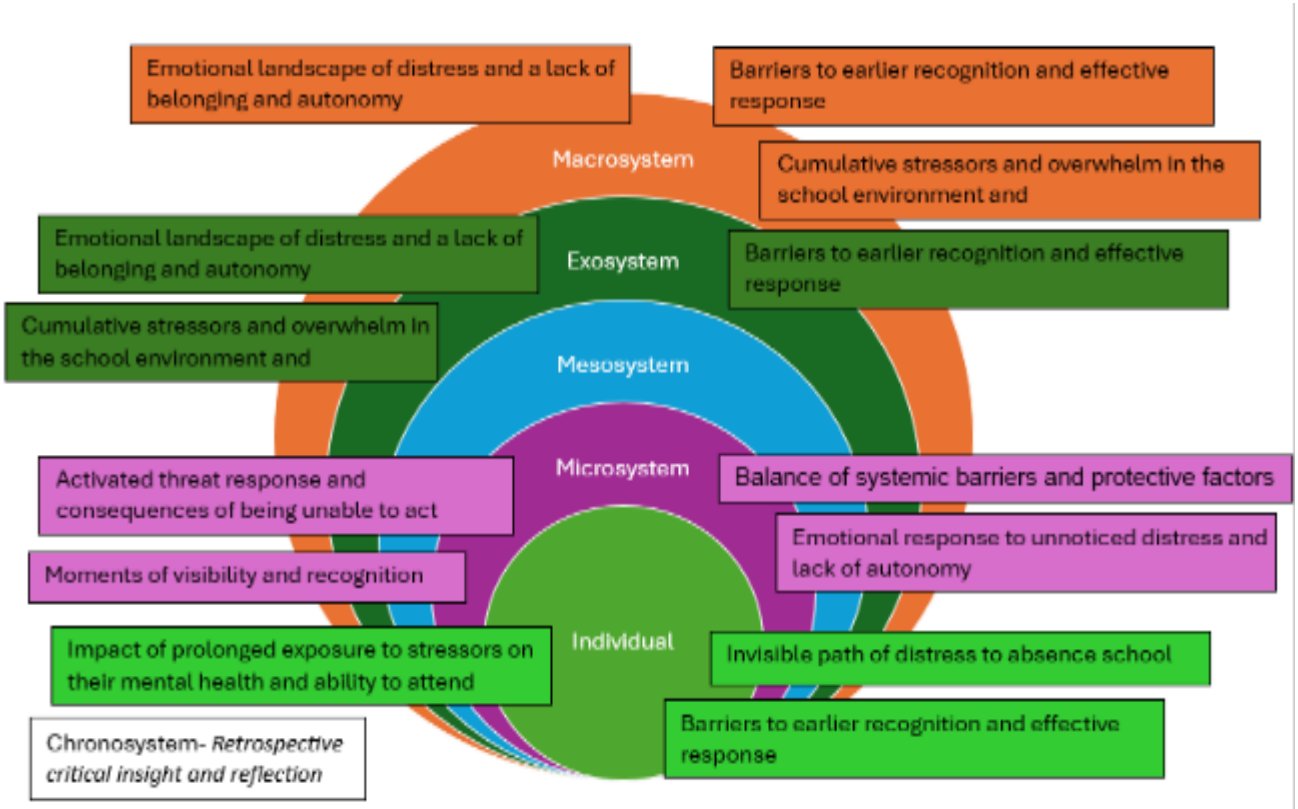
6.2 *Part one*- Emerging theoretical framework and existing theories

This part of the chapter will explore the theoretical framework generated from the interpretation of the findings, linked to existing psychological theories and frameworks, including Ecological Systems Theory, the continuum of school refusal behaviour, and the models of disability considered in section 3.2, plus Self-Determination Theory and resilience not previously considered.

6.2.1 Ecological Systems Theory

Bronfenbrenner's ecological systems theory (1979) was developed in relation to child development (Kagan et al., 2019) and considers the CYP and the systems they are in contact with as influencing their situation. Linking this to the current emerging framework, we can see that this model has implications across its different components in Figure 26. In this model, the current study's theoretical codes are mapped onto the model.

Figure 26 *Overlay Of Theoretical Framework Mapped On To Ecological Systems*



At the *microsystem* level, several codes are implicated as shown in the diagram above, relating to the school system, teachers' responses, parental concerns being dismissed, and the impact of peers. The *exosystem* is also evident in terms of teachers' awareness and understanding of female autistic needs and the role of teacher training in this. The *macro system* is implicated through the wider education system and the governmental policies that guide it. Participants reported 'learning differently' from how they were taught in their schools, and some felt they could learn better by themselves. The *chronosystem* is also a factor in the current study, as with time (and guidance), the participants were able to reflect on their experiences and on what was happening for them, with the newer knowledge afforded by their diagnosis, something they were unable or unsupported in doing at

the time. Finally, crucial to the study, is the *individual,* both from a point of view of their autistic differences and atypical presentation, and the significant impact their experiences within the school system had on their health and well-being.

While this theory is relevant in outlining the different systems involved, and also highlights an interaction between them (the *mesosystem*), the model does not show *how* these different systems interact or the underlying processes. The current theoretical framework can be viewed as operating within the mesosystem and considers this and its impact on the participants. It also takes account of their autistic differences and how these combine with the same systems, alongside the clear within-child impact that this has on their mental and physical health.

6.2.2 Continuum of school refusal behaviour

This continuum, outlined in section 3.2.3, is highly relevant to the emerging theory. Kearney (2008) presented school non-attendance as occurring on a continuum from initial distress to complete non-attendance.

All participants reported early signs of distress, which they traced back to primary school, a substantial period before their difficulties were evident in their attendance data. Most participants appeared to experience most of these stages; however, the very early stages (pleas for non-attendance and ‘misbehaviour’ in the mornings) were less frequently reported. This may be because they did not realise they were anxious or overwhelmed with school until these feelings became more pronounced. This continuum fits within the current emerging model, perhaps running from **balance of systemic barriers and early protective factors** through to the

activated threat response and consequences of being unable to act theoretical codes.

However, Kearney's continuum does not describe what might be occurring at these times, and participants' experiences of mental health needs are not captured within this model. While it is helpful in outlining a pattern, it does not go far enough to explain the complexity of the factors underlying this continuum. For example, it was evident that for some participants, their attendance did not always follow a linear pattern, with occasional temporary improvements followed by a return to complete non-attendance. Additionally, progression through the stages was characterised by anxiety and distress and, ultimately, burnout. This model refers only to the behavioural stages of non-attendance, which may serve to reinforce the notion of EBSNA as a behavioural choice. This continuum is demonstrated on the current theoretical framework in Figure 27.

6.2.3 Self-Determination Theory (SDT)

SDT was not included in the literature review but has become apparent across several codes in the emerging model. In brief, this theory was developed by Deci and Ryan (1985), and suggests that people become self-determined when they experience feelings of competence, relatedness, and autonomy. Self-determination is believed to explain what motivates an individual's behaviour, such as attending school and overcoming challenges (Lopez-Garrido, 2023).

Deci and Ryan (1985) applied SDT to education, arguing that an individual's curiosity and desire to learn are intrinsic motivators that can serve as central drivers of educational engagement. However, they argued that education is often viewed as

an extrinsic process done ‘to’ CYP. Despite this being a statement made forty years ago, the current researcher would argue that little has changed in that respect. This is evident in the **emotional response to unnoticed distress and lack of autonomy** and the **activated threat response and consequences of being unable to act** theoretical codes. Participants felt a lack of control, did not feel ‘aligned’ to the learning system, felt threatened and forced. However, what further supports this theory and its’ application to the current emerging model, is that for all participants, when they were able to experience feelings of competence (through achievement at College or alternative provision), autonomy (the ability to choose what they wanted to study), and relatedness (feeling better understood and supported), they engaged and achieved, demonstrated in the **re-engagement, autonomy and resilience** theoretical code.

For the participants, an increased sense of self-determination may have motivated them to manage the anxieties they continued to experience. In this way, this theory is highly relevant and helpful, but it only explains their experience in part. Simply giving them more control and autonomy would not make all the difficulties and anxieties vanish, and for some, it would require more than this (such as alternative educational provision). Resilience is further discussed below, but Hart et al. (2016) present a definition of resilience that could also align with SDT by giving individuals autonomy and control to make changes for themselves.

6.2.4 Resilience

Resilience, also not covered in the literature review, is typically thought of as a person’s ability to ‘bounce back’ from challenges and adversity, and to succeed

despite them (Pearson et al., 2025). However, this view assumes the inevitability of disadvantage in society and that resilience is ‘demanded’ to cope and succeed within wider structures, perceptions and attitudes, which should be challenged (Hart et al., 2016). As such, definitions offered by Hart et al. (2016) and Pearson et al. (2025) combine the notions of resilience, social justice, and empowerment, viewing them as not only overcoming adversity in the traditional sense but also potentially transforming that adversity. The traditional notion of resilience is more deficit-based, framing the person’s lack of resilience as the cause of their struggles, while this view identifies that environmental and societal factors are involved. In their review of theories, Pearson et al. (2025) highlight that key resilience frameworks view it as an interaction between the child and their environment, rather than as a single trait or experience. They refer to protective and risk factors that contribute to resilience, including the impact of the environment and the systems in which they operate. The researcher prefers this definition and conceptualisation, which combine a within-child process with one influenced by wider societal systems and experiences, aligning with her critical realist perspective.

In the emerging framework, this links closely to several codes, including **the balance of systemic barriers and early protective factors**; **unnoticed distress; emotional response to unnoticed distress** and **lack of autonomy**; and their positive outcomes in **long term outcomes- re-engagement, autonomy, and resilience**. While attending secondary school, they did not experience sufficient protective factors to outweigh the system's stress, either in the early stages or later, when their attendance and struggles became more evident. When experiencing that level of stress or perceived threat, learning or developing skills is known to be

difficult (Aridah, 2025; Kaufeldt, 2021), and so developing resilience in the face of the perceived threat they were experiencing would likely have been highly challenging. However, in later stages of their education, when they were better supported and had greater self-determination, their resilience may also have increased, enabling them to manage the challenges they would still have faced.

Whilst resilience theory also very closely relates to the emerging theoretical framework, and newer conceptualisations of it consider the environmental and systemic interactions on the individual (van Breda, 2018), the current researcher still feels discomfort. It still places the CYP's difficulty in attending in their inability to cope with the overwhelming nature of school, with the ownness on them (with support and mediation) to better cope with the environment and demands. Garrett (2016) highlights similar concerns, and considers what values are used to determine what 'coping' looks like across different cultures and backgrounds. He argues, that by focusing on resilience we risk ignoring the inequalities that create hardship and adversity. As such, resilience theory, whilst pertinent, does not do enough to account for and promote the need for significant change related to the systemic factors involved by itself.

6.2.5 Models of disability

The literature review outlined the main models of disability, and the current researcher noted that her position sits between them. The participants' accounts and the emerging theoretical framework reflect a similar stance: they acknowledge the role of autistic differences (medical model) while emphasising the influence of environmental, relational, and systemic factors (social model).

Participants also expressed elements of both perspectives. Several described their diagnosis as a moment of clarity and relief, while others took longer to accept it but then valued the explanation it provided, particularly evident by wishing they had known earlier. At the same time, they aligned with social model and neurodiversity informed views, arguing that support should not depend on diagnoses and recognising that late diagnosis sometimes brought unexpected benefits.

However, the neurodiversity paradigm also presents limitations for the current researcher. While the idea that “everyone is different” is not disputed, critics highlight that framing autism solely as natural variation can obscure the significant challenges some individuals face (Casanova & Widman, 2021). It can trivialise the impact their differences have and reduce the likelihood of them seeking or accepting support, as expressed by Lina.

The theoretical framework developed in this study, therefore, extends existing models by holding these positions in view: autistic differences shape how CYP experience and interpret their environments, and these environments, often complex, inflexible, and overwhelming, can in turn exacerbate stress and disadvantage. This dual focus aligns with a critical realist position, recognising autism and EBSNA as real phenomena, while understanding that experiences and meanings are shaped by context.

Casanova and Widman’s (2021) ‘biological gradient model’ offers a helpful bridge between these models. It retains biological grounding without deficit-based assumptions and conceptualises disability along a spectrum rather than as a binary state (of either having a disability or not), which is helpful for conditions such as autism, which can sit within grey areas. This model resonates strongly with the findings of the current study and with participants’ nuanced views.

Schools provide a good example which highlights the tensions between these models. They contain many of the sensory, social, and cognitive demands that autistic CYP may find most challenging. Yet policy continues to mandate full-time attendance and emphasises attainment, while offering limited detail on how environments will be adapted to meet diverse needs. Even recent proposals (DfE, 2026a) risk placing further expectations on already stretched schools without addressing the systemic inflexibilities of the curriculum and delivery that contributed to participants' difficulties.

The critical realist theoretical underpinning of this research also aligns well, with the framework's emphasis on the interplay between the individual's autistic differences (real), their subjective experiences in school (actual) and the observable outcomes experienced when supportive factors are not sufficient (empirical).

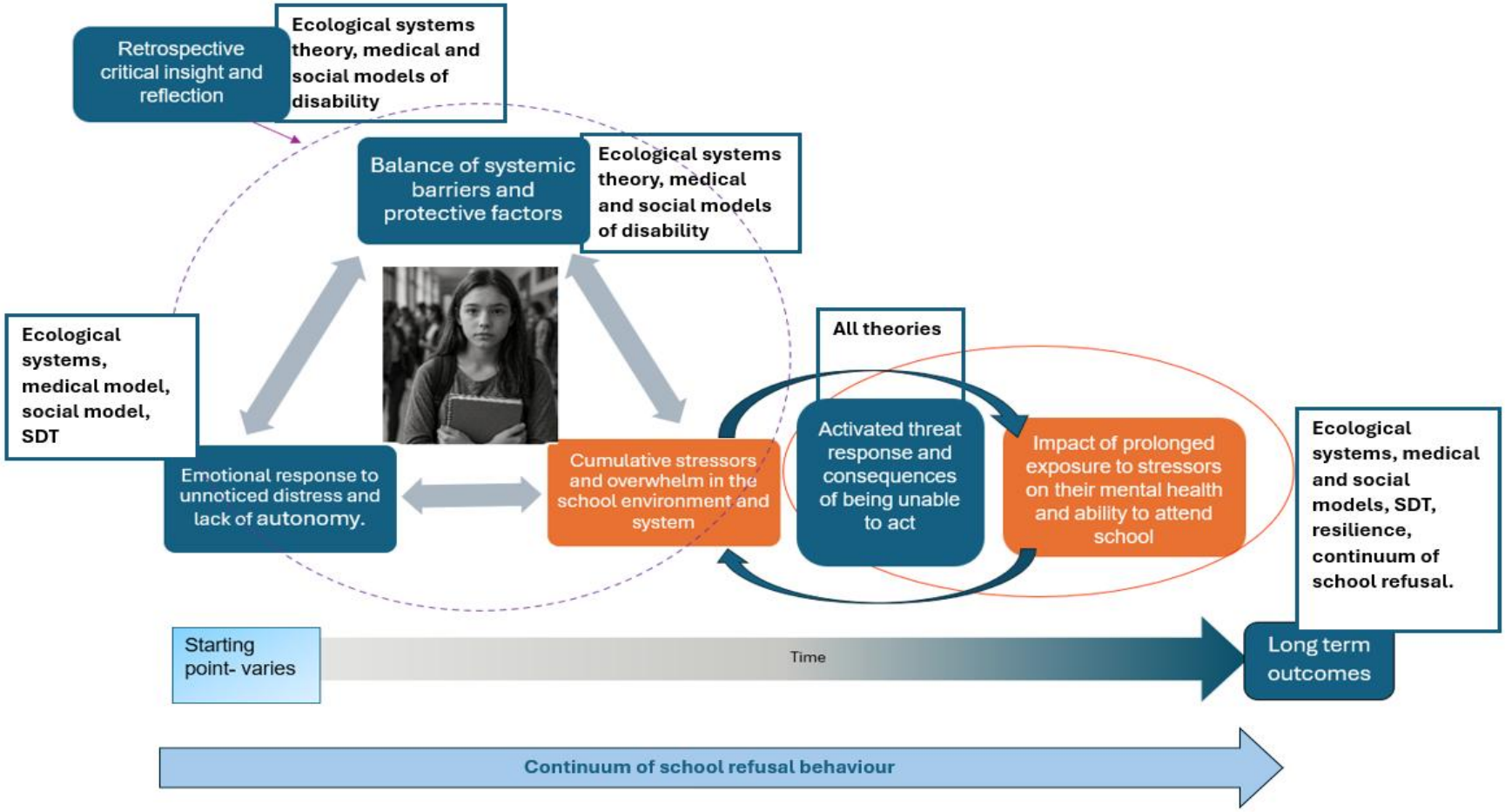
6.2.6 Current theoretical framework and integration of existing theories

Figure 27 indicates where existing theories integrate in the current theoretical framework- Accumulating Barriers to Education[2].

[2] This is a working title and therefore may change

Figure 27

Existing Theories And Frameworks Mapped On To Current Emerging Framework



The model title does not refer to ‘attendance’, which differs from most current models and terminology that do. This has been deliberate and aligns with the change of emphasis recommended in these findings; from intervention once non-attendance has begun, to earlier recognition and intervention. By changing the focus to ‘education’ instead of attendance, it is hoped to reframe the focus to the importance of monitoring for changes in engagement and concerns from parents and carers, which may well present before difficulties become more embedded and attendance is impacted.

6.2.7 Summary

There are several existing theories and frameworks that are relevant to the emerging theory outlined above. However, by themselves, these do not account for everything implicated by the participants in this study. For example, ecological systems theory is closely related but does not capture the impact on the individual, which could then further contribute to a cycle of interactions between the individual and the systems and supports around them. SDT is also highly relevant but does not account for environmental factors, the CYP’s differences, and how these affect motivation and feelings of self-determination. The main models of disability are not comprehensive and do not consider the interactions between individual differences, biology and genetics, and the systems around them, although the Biological Gradient Model does go some way to bridge those limitations.

The Accumulating Barriers to Education model accounts for this complex cyclical interaction, the impact it had on the participants, and how that fed back into the cycle. It also changes the focus away from school attendance as being the

indicator, to changes to engagement and other more subtle signs of developing school related anxiety.

6.3 Part Two- Comparison with existing literature

In part two, existing literature relevant to the emerging model will be considered. This section will be organised by the theoretical codes. In some cases, literature might be relevant across several codes, however it will not be repeated.

By way of a reminder, the theoretical and related focused codes are shown in Table 71.

Table 71

Theoretical Codes And Linked Focused Codes

Theoretical code	Focused code
Balance of systemic barriers and early protective factors	Barriers to earlier recognition and effective response Moments of visibility and recognition
Emotional response to unnoticed distress and lack of autonomy.	Invisible path of distress to absence Emotional landscape of distress, and a lack of belonging and autonomy
Activated threat response and consequences of being unable to act	Cumulative stressors and overwhelm in the school environment and system Impact of prolonged exposure to stressors on their mental health and ability to attend school

Theoretical code	Focused code
Long term outcomes- Re-engagement, autonomy and resilience	Conditions enabling re-engagement and fostered feelings of safety and belonging Resilience, achievement and hope
Retrospective critical insight and reflection	Participant hindsight on missed opportunities Diagnostic journey and its impact on identity, acceptance, and support

6.3.1 Balance of systemic barriers and early protective factors

This theoretical code consists of two elements- barriers to early identification of need, and early supportive factors. For all participants, barriers substantially outweighed supports, an imbalance likely shared by many CYP in the early stages of EBSNA.

Essentially, these barriers (often present from primary school) both prevented their needs from being recognised by school staff or, when they were recognised, impacted the effectiveness of the adaptations offered, aligning with the literature presented in the literature review (e.g. Anderson et al., 2020; Gaffney, 2020; Tomlinson et al., 2022).

All participants also described limited awareness of their own distress at the time, with some not realising they were struggling at all. This hindered their ability to articulate difficulties and, combined with a lack of observable signs, reduced the adults' ability to intervene. There is little research exploring CYP's real-time

understanding or attribution of their non-attendance. Misattribution theory (Schachter, 1964), though inconsistently supported (Cotton, 1981), may offer a useful lens for future research in EBSNA. An interesting concept arose throughout their accounts through repeated use of the phrase ‘it depends’, highlighting that their ability to cope varied across contexts, e.g., tolerating group work when able to choose peers. Such variability may also obscure distress and lead staff to interpret avoidance as selective (e.g. ‘she can do it when she wants to’). Although underexplored in relation to impact on recognition of need, this aligns with research showing that participation fluctuates across environmental, activity, and social contexts (Bailey & Baker, 2020; Tsou et al., 2024).

Participants described moments when their needs were noticed, when efforts were made to support them, and peer contact encouraged attendance in the early stages, supporting other findings that student-teacher relationships are crucial (e.g. Halsall et al., 2021; Tomlinson et al., 2022). Peer relationships were a supportive factor in the early stages and is highlighted in existing literature as an important component to attendance and feelings of belonging (e.g. Ayirebi & Thomas, 2024; O’Hagan et al., 2024).

However, these protective factors were outweighed by the barriers they faced. This imbalance is present not only in the early stages of EBSNA but persisted, and intensified, over time.

6.3.2 Emotional response to unnoticed distress and lack of autonomy.

This theoretical code shows a path which starts with unnoticed distress, escalating emotional distress and feelings of threat, to loss of autonomy and belonging and ending in withdrawal.

This gradual escalation was largely unnoticed by adults, despite all participants noting physiological symptoms. However, related absences were typically reported as illness and so likely not recognised as early indicators of EBSNA. Although somatic signs are well-documented in wider anxiety research (Li et al., 2021, 2024), they remain under-acknowledged in EBSNA literature, meaning these concrete behavioural indicators fell “under the radar” (Connolly et al., 2023) despite mapping onto early stages of Kearney’s (2008) continuum in terms of periodic absence.

Because these signs were missed, participants continued to be exposed to their stressors. Over time, this intensified into feelings of fear, threat, and emotional unsafety. For some, this involved explicit pressure (e.g., staff arriving at home to ‘force’ attendance); for others, the threat was internalised, such as a fear of doing something wrong, being told off, or failing. These findings extend existing research by illustrating not only the challenges autistic pupils face in school environments (Ayirebi & Thomas, 2024; O’Hagan et al., 2024) but also their emotional responses to these challenges and how they accumulate.

As distress escalated, participants’ sense of autonomy, belonging, and control was eroded. They described feeling powerless within school systems, and as attendance declined, their sense of belonging and ability to maintain friendships diminished further and became increasingly unattainable for them. This further reinforces the importance of early recognition and intervention.

6.3.3 Activated threat response and consequences of being unable to act

This outlines the experiences that led participants to experience stress, and the emotional responses outlined above. It highlights that these stressors are also

cumulative, their effects building over time until eventually chronic stress, mental health needs and total or near total school absence were necessary for the participants to recover. The current researcher notes that her previous experience and conception of the impact of school environments on CYP are important to consider, and is discussed further in the reflective section.

Participants described patterns of escalating stress within school environments that activated a sustained threat response and ultimately exceeded their capacity to cope. Their accounts highlighted how multiple stressors across sensory, social, academic, and relational domains, accumulated over time, became increasingly overwhelming and contributed to chronic stress, mental health difficulties, and eventual non-attendance of varying degrees.

Research shows that autistic CYP experience commonly upsetting school events at school more frequently and more intensely than their neurotypical peers (Lukito et al., 2025). For the current participants, several stressors consistently generated significant anxiety related to their autistic differences. Many of these represent modifiable aspects of school practice (e.g. teacher consistency, communication and responses, social impact in group work) that could be addressed proactively and helpfully for all pupils. However, except for Sam, participants felt invisible, underestimated, or unsupported by adults, which intensified their sense of threat and reduced their feeling of emotional safety, mirroring findings by Corcoran and Kelly (2024). Interestingly, while Sam did experience significant anxiety and burnout, she did not describe or experience the more considerable mental health consequences compared to the other participants. It is interesting to consider whether her experience of wider support from school adults (as detailed in section 5.3.1) contributed to this.

These stressors were dynamic rather than static. As participants became increasingly overwhelmed and burnt out, situations that were initially manageable became more difficult. Overtime, their threat response intensified in parallel with their declining wellbeing, illustrating how repeated exposure to unaddressed stressors can erode capacity to cope over time. This aligns with Kaufeldt's (2021) conceptualisation of chronic stress as arising when a person experiences prolonged pressure without a sense of control or a way out.

> '…stress is the body's response to excessive pressures, confusion, and trauma. As one experiences real danger, perceived threats, or chaos, the fight or flight or "reflex response" kicks into gear' (Kaufeldt, 2021. P. 387)

For the participants in the current study, the consequences of this prolonged exposure were profound. Four participants described significant mental health difficulties to varying degrees, including anxiety, depression, shutdown, disordered patters of eating, and trauma-like responses. These findings echo wider evidence that perceived threat and increased 'emotional burden' increases vulnerability to mental health difficulties (Conley et al., 2023; Lukito et al., 2025) and that autistic girls, particularly those identified later, are at heightened risk (Ayirebi & Thomas, 2024; Gaffney, 2020; Gray et al., 2021).

Participants' accounts were suggestive of their school experiences being traumatic, or of causing trauma like responses, even if they did not meet the formal diagnostic threshold for Post Traumatic Stress Disorder (PTSD) (APA, 2013; WHO, 2022). While no participant described exposure to actual or threatened harm (required for a classification of PTSD), most described symptoms consistent with trauma responses, including persistent fear, hyperarousal, avoidance, sleep

disturbance, intrusive memories, and a pervasive sense of threat. Trauma related to typical school experiences is under-explored in the literature. It tends to focus on traumatic events experienced outside of school, or more significant traumatic events within school (e.g. serious bullying). Impact of school on CYP tends to focus more broadly on anxiety or mental health impact rather than trauma-specific processes.

Given the intensity of participants' emotional, psychological, and physiological responses, these findings highlight an important gap: the need to consider school acquired trauma as a potential outcome of prolonged, unrecognised exposure to typical school experiences causing chronic stress, particularly for autistic girls whose needs remain unidentified. This could have significant implications for how schools conceptualise, prevent, and respond to EBSNA, and challenges the appropriateness of blanket attendance expectations given to schools under current and new proposals (e.g. DfE, 2025d).

6.3.4 Long Term Outcomes- Re-engagement, autonomy and resilience

Despite the significant challenges described earlier, all participants eventually re-engaged with education and experienced success, offering a counter-narrative to dominant assumptions that CYP with prolonged non-attendance inevitably experience poorer outcomes (Bond et al., 2024; Children's Commissioner, 2023; DfE, 2024). This suggests that, under the right conditions, re-engagement and achievement were possible for the current participants, raising important questions about what enabled these outcomes compared with the wider EBSNA population.

Re-engagement occurred when participants experienced greater autonomy, choice, and control in their learning, aligning with SDT (see 6.2.3) and mirror wider findings that autonomy is central to re-engagement (Corcoran et al., 2022; Ward &

Kelly, 2024). Participants described thriving in settings that allowed them to influence what, how, and when they learned, echoing research showing that CYP in alternative or vocational pathways often flourish when given more agency (McPherson et al., 2023). These findings have implications for the structure and flexibility of the UK curriculum, discussed further in the Conclusion Chapter.

It is also important to consider how this participant group differ from the broader EBSNA population, and whether these could explain their good outcomes. Risk factors commonly associated with EBSNA and poorer outcomes appeared largely absent. Furthermore, participants had at least average cognitive potential (assumed from their grades despite their non-attendance), and parental support and advocacy was also a notable factor. Further research exploring these would be helpful to further inform factors influencing outcomes for those who have experienced EBSNA.

In summary, although causal claims cannot be made within a grounded theory study, several factors appear to have contributed to participants' re-engagement and, for most, to above-average outcomes. While some of these factors lie beyond the influence of educators and professionals, others, particularly those relating to autonomy, flexibility, and systemic responsiveness, fall within the capacity to change.

6.3.5 Retrospective critical insight and reflection

This theoretical code captures participants' reflections on their school experiences, what might have made a difference, and how later diagnosis reshaped their understanding of earlier events. Their accounts align with Bronfenbrenner's (1979) chronosystem (section 6.2.1), illustrating how meaning-making evolves over time and how hindsight reframes past experiences.

Participants did not identify interventions that could have helped once their non-attendance was entrenched; by that stage, they felt nothing would have made enough of a difference. Instead, their reflections centred on missed opportunities to recognise the signs they believed were present earlier, which they believed could have changed the outcome. It is possible that if these early indicators had been noticed and acted upon, the balance between barriers and protective factors might have shifted, potentially preventing the escalation they experienced (section 5.3.3). This aligns with the SEN Code of Practice (2014) and wider literature emphasising the importance of early identification for autistic CYP (Corcoran & Kelly, 2024; Hull et al., 2020; Wood-Downie et al., 2021). Although the current participants ultimately achieved positive outcomes, they recognised this was not necessarily typical, and described themselves as “lucky,” noting that many others experience far more detrimental consequences.

Two aspects of early identification were highlighted. The first concerned recognising their needs. Existing identification tools for EBSNA often rely on risk factors such as trauma, bereavement, or known additional needs (Brighter Futures for Children, 2022; Trafford Council, 2021), meaning autistic CYP with unidentified needs may not meet these criteria and remain unidentified. These tools also tend to be used reactively rather than preventively. Participants’ reflections, combined with the early indicators described in section 5.3.2, support the need for a proactive screening approach to identify subtle signs of emerging anxiety before CYP and families reach crisis. This is explored further in the Conclusion Chapter.

The second aspect concerned earlier recognition of autism. All participants felt that earlier recognition of their autistic needs, would have made a meaningful difference. For the current participants, identification occurred only after chronic

non-attendance or psychiatric involvement for eating disorders, consistent with the wider literature that autistic girls are often identified only once difficulties become externalised or co-occurring needs emerge (Gaffney, 2020; Hull et al., 2020).

Participants' reflections on their diagnostic journeys revealed a nuanced picture. All described overwhelmingly positive feelings about receiving their diagnosis, viewing it as a turning point that brought relief, validation, and a clearer understanding of their struggles. They believed an earlier diagnosis would have been helpful, yet also acknowledged that they might not have accepted it sooner, with some describing initial dismissal. This mirrors mixed findings in the literature, which range from relief and increased self-awareness to distress or rejection (Gaffney, 2020; Halsall et al., 2021; O'Hagan et al., 2024; Tomlinson et al., 2022).

Overall, their reflections suggest a balanced "both/and" position, challenging binary framings within medical and neurodiversity paradigms and instead perhaps aligns with Casanova and Widman's (2021) biological gradient model, suggesting grey areas, variation and fluidity relating to diagnoses and disability, instead of an either or conceptualisation.

6.4 Part Three- Study evaluation

This section will explore the unique contribution offered by this research, its strengths, limitations, suggestions for further research, and the dissemination strategy.

6.4.1 Evaluation of findings and conceptual contributions

Taken individually, the findings broadly support the existing literature as presented in Figure 28.

Rather than contradicting existing literature, the findings extend and deepen current understanding, highlighting mechanisms underlying these patterns and nuances that are often overlooked.

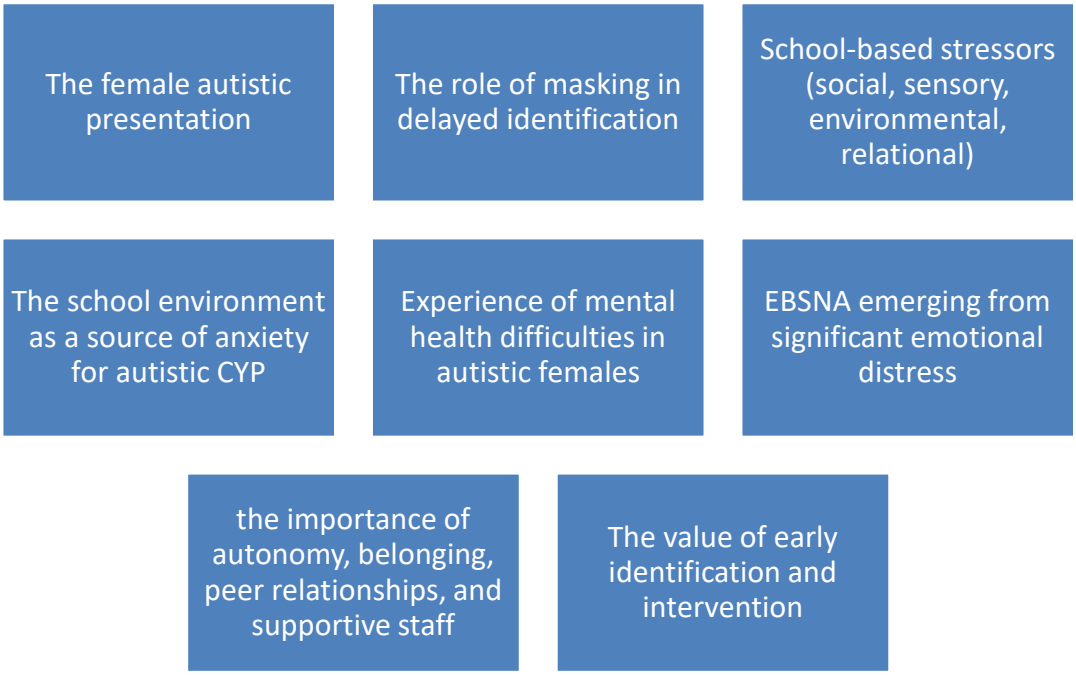
One area of difference concerns pupil voice. While its importance is widely emphasised and not in question here, participants in this study often did not recognise or understand their own distress at the time. Being asked what was wrong sometimes increased their anxiety. This suggests that *how* and potentially *when* pupil voice is elicited matters, and highlights the value of visual tools (e.g., Mapping the Landscape of Fear) that help break down experiences into concrete, accessible components instead of ambiguous and open-ended questions.

A second divergence relates to participants' experiences of diagnosis. Whilst overall they were very positive about their diagnoses, their reflections were complex, shifting over time, and best understood as a "both/and" experience, rather than aligning neatly with either the medical model (diagnosis as positive) or the neurodiversity paradigm (diagnosis as problematic). This nuanced framing is less evident in current literature.

Finally, much existing research focuses on autistic CYP who are already diagnosed and receiving support. By exploring the experiences of girls whose needs were *unidentified* and who received no adaptations, this study offers a clearer account of how unmodified school environments contribute to distress. It extends the literature, as outlined below.

Figure 28

Findings Supported by the Current Study



6.4.2 Study Strengths

Assessing quality in a CGT study was outlined in section 4.7, with credibility being discussed. In this section, the markers of originality, resonance, and usefulness are explored.

Charmaz (2014) suggests that signs of *originality* include categories that offer fresh and new insights, a new understanding from the data, has theoretical significance, and whether it challenges, extends, or clarifies existing ideas. Subtle nuances have been identified which provide further information on how more subtle signs might be missed, in particular the inconsistent nature of the presentation of difficulties depending on context. Connections have been made between the participants experiences whilst individual differences have also been demonstrated.

The cumulative nature of their needs have also been shown, alongside the interaction between the participants and the school system.

Linked to this, *resonance* relates to whether the categories represent the full scope of the experience studied, whether they have revealed subtle nuances that might otherwise remain unknown, whether connections between collective and individual data have been established, and whether they make sense to participants or others in similar circumstances (Charmaz, 2014). The current researcher believes that these nuances would not have been identified without this research and that there was saturation across participants. She also believes that, from her experience, the findings mirror the experiences of others in similar positions, however until the findings are shared with the participants, how much it resonates with them is currently unclear.

Usefulness considers the application of the findings and whether it provides information that can be used in everyday lives, whether any general processes are suggested and, if so, what these imply (Charmaz, 2014). The implications section will highlight this in more detail, but its findings have considerable usefulness which can inform practice going forward, primarily in early identification and screening tools to be able to respond to earlier signs of anxiety.

Finally, this study does not claim to have uncovered entirely new phenomena. However, its *originality* lies in the depth, integration, and conceptual clarity it brings to under-explored areas, and the new theoretical framework generated as a result of the CGT method used. This and its implications are a significant strength of the study, linked to originality and usefulness. Its unique contributions are explored in the following section.

6.4.3 Unique Conceptual contributions

The current study extends descriptive accounts by generating a theory, identifying mechanisms for change, and highlighting *why* change is needed.

Specific observable indicators of EBSNA. Most EBSNA research refers to anxiety in broad, subjective terms. Early signs are frequently missed, particularly in autistic girls who camouflage extensively. This study identifies concrete, observable signs of school-based anxiety that could inform proactive screening and earlier intervention, rather than waiting for attendance to decline. This is also reflected in the framework's title, which moves away from attendance as a primary factor.

Mapping the emotional consequences. Existing literature typically describes anxiety, burnout, or social difficulties without tracing their origins or impact. This study shows how school experiences generate fear, perceived threat, and erosion of belonging and autonomy, and how these accumulate over time, mirroring findings from Corcoran and Kelly (2024), but greater detail. It clarifies the pathway from emotional distress to mental health crisis and chronic non-attendance, underscoring the need for systemic change.

Camouflaging. While camouflaging is well-documented, this study demonstrates how, alongside competence and high attainment, it conceals distress until crisis, also integrating autistic burnout, masking, and EBSNA. This process, shown in figure 29, is not typically articulated in existing research.

Figure 29

Pathway from Camouflaging to EBSNA



The cumulative, layered nature of stressors in autistic girls with EBSNA. Most studies list stressors but do not map their cumulative or interactive nature. This study shows that stress does not operate as a simple stimulus–response pattern; instead, it forms a spiralling accumulation that reduces tolerance and heightens fear. This offers a new explanatory model for how school-based stress leads to non-attendance and, for some, severe mental health crises.

Mechanisms for change. Rather than simply identifying where CYP are let down, this study clarifies *what* was missed, *how* it was missed, and *what* could be changed. Both the theoretical framework generated and the early identification tool provide actionable mechanisms for earlier recognition and more effective support, which will be introduced in the Implications Section.

Trauma like responses to school. Trauma in school contexts is rarely considered beyond extreme events such as severe bullying. Participants in this study described trauma-like symptoms, and some referred directly to their school experiences as being or causing some trauma. Despite extensive searching, there appears to be no literature exploring the potential for repeated exposure to chronic

school-based stress to produce trauma-like responses in autistic or non-autistic CYP with EBSNA. This is a significant gap.

These findings suggest that, for some CYP, school environments and attendance policies may inadvertently expose them to situations that feel threatening and traumatic. This underscores the urgency of systemic change to prevent further harm.

Summary. This study makes a distinctive contribution to the field by moving beyond descriptive accounts of autistic girls' school experiences and generating a grounded theory that explains *how* and *why* school-based distress develops into EBSNA, particularly relating to unidentified autistic needs. It offers several interlinked contributions that extend current knowledge and provide tangible mechanisms for change, discussed in the implications section below.

6.4.4 Research Limitations

Despite the strengths and contributions of this study, several limitations should be acknowledged and follow the same criterion for assessing quality as the above section.

As common in most qualitative research, the analysis is interpretive and shaped by the researcher's perspective. Although steps were taken to enhance *credibility*, such as supervisory oversight and peer discussion of coding, alternative interpretations are possible. Member checking was offered, but only two participants expressed interest, and neither responded to the summaries sent to them. This limited the extent to which participants could verify or challenge the interpretations.

Given the complexity and individuality of participants' experiences, and the constraints of time, word count, and recruitment, the study cannot represent the full

breadth of autistic girls' experiences of EBSNA and so may not resonate with everyone. Initial codes were prioritised based on relevance and frequency, meaning some potentially meaningful data were not developed into focused codes.

The sample size is small for a grounded theory study. Although saturation appeared to be reached for the core categories, a larger or more diverse sample may have elicited additional nuances. Recruitment through social media and autism support networks may also have biased the sample toward individuals who accept their diagnosis and are active within autistic communities. Attempts to broaden recruitment through colleges and universities were unsuccessful.

All participants lived in the South of England and most came from middle to higher socio-economic backgrounds, which may have shaped both their experiences and outcomes. This may reflect the recruitment strategy or may be coincidental, but it nonetheless limits transferability.

Through only seeking the views of the autistic CYP, the findings represent one side of a multifaceted system. Furthermore, external factors beyond school, such as family dynamics or wider contextual influences were not explored directly and may have contributed to attendance difficulties. Nevertheless, the participants' accounts remain valid and important as representations of their lived experiences and are unlikely to be unique to them.

There are also limitations associated with using retrospective accounts, particularly in relation to memory recall, which can be vulnerable to bias, reconstruction, and both conscious and unconscious filtering. These processes can lead to inaccuracies or partial accounts of past experiences (Hardt & Rutter, 2004). However, Hardt and Rutter (2004) found that individuals are more likely to *under-report* events than to overstate them; a pattern they describe as "false

negatives.” Overall, their review concluded that although retrospective bias is possible, it is not sufficient to invalidate retrospective studies, however it should be considered within the possible limitations of this study.

Finally, demographic information about school settings was not systematically collected and was inferred only from participants’ descriptions. This limits the ability to determine how comparable their school contexts are to other settings, and therefore how the findings could transfer elsewhere.

In summary, despite these limitations, the study remains robust in its methodological grounding and theoretical contribution. The consistency of core categories across participants, the depth of the analytic process, and the alignment with CGT principles support the credibility and value of the findings. Furthermore, whilst the participant sample is small, the current researcher’s experience suggests that the findings are shared by others. The centrality of the voices of the young women at the heart of this topic has been prioritised throughout the research and represents a considerable strength of the study.

6.4.5 Further research

Several possibilities for further research have been identified in this study, most of which aim to deepen understanding of those specific findings. The following are those which the current researcher views as most important or interesting to either deepen our knowledge and understanding of the concepts, or to explore links between findings.

A first area concerns the potential relationship between EBSNA and later autism diagnosis. From her experience, the researcher suspects that a high proportion of those experiencing EBSNA, may well go on to receive a diagnosis of

autism; but this could be after they have left school and so the incidence of this may not be known. This is currently not explored in the current literature, and so a longitudinal study exploring this could shed further light on a potential association between EBSNA and unidentified autistic needs. This also sits within the researcher's philosophical positioning in combining autistic differences with outcomes experienced.

Finally, and most crucially for the current researcher, the current study highlights trauma-like responses arising from chronic school-based stress. Further exploration of trauma linked specifically to prolonged exposure to daily stressful school experiences, particularly in autistic CYP without other traumatic histories, would be an important and timely contribution. The findings have highlighted a possible association between these which needs to be understood in more depth.

In summary, the current research has highlighted some new directions for research to take to understand this complex phenomenon in more depth, with the final one of being of particular interest to the current researcher.

6.4.6 Researcher reflections

This section represents my reflections on the research process, findings, and how some of my assumptions have shifted. As such, it will be written in the first person.

Throughout this research journey, many of my assumptions about methodology, autistic girls' experiences, and EBSNA, were challenged and reshaped. At the outset, I was uncertain about my aims and considered mixed methods or IPA. Although familiar, IPA felt too narrow for what I hoped to understand. When a supervisor suggested grounded theory, I was sceptical and

anxious about whether it would offer anything ‘more’. Early analysis intensified this uncertainty: the constant comparison, lack of direction, and meticulous attention to detail felt overwhelming. Yet as I immersed myself in the data, I began to appreciate the power of CGT to reconstruct and reorganise my understanding. Sutcliffe’s (2016) description of GT as moving from chaos to order resonated strongly with my experience.

Applying theoretical sampling and saturation in practice was challenging. Ideally, interviewing more participants would have strengthened the saturation of core concepts, but time constraints and the realities of completing a doctoral thesis as a single researcher limited what was feasible. This represents a clear methodological limitation. Even so, the greatest strength of the approach was my ability to genuinely ‘follow the data’ rather than impose pre-existing categories. Being able to adapt questions and pursue unexpected directions proved invaluable, particularly in a field dominated by descriptive rather than explanatory research. CGT enabled the development of a theoretical framework that not only reflects participants’ experiences but also identifies mechanisms for change.

My assumptions about the findings were also challenged. I expected participants to offer clear answers to questions such as ‘what should adults have done differently?’, but all of them told me that by the time their non-attendance began, it was already too late. This shifted my focus to early identification and support. I had also assumed that diagnosis would always be welcomed and helpful. Instead, participants described diagnosis as a highly individual journey, often involving initial ambivalence, relief, confusion, or delayed acceptance. This added challenge to my assumption that diagnosis is universally beneficial and desired.

Similarly, I had assumed that school staff would not have tried. Participants complicated this: some adults did try once difficulties were recognised, but systemic constraints limited what they could offer. At the same time, early parental concerns were often dismissed due to limited awareness of autistic presentations, which aligned with my initial expectations. I also believed that CYP would want and accept support when offered. This was quickly challenged by my first participant, who declined adaptations because she feared standing out and did not recognise she was struggling. Her account highlighted how asking CYP to articulate 'why' they are struggling can itself be an additional stressor, something which is under-acknowledged in current research.

Two theoretical codes prompted particularly deep reflection: '*emotional response to unnoticed distress and lack of autonomy',* and '*activated threat response and consequences of being unable to act'*. My professional experience includes hearing many parents describe their autistic child as traumatised by mainstream schooling, and I have witnessed trauma-like responses in CYP whose fear prevented them from entering any building associated with a school. I questioned in supervision whether I was over-interpreting the data due to this. Through repeated supervision and systematic re-engagement with the data, I remain confident that the interpretation is grounded in participants' narratives. Their descriptions of persistent fear, hyperarousal, avoidance, and threat strongly support this, and I believe participants, particularly those with chronic nonattendance and significant mental health needs, would recognise it. Nonetheless, I acknowledge that my professional history may have sensitised me to noticing trauma-related patterns, and this remains an important potential source of bias.

Finally, I had hoped that entrenched EBSNA could be reversed with the right intervention. While this may be possible for some, participants' insights showed that by the time their attendance collapsed, it was too late without a complete reset or systemic change. Much current intervention focuses on those already experiencing absence; this study highlights the need for a parallel focus on early, preventative approaches. Although the theoretical framework developed here is grounded in the experiences of five autistic participants, I believe it has relevance for others experiencing EBSNA, whether autistic or not. However, it is not a predictive trajectory, many CYP experiencing early signs of EBSNA will not necessarily progress to chronic non-attendance and mental health needs.

Challenging and highlighting these assumptions and biases through personal and supervisory reflection is crucial within the context of a CGT study, in which the theory developed is grounded in the data, but constructed by my interpretation of it. Overall, this research has reshaped my assumptions, deepened my reflexivity, and strengthened my appreciation of CGT as a method capable of illuminating complex, systemic processes. These reflections align closely with the implications outlined in the final chapter.

6.4.7 Chapter Summary

This chapter has outlined the study's findings in relation to existing theories, frameworks, and literature. Broadly speaking, the findings support the existing literature but extend it by deepening our understanding of the complex interrelated and cumulative process involved. The importance of early identification of developing school anxiety has been highlighted and through the study's exploration, observable signs of this have been identified which could aid earlier identification.

This deeper understanding of interrelated process and specificity in the experiences which cause stress, represents some of the unique contributions for this study and carries with it some tangible implications and mechanisms for change which will be explored in the final chapter which follows.

7. Conclusion

This final chapter presents a conclusion to the study, outlining the main findings, implications and recommendations, and will introduce an early screening tool and support pathway being developed from the findings of this study. The intended dissemination strategy will also be considered, before closing with the researchers' concluding thoughts.

This research has produced a considerable number of findings which have been presented in the chapters above. These can. however, be summarised into three primary ones. The findings have highlighted that the participants early needs remained invisible, that chronic stress led to escalating anxiety and withdrawal, and that re-engagement in education was possible under the right conditions.

The implications of these findings will be outlined in the next section.

7.1 Implications

The recommendations arising from this study span multiple systems, consistent with Bronfenbrenner’s ecological framework (3.2.3). Early identification of emerging school-based anxiety is essential so that graduated support can be implemented at the right level and at the right time, rather than only once crisis is reached through non-attendance or significant mental health difficulties. This early recognition and a graduated response framework can be implemented at a school level, supported by Educational Psychology Services and other external agencies.

Although there is substantial literature recommending interventions for supporting autistic CYP and those experiencing EBSNA in mainstream settings (e.g. Ayirebi & Thomas, 2024; Gray et al., 2021; Halsall et al., 2021; O’Hagan et al., 2024;

Tomlinson et al., 2024), these often focus on developing the CYP's resilience, coping strategies, friendship skills, or emotional literacy, emphasising a within-child focus. While valuable, this study highlights that learning of skills is unlikely during times of chronic stress, and that systemic change is required so that schools can identify CYP at risk earlier and provide support before difficulties escalate, enabling them to adapt the environment and develop skills earlier. Blasé et al. (2012) emphasise that evidence-based interventions alone are insufficient; long-term, effective change depends on core systemic components such as infrastructure, leadership commitment, and coherent organisational processes.

Rather than reiterating the existing strategies which are evidenced to support CYP with their attendance, this research indicates a clear need for systemic change across schools, Educational Psychology Services, and the wider education system to enable earlier identification and support for CYP. These changes centre on monitoring, and actively supporting the well-being of CYP within school environments where concerns arise at a much earlier stage.

Although this study focused on a specific participant group, the mechanisms it identifies, such as early warning signs of reduced school well-being, the need for proactive monitoring, and the importance of systemic responsiveness, are not unique to neurodivergent CYP experiencing EBSNA (Antalek et al., 2025; Reinke et al., 2025; Sampson & Sampson, 2026). These processes reflect broader patterns seen across other cohorts and the general population, where reduced well-being, emerging anxiety, and relational or environmental stressors can arise for CYP in wider populations (e.g. Antalek et al., 2025; Sampson & Sampson, 2026). Consequently, the systemic changes recommended here are relevant to any CYP whose school experience becomes compromised.

The findings also align with wider literature demonstrating that early identification, systemic adaptation, and timely support function as universal protective factors rather than condition-specific ones (e.g. Brighter Futures for Children, 2022; Chian, 2024). As such, the implications extend beyond the current participant group and are applicable to CYP with neurodivergent, learning, or mental health needs, as well as neurotypical CYP experiencing EBSNA.

The implications for Educational Psychologists, school settings and wider policy are considered below.

7.1.1 Implications for Educational Psychology practice (service and individual EPs)

Many EPSs already support schools in responding to rising rates of EBSNA, including within the researcher's own Authority. However, current efforts largely focus on intervention once difficulties are established. While this work must continue, EP practice should also shift towards helping schools develop early identification systems and graduated response pathways. Early recognition of emerging needs (not diagnosis) will lead to earlier intervention and improved outcomes, as is central to the CoP (DfE & DoH, 2014), and likely to be equally relevant here. However, such change will be gradual, and its impact will be reflected over years; but could result in longer term embedded improvement in levels of EBSNA, rather than short-term gains with inconsistent outcomes that do not address the cause.

Recommendations. EP services and individual EPs should work with schools to understand the early warning signs identified in this research, develop systems for earlier identification of emerging needs, establish a graduated response

pathway, and shift terminology away from “non-attendance,” which reinforces the assumption that support is only warranted once attendance declines.

1. Well-being and resilience pathway. EP services should incorporate a school well-being and resilience pathway into their core offer. This should include training and resources on well-being, resilience, relational approaches, and their roles in sustaining attendance and positive mental health, alongside evidence that reduced well-being can be an early indicator of emerging barriers to education.

2. Graduated response. EPs should support schools to implement systematic response pathways and differentiated levels of support such as the one shown in Appendix 42, in line with NAPEP (2026). This includes staff awareness-raising, training, and supervisory support in relational approaches or similar frameworks.

3. Terminology, narrative and perception change. Current language around school non-attendance continues to imply that CYP are “fine at school” until attendance drops, reinforcing a child-located narrative and delaying support. Although progress has been made in moving away from notions of choice, further change is needed. EP services should lead this shift by adopting terms such as “barriers to education” and by promoting a focus on school well-being and resilience in conversations with schools and parents.

4. Transition. Given the importance of transitions and the higher rates of EBSNA in secondary settings, EPs should facilitate collaboration between primary and secondary schools for CYP identified through the pathway. This could begin with trialling screening tools with Year 6 cohorts to identify CYP of concern. Secondary schools should then implement enhanced pastoral support and wider staff awareness, aligned with the support pathways developed with EPs.

7.1.2 Implications for schools

The critical implication highlighted by this research is the importance of earlier identification of CYP developing school-based stress. Early signs are present but typically missed by adults at school. Furthermore, the importance of student-school adult relationships has been highlighted, with most participants reporting that these were unsupportive and inconsistent. Adults were predominantly viewed as unapproachable and unpredictable and identified as a primary cause of their anxiety.

Recommendations. As such, school based recommendations centre on developing early identification procedures, implementing graduated response pathways (as outlined in the appendices and below) and developing their use of relational approaches as a core ethos.

Relational approaches. The researcher argues that relational approaches should be embedded across mainstream education. Investing time in developing these skills and practices will help all CYP, not only autistic pupils, feel safer in school and better able to learn. Mainstream secondary schools should prioritise relational work grounded in unconditional positive regard, consistency, and fairness, with fairness understood as responding to individual needs, rather than treating all pupils identically.

Once a CYP is identified as experiencing school as stressful, their profile should be shared with all staff who interact with them to ensure consistent awareness and sensitive support. This study suggests that widespread adult understanding may be more effective than reliance on one or two key adults; therefore, relational approaches should be developed across multiple teachers and support staff in ways that are achievable for the setting.

Teachers require training and practical guidance to build these relational skills, which foster belonging and help rebalance early barriers and protective factors. Ongoing supervisory support from leaders, other professionals, or experienced peers will further embed these practices. Blasé et al. (2012) highlight this as another core component of effective implementation.

Example school well-being and resilience pathway. The current researcher has worked with a group of primary and secondary school SENCos in her service to develop one such pathway, including the development of a graduated response, and screening checklist to monitor school wellbeing and resilience. This example is explained below and provided in Appendix 42-44, to add context to the above recommendations.

1. Graduated response pathway. This (Appendix 41) outlines the steps to take from the moment concerns are identified through any of the recognised routes. Crucially, consistent with existing research (e.g., Mullally & Connolly, 2024) and the findings of this study, parents often report feeling blamed, disbelieved, or dismissed. This pathway therefore positions parental voice as central. At the same time, it emphasises the importance of gathering additional information to triangulate initial concerns, enabling schools to determine the appropriate level of response. This helps prevent unnecessary allocation of time and resources where concerns may not escalate, while ensuring that CYP who do require support are identified early and responded to proportionately.

Pupil voice and assessment are central at the second stage of the pathway. The researcher recommends using self-report measures for CYP identified as at risk, to further corroborate emerging mental health needs linked to school experiences.

Tools such as the My Emotions in School Inventory (MESI; Lukito et al., 2025), Mapping the Landscape of Fear (Ripley, 2014), or the Barriers to Education card-sort tool (Barriers to Education, 2025) may be particularly useful.

A flowchart as part of this pathway, included within Appendix 42, can be used at stage 3 of the pathway to help school staff determine the level of response required. It is intended as a flexible guide rather than a rigid categorisation system; inevitably, some CYP will not fit neatly into defined categories.

The graduated response (Appendix 43) identified by the collaborative work by the current researcher and her linked schools are intended to be used alongside mainstream core standards. This details the suggested responses at different levels of concern from a CYP who is attending and engaging but showing distress at home, through to those whose attendance is already reduced. It is hoped that, in time, reduced attendance will not become the first time schools become concerned about a CYPs well-being and engagement in learning.

2. Screening tool. To support earlier identification of CYP experiencing school as stressful, the author recommends that schools use a screening tool with parents for CYP up to the end of Year 7. This would involve an initial roll-out to all parents of pupils in Years 1–6 in primary school, and for parents whose child is at the end of Year 7 in secondary school. This process should identify most CYP at risk of, or beginning to develop, school-based anxiety. A checklist is being developed by the current researcher, and a working example of this can be found in Appendix 44.

It is acknowledged that this approach may highlight a large number of CYP, given recent evidence of increasing anxiety and reduced well-being among pupils (Chollet et al., 2025) in recent years. To minimise unnecessary identification, the

researcher is working with her borough to standardise the checklist so that only CYP whose difficulties exceed those of their peers are prioritised.

The tool is currently termed the school well-being and resilience checklist, with most questions phrased positively to reduce the likelihood of parents searching for problems they had not previously noticed. The framing of this approach is crucial to avoid causing undue concern among parents and inadvertently increasing EBSNA.

7.1.3 Implications for policy and approaches to EBSNA

This research has demonstrated the experience of chronic stress and resulting mental health needs for the participants in this study. The consequence of a CYP being forced into an environment they are experiencing as traumatising *must* be considered. Currently, schools are under strain. They are meeting an increasing level of need with reducing resources. By mandating that CYP must attend for 95% of their time, or face consequences (parental fines etc.), they are experiencing feelings of force and threat. Schools must be supported if they are expected to be able to meet the needs of CYP at risk of reduced mental well-being, otherwise we are setting these CYP up to fail and exposing them to chronic stress.

The current researcher views that in its current form, mainstream education system is not suitable for all. The curriculum is too inflexible and its broadness, while important for some, does not allow for autonomy. This needs to be recognised and alternatives should not be reserved for those who have reached crisis, or whose parents have the capacity (emotional, educational and financial) to fight. How the system needs to reform is beyond the scope of this paper, but suggestions would include increasing autonomy, and true individualisation of curricula and available

support for all, so that those who need it are not ostracised and made to feel different.

7.2 Dissemination strategy

The findings from this research and its implications are already being discussed with key EPs and schools within the researcher's service, where she will be employed post-qualification. She is involved in the service's EBSNA working group to share findings and support the development of practice and systems.

A summary sheet of findings will be created and shared with participants and, if allowed, on the social media forums the participants were recruited from, following interest from members to do so.

The current researcher has also attended an EP autism interest group event focused on the intersection between autism and EBSNA, where she presented her findings through a poster at the event. Finally, she currently intends to publish the findings as a journal article due to the significance and importance of the findings.

7.3Concluding thoughts

This study set out to illuminate the processes shaping the early experiences of five autistic young people whose EBSNA developed before their needs were recognised. By examining their retrospective accounts, the research offers a deeper understanding of how everyday school environments can become sites of cumulative stress for autistic CYP, and how this stress can, for some, escalate into chronic non-attendance and significant mental health needs. The theoretical framework extends existing knowledge by mapping the complex and cyclical trajectory from early signs of distress, through prolonged exposure to unmet needs, to withdrawal

from education and mental health needs. Based on the participants' outcomes, possible factors contributing to their re-engagement and achievement were also incorporated.

The five participants, aged 17–25, described in rich detail how their autistic differences shaped their experiences of mainstream secondary school. At the time their EBSNA began, their needs were unrecognised and unsupported. Semi-structured interviews, supported by visual tools to scaffold recall and reflection, enabled participants to express the nuanced ways in which sensory, social, cognitive and emotional demands accumulated over time. Using a CGT methodology, these accounts were analysed to generate a theory that situates their experiences within broader systemic processes.

The findings demonstrate that many features typical of mainstream secondary environments were experienced as stressful, unpredictable or threatening. Without recognition of their needs, participants remained exposed to these stressors over extended periods, contributing to the development of chronic stress responses. This manifested in heightened anxiety, depression and, for two participants, eating disorders. Several participants described trauma-like responses, and their eventual non-attendance could be understood as a protective response to environments that had become overwhelming.

Contrary to the well-documented poorer outcomes associated with EBSNA, all participants in this study were able to re-engage with education when conditions aligned with their needs, most commonly in post-16 settings or contexts that afforded greater autonomy, flexibility and control. Their eventual academic and vocational achievements reflect their resilience, cognitive strengths, and determination, as well as their parents' sustained advocacy. Participants were acutely aware that their

positive outcomes are not typical, and they expressed a sense of luck in having accessed environments that finally enabled them to thrive.

The study offers a distinctive contribution by providing a theoretical account grounded in participants' lived experiences of how CYP may progress from early signs of distress to chronic non-attendance, linking these individual trajectories to wider systemic patterns. By integrating and extending existing concepts, it develops a coherent framework that explains the participants' experiences and outcomes in ways that are potentially transferable to other CYP in similar circumstances, including those from the wider population experiencing school stress or non-attendance. In doing so, it highlights the mechanisms through which change might occur, moving beyond individual-level interventions and offering a set of theoretically informed levers for systemic improvement at different levels, outlined by Ecological Systems Theory.

The findings have demonstrated the importance of acting at a much earlier stage of the continuum of school non-attendance. Whilst not wishing to add yet another label, the current researcher wonders whether the terms used, relating to 'attendance' (e.g. barriers to school attendance or emotionally based school non-attendance) provides an assumption that only once attendance is impacted should schools notice and offer support. Consequently, the framework developed from this study has been labelled '*accumulating barriers to education'* to highlight a subtle shift in focus. In their recent publication on EBSNA, the National Association of Principal Educational Psychologists (NAPEP) have also begun to consider barriers to both attendance and engagement and propose that focusing on attendance only, we may well be overlooking other aspects of wellbeing that impact readiness and progress (NAPEP, 2026).

If CYP who experience elevated emotional burdens in response to everyday school demands are to remain in mainstream settings, then substantial reform is required. This includes changes to the physical and sensory environment, enhanced training and expectations for staff, genuine personalisation of curriculum and pedagogy, and earlier opportunities for autonomy and self-direction. The current system is not designed with neurodiversity in mind, and insisting on attendance without addressing these structural issues risks perpetuating cycles of chronic stress and trauma-like responses. The White Paper (DfE, 2026) has acknowledged the importance of school belonging and proposes ways for schools to monitor this and target change. However, there remains a strong focus on attainment and attendance and, if schools are still judged primarily on these factors, then there is little incentive for them to put the work in to increasing the wellbeing of CYP. For many CYP, progress is not just about maths or literacy, but in being able to get out of bed in the morning and step through the school gates. CYP like the participants in the current study will continue to fall through the gaps if more systemic and curriculum changes are not made.

In the interim, this study proposes recommendations for the support EPs can provide to schools, specifically related to earlier identification of CYP showing emerging signs of school-related anxiety, including the use of screening tools and clear pathways for responsive support. However, the findings make clear that meaningful change will only occur through multi-system reform. Calls for increased attendance, without corresponding *structural change*, continues to place responsibility on the individual and already struggling schools to cope, rather than on the systems that shape their experiences. A shift towards systemic accountability is

essential if we are to prevent future generations of autistic CYP from experiencing similar trajectories.

8. References

Adamou, M., Fullen, T., Clarke, C., Godley, C. & Jones. S. (2025). Patient Expectations of an Autism Diagnosis: A Thematic Analysis. *Journal of Autism and Developmental Disorders*, ahead of print. https://doi.org/10.1007/s10803-025-07115-0.

Al-Ababneh, M. (2020). Linking Ontology, Epistemology and Research Methodology. *Science & Philosophy, 8*(1)*,* 75-91. https://papers.ssrn.com/abstract=3708935

American Psychiatric Association [APA]. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). APA. https://doi.org/10.1176/appi.books.9780890425596

Anderson, J., Marley, C., Gillespie-Smith, K., Carter, L. & MacMahon, K. (2020). When the Mask Comes off: Mothers' Experiences of Parenting a Daughter with Autism Spectrum Condition. *Autism* 24, no. 6 1546–56. https://doi.org/10.1177/1362361320913668.

Antalek, C., Dixon, F., Loyd, D., Peter, S., Roberts, A., Sharxhi, E. & Somerville, M. (2025). *Identifying and supporting children and young people with social, emotional and mental health needs: a rapid evidence review.* DfE. https://assets.publishing.service.gov.uk/media/68d65e5dc908572e81248d43/Identifying_and_supporting_children_and_young_people_with_social_emotional_and_mental_health_needs_a_rapid_evidence_review.pdf

Aridah. (2025). How Stereotype Threat and Stress Affect Learning: From Theory to Empirical Evidence. *International Journal of Research in Education*, *5*(1), 175–190. https://doi.org/10.26877/ijre.v5i1.1111

Ayirebi, K. & Thomas, G. (2024). What Could Be Considered as Effective Support for Autistic Females in High School? A systematic Literature Review. *Journal of Research in Special Educational Needs* 24, no. 3. 441–53. https://doi.org/10.1111/1471-3802.12641.

Baethge, C., Goldbeck-Wood, S. & Mertens, S. (2019). SANRA—a scale for the quality assessment of narrative review articles. *Research Integrity and Peer Review, 4*(5). https://doi.org/10.1186/s41073-019-0064-8

Bailey, J. & Baker, S. (2020). A Synthesis of the Quantitative Literature on Autistic Pupils' Experience of Barriers to Inclusion in Mainstream Schools. *Journal of Research in Special Educational Needs 20*(4), 291–307. https://doi.org/10.1111/1471-3802.12490

Baron-Cohen, S. & Hammer, J. (1997). Is autism an extreme form of the "male brain"? *Advances in Infancy Research, 11,* 193-217.

Barriers to Education. (2025). Barriers to Education Card Sort Tool. https://barrierstoeducation.co.uk/bte_tools/barriers-to-education-card-sort-tool/

Belcher, H., Morein-Zamir, S., Stagg, S. & Ford, R. (2023). Shining a Light on a Hidden Population: Social Functioning and Mental Health in Women Reporting Autistic Traits but Lacking Diagnosis. *Journal of Autism and Developmental Disorders, 53*(8), 3118–32. https://doi.org/10.1007/s10803-022-05583-2

Bernardin, C., Lewis, T., Bell, D. & Kanne, S. (2021). Associations between Social Camouflaging and Internalizing Symptoms in Autistic and Non-Autistic Adolescents. *Autism: The International Journal of Research and Practice 25*(6), 1580–91. https://doi.org/10.1177/1362361321997284

Bhaskar, R. (1989). Reclaiming Reality: a critical introduction to contemporary philosophy. London.

Blasé, K., Van Dyke, M., Fixsen D., & Bailey F. (2012). Implementation Science: Key Concepts, Themes, and Evidence for Practitioners in Educational Psychology. In: B. Kelly & D. Perkins. (Eds). *Handbook of Implementation Science for Psychology in Education.* 13-34. Cambridge University Press.

Boaler, R., Bond, C. & Knox, L. (2024). The Collaborative Development of a Local Authority Emotionally Based School Non-Attendance (EBSNA) Early Identification Tool. *Educational Psychology in Practice 40*(2), 185–200. https://doi.org/10.1080/02667363.2023.2300027

Bond, C., Kelly, C., Atkinson, C. & Gulliford, A. (2024). Guest Editorial: School Non-Attendance. *Educational & Child Psychology, 41*(1), 5-8. https://explore.bps.org.uk/content/bpsecp/41/1/5

Boucher, J. (2009). *The Autistic Spectrum: Characteristics, Causes and Practical Issues*. SAGE Publications Ltd.

Brighter Futures for Children. (2022). EBSA Guidance: Emotionally Based School Avoidance Guidance and Toolkit for Professionals and Families. https://brighterfuturesforchildren.org/wp-content/uploads/2022/11/BFfC-EBSA-Guidance-Updated-Feb-2024.pdf

British Medical Association. (2026). Children and young people's mental health services in England. Accessed 02/05/2026. https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/children-and-young-people-s-mental-health-services-in-england

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press.

Browne, R. (2018). *An exploration into the parental experience of Emotionally Based School Non Attendance in young people.* [Doctoral thesis]. Tavistock and

Portman NHS Foundation Trust / University of Essex. https://repository.tavistockandportman.ac.uk/2074/

Burnham, J. (2012). Developments in social GRRRAAACCEEESSS: Visible-invisible and voiced-unvoiced. In I-B. Krause (Ed.) *Culture and Reflexivity in Systemic Psychotherapy. Mutual Perspectives*. London: Karnac.

Casanova, E. & Widman, C. (2021). A sociological treatment exploring the medical model in relation to the neurodiversity movement with reference to policy and practice. *Evidence & Policy, 17*(2), 363–381.

CASP. (2024a). Qualitative Research Checklist. https://casp-uk.net/casp-tools-checklists/qualitative-studies-checklist/

CASP. (2024b). Cross-Sectional Studies Checklist**.** https://casp-uk.net/casp-tools-checklists/cross-sectional-studies-checklist/

CASP. (2024c). Systematic Review Checklist. https://casp-uk.net/casp-tools-checklists/systematic-review-checklist/

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Sage.

Charmaz, K & Henwood, K. (2017). Grounded Theory Methods for Qualitative Psychology. In Willig, C. and Rogers, W. (Eds) *The SAGE Handbook of Qualitative Research in Psychology.* (2nd Edition) (pp. 193-211). Thousand Oaks, California. https://search.ebscohost.com/login.aspx?direct=true&site=eds-live&db=nlebk&AN=1538522

Chian, J., Holliman, A., Pinto, C. & Waldeck, D. (2024). Emotional based school avoidance: Exploring school staff and pupil perspectives on provision in mainstream schools. *Educational & Child Psychology, 41*(1), 55-75.

Children's Commissioner, (2023). *Missing Children, Missing Grades.* *https://www.childrenscommissioner.gov.uk/resource/missing-children-missing-grades/*

Chollet, D., Johnson, M., Fédia, B. & O'Neill, J. (2025). *The Good Childhood Report 2025*. London: The Children's Society. https://www.childrenssociety.org.uk/sites/default/files/2025-10/GCR2025%20Summary%20Report.pdf

Connolly, S. E., Constable, H. L., & Mullally, S. L. (2023). School distress and the school attendance crisis: A story dominated by neurodivergence and unmet need. *Frontiers in Psychiatry, 14*. https://doi.org/10.3389/fpsyt.2023.1237052

Conley, M., Hernandez, J., Salvati, J., Gee, D. & Baskin-Sommers, A. (2023). The Role of Perceived Threats on Mental Health, Social, and Neurocognitive Youth Outcomes: A Multicontextual, Person-Centered Approach. *Development and Psychopathology 35*(2), 689–710. https://doi.org/10.1017/S095457942100184X

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in Autism: A Systematic Review. *Clinical Psychology Review, 89*. https://doi.org/10.1016/j.cpr.2021.102080.

Cook, J., Hull, L., & Mandy, W. (2024). Improving Diagnostic Procedures in Autism for Girls and Women: A Narrative Review. *Neuropsychiatric Disease and Treatment, 20,* 505-514.

Cooper, Jodi (2019) *An in-depth exploration into secondary school pupils' experiences of having autism spectrum disorder.* [Other thesis]. University of Essex & Tavistock and Portman NHS Foundation Trust. https://repository.essex.ac.uk/25282/

Corbin, J. & Strauss, A. (2015). *Basics of Qualitative Research* (4th ed). Sage.

Corcoran, S., Bond, C & Knox, L. (2022). Emotionally Based School Non-Attendance: Two Successful Returns to School Following Lockdown. *Educational Psychology in Practice 38*(1), 75–88. https://doi.org/10.1080/02667363.2022.2033958

Corcoran, S. & Kelly, C. (2023). A meta-ethnographic understanding of children and young people's experiences of extended school non-attendance. *Journal of Research in Special Educational Needs, 23*(1), 24-37. https://doi.org/10.1111/1471-3802.12577

Corson, D. (1991). Bhaskar's Critical Realism and Educational Knowledge. *British Journal of Sociology of Education, 12*(2). 223-241.

Cotton, J. (1981). A Review of Research on Schachter's Theory of Emotion and the Misattribution of Arousal. *European Journal of Social Psychology 11*(4), 365–97. https://doi.org/10.1002/ejsp.2420110403

Cresswell, J. & Cresswell, J.D. (2023) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches (6th ed).* SAGE.

Cruz, S., Zubizarreta, S. C.-P., Costa, A. D., Araújo, R., Martinho, J., Tubío-Fungueiriño, M., Sampaio, A., Cruz, R., Carracedo, A., & Fernández-Prieto, M. (2024). Is there a bias towards males in the diagnosis of autism? A systematic review and meta-analysis. *Neuropsychology Review*, *35,* 153-176. https://doi.org/10.1007/s11065-023-09630-2

Daulby, B. (2017). *The mathematical biographies of primary school teachers and how this may affect their teaching: A grounded theory study*. [Doctoral thesis],

Tavistock and Portman NHS Foundation Trust / University of Essex. https://repository.tavistockandportman.ac.uk/2762/

Deci, E. L., & Ryan, R. M. (1985). *Intrinsic Motivation and Self-Determination in Human Behavior*. Springer. http://ebookcentral.proquest.com/lib/universityofessex-ebooks/detail.action?docID=3086782

Department for Education. (2024). *Working together to improve school attendance: Statutory guidance for maintained schools, academies, independent schools and local authorities.* https://www.gov.uk/government/publications/working-together-to-improve-school-attendance

Department for Education. (2025a). *Pupil attendance in schools.* https://explore-education-statistics.service.gov.uk/find-statistics/pupil-attendance-in-schools/2025-week-29

Department for Education. (2025b). *Pupil absence statistics: methodology*. https://explore-education-statistics.service.gov.uk/methodology/pupil-absence-statistics-methodology#105a-3-2-persistent-absence-methodology

Department for Education. (2025c). *Pupil attendance in Schools in England*. https://explore-education-statistics.service.gov.uk/find-statistics/pupil-absence-in-schools-in-england/2023-24 Accessed 26/05/2025

Department for Education. (2025d). *Press Release: Education Secretary sets roadmap to improve attendance levels. Published 12th November 2025.* https://www.gov.uk/government/news/education-secretary-sets-roadmap-to-improve-attendance-levels

Department for Education. (2026a). *Every Child Achieving and Thriving.* Crown Copyright. https://www.gov.uk/government/publications/every-child-achieving-and-thriving

Department for Education. (2026b). *Pupil attendance in schools; week 4 2026. Accessed 15/02/2026. https://explore-education-statistics.service.gov.uk/find-statistics/pupil-attendance-in-schools/2026-week-4*

Department for Education & Department of Health. (2014). *Special educational needs and disability code of practice: 0 to 25 years.* Crown Copyright. https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Doolan Maher, R., Flynn, S. & Byrne, J. (2025). Through a Critical Realist Lens: Investigating Data Collection and Analysis Techniques in a Qualitative Study About Internet-Related Child Protection Risks for Children and Young People with Disabilities. *International Journal of Qualitative Methods, 24*, 1-13. https://journals.sagepub.com/doi/pdf/10.1177/16094069251370188?utm_source=copilot.com

Dowd, D. (2024). *'If we are not great, then we can't be great with the kids': A grounded theory of successful teaching assistant-teacher partnerships for inclusive education.* [Unpublished doctoral thesis]. University of Essex. https://repository.essex.ac.uk/38823/

Drew, C. (2022). *7 Macrosystem Examples (from Ecological Systems Theory)*. Helpful Professor. https://helpfulprofessor.com/macrosystem-examples/

Eaton, J (2024). *Autism Missed and Misdiagnosed; Identifying, Understanding and Supporting Diverse Autistic Identities*. Jessica Kingsley Publishers.

Eatough, V. & Smith, J. (2017). Interpretative Phenomenological Analysis. In Willig, C. and Rogers, W. *The SAGE Handbook of Qualitative Research in*

Psychology. (2nd Edition). (193-211). Thousand Oaks, California. https://search.ebscohost.com/login.aspx?direct=true&site=eds-live&db=nlebk&AN=1538522

Eaveson, L. (2024). *Narrative Experiences of Young People with Autism who Experience Anxiety Related to Attending School.* [Doctoral thesis]. University of Sheffield. https://etheses.whiterose.ac.uk/id/eprint/33964/

Education Act 1996, c.56, https://www.legislation.gov.uk/ukpga/1996/56/contents

Elliott, R., Fischer, C. & Rennie, D. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38,* 215-229. https://doi.org/10.1348/014466599162782

Fletcher, A. J. (2017). Applying Critical Realism in Qualitative Research: Methodology Meets Method. *International Journal of Social Research Methodology*, *20*(2), 181–194. https://doi.org/10.1080/13645579.2016.1144401

Fox, M., Martin, P. & Green, G. (2007). Doing Practitioner Research. SAGE. https://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=251366&authtype=shib&site=eds-live&scope=site

Gaffney, J. C. (2020). 'It's autism, it's just a name': Exploring the impact of autism spectrum diagnosis with adolescent females using Interpretative Phenomenological Analysis. *Educational & Child Psychology*, *37*(1), 136–149. https://doi.org/10.53841/bpsecp.2020.37.1.136

Garrett, M. (2016). Questioning Tales of "Ordinary Magic": "Resilience" and Neo-Liberal Reasoning. *The British Journal of Social Work, 46*(7), 1909–25. https://doi.org/10.1093/bjsw/bcv017.

Glaser, B. & Strauss, A. (1967). *The Discovery of Grounded Theory*. Aldine.

Guldberg, K., Bradley, R., Wittemeyer, K., Briscombe, J., Phillips, C. & Jones, G. (2019). *Good Autism Practice: Full Report*. Autism Education Trust. https://www.nen.org.uk/sites/default/files/2022-01/GAP-report-mainReport_I-S.pdf

Gough, D. (2007). Weight of Evidence: A framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, *22*(2), 213–228. https://doi.org/10.1080/02671520701296189

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism*, *21*(6), 703–705. https://doi.org/10.1177/1362361317706174

Gray, L., Bownas ,Ella, Hicks ,Lucy, Hutcheson-Galbraith ,Emma, & Harrison, S. (2021). Towards a better understanding of girls on the Autism spectrum: Educational support and parental perspectives. *Educational Psychology in Practice*, *37*(1), 74–93. https://doi.org/10.1080/02667363.2020.1863188

Grant, M. (2020). Pupils with SEMH needs' experiences of a successful transition To secondary school. A Grounded Theory study. [Doctoral thesis], Tavistock and Portman NHS Foundation Trust / University of Essex. https://repository.essex.ac.uk/28892/2/Thesis%20%20Marisha%20Grant%2007032942%20FINAL%20PDF.pdf

Gregory, I. R., & Purcell, A. (2014). Extended School Non-Attenders' Views: Developing Best Practice. *Educational Psychology in Practice*, *30*(1), 37–50. https://doi.org/10.1080/02667363.2013.869489

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), 2074–86. https://doi.org/10.1177/13623613211012819

Hamilton, L. (2024). Emotionally Based School Avoidance in the Aftermath of the COVID-19 Pandemic: Neurodiversity, Agency and Belonging in School. *Education Sciences 14*(2), 156. https://doi.org/10.3390/educsci14020156

Hardt, J. and Rutter, M. (2004), Validity of adult retrospective reports of adverse childhood experiences: review of the evidence. *Journal of Child Psychology and Psychiatry, 45*. 260-273. https://doi.org/10.1111/j.1469-7610.2004.00218.x

Hart, A., Gagnon, E., Eryigit-Madzwamuse, S., Cameron, J., Aranda, K., Rathbone, A., & Heaver, B. (2016). Uniting Resilience Research and Practice With an Inequalities Approach. *Sage Open*, 6(4). https://doi.org/10.1177/2158244016682477

Hennick, M. & Kaiser, B. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine, 292*. https://www.sciencedirect.com/science/article/pii/S0277953621008558?via%3Dihub

Higgins, M. (2022). *The Ideal School: Exploring the Perceptions of Autistic Students Experiencing Emotionally Based School Non-Attendance (EBSNA)*. [Doctoral Thesis]. Tavistock and Portman NHS Foundation Trust / University of Essex. https://repository.tavistockandportman.ac.uk/2718/

Holder, J. (2025). School Wellbeing and Resiliency Cards. https://www.schoolwellbeingcards.co.uk/

Hong, QN., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M-P., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M-C., & Vedel, I. (2018). *Mixed Methods Appraisal Tool (MMAT), version 2018*.

McGill. http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf

Hull, L., Petrides, K. & Mandy, W. (2020). The Female Autism Phenotype and Camouflaging: A Narrative Review. *Review Journal of Autism and Developmental Disorders 7*(4), 306–17. https://doi.org/10.1007/s40489-020-00197-9.

Kagan, C., Burton, M., Duckett, P., Lawthom, R. & Siddiquee, A. (2019). *Critical Community Psychology: Critical Action and Social Change*. Taylor & Francis Group. http://ebookcentral.proquest.com/lib/universityofessex-ebooks/detail.action?docID=5896627

Kapp, S., Gillespie-Lynch, K., Sherman, L. & Hutman, T. (2013). Deficit, Difference, or Both? Autism and Neurodiversity. *Developmental Psychology, 49*(1), 59–71. DOI: 10.1037/a0028353

Kaufeldt, M. (2021). How the Stress Mess Impacts Learning. In K. A. Thomas, J. V. Kureethara, & S. Bhattacharyya (Eds), *Neuro-Systemic Applications in Learning* (pp. 387–402). Springer International Publishing. https://doi.org/10.1007/978-3-030-72400-9_19

Kearney, C. (2008). School absenteeism and school refusal behavior in youth: A contemporary review. *Clinical Psychology Review, 28*(3), 451–471. https://doi.org/10.1016/j.cpr.2007.07.012

Kearney, C. & Silverman, W. (1993). Measuring the Function of School Refusal Behavior: The School Refusal Assessment Scale. *Journal of Clinical Child Psychology,* 22(1), 85-96. https://doi.org/10.1207/s15374424jccp2201_9.

Lai, M-C., Lombardo, M., Pasco, G., Ruigrok, A., Wheelwright, S., Sadek, S., Chakrabarti, B., MRC AIMS Consortium & Baron-Cohen, S. (2011). A Behavioral Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions. *PLOS ONE 6*(6). https://doi.org/10.1371/journal.pone.0020835

Larkins, C. (2019). Excursions as corporate agents: A critical realist account of children's agency. *Childhood, 26*(4), 414-429. https://journals.sagepub.com/doi/pdf/10.1177/0907568219847266?utm_source=copilot.com

Lewis, K., Hamilton, L. & Vincent, J. (2023). Exploring the experiences of autistic pupils through creative research methods: Reflections on a participatory approach. I*nfant and Child Development, 33*(3). https://doi.org/10.1002/icd.2467

Li, A., Guessoum, S., Ibrahim, N., Lefèvre, H., Moro, M. & Benoit, L. (2021). A systematic review of somatic symptoms in school refusal. *Psychosomatic Medicine 83*(7), 715-723, https://doi.org/10.1097/PSY.0000000000000956

Li, A., Dawei Yang, D., Beauquesne, A., Moro, M., Falissard, B. & Benoit, L. (2024). Somatic Symptoms in School Refusal: A Qualitative Study among Children, Adolescents, and Their Parents during the COVID-19 Pandemic. *European Child & Adolescent Psychiatry 33*(7), 2243–51. https://doi.org/10.1007/s00787-023-02313-6

Lincoln, Y., Lynham, S. & Guba, E. (2024). Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited. In Denzin, N., Lincoln, Y., Giardina, M. & Cannella, G. (Eds). *The SAGE Handbook of Qualitative Research* (6th Edition). SAGE

Long, É. (2023). 'Difference which makes a difference' (Bateson, 1972): How the neurodiversity paradigm and systemic approaches can support individuals and organisations to facilitate more helpful conversations about autism. *Journal of Social Work Practice*, *37*(1), 109–118. https://doi.org/10.1080/02650533.2022.2142768

Lopez-Garrido, G. (2023). *Self-Determination Theory: How It Explains Motivation.* https://www.simplypsychology.org/self-determination-theory.html

Lukito, S., Chandler, S., Kakoulidou, M., Griffiths, K., Wyatt, A., Funnell, E., Pavlopoulou, G., Baker, S., Stahl, D., Sonuga-Barke, E. & on behalf of the RE-STAR team. (2025). Emotional Burden in School as a Source of Mental Health Problems Associated with ADHD and/or Autism: Development and Validation of a New Co-Produced Self-Report Measure. J*ournal of Child Psychology and Psychiatry 66*(10), 1577–92. https://doi.org/10.1111/jcpp.70003

MacLennan, K., Rossow, T. & Tavassoli, T. (2021). The relationship between sensory reactivity, intolerance of uncertainty and anxiety subtypes in preschool-age autistic children. *Autism 25*(8) 2305–2316.

Masataka, N. (2017). Implications of the idea of neurodiversity for understanding the origins of developmental disorders. *Physics of Life Reviews, 20,* 85–108. http://dx.doi.org/10.1016/j.plrev.2016.11.002

McKinney, A., O'Brien, S., Maybin, J., Chan, S., Richer, S. & Rhodes, S. (2024). Camouflaging in Neurodivergent and Neurotypical Girls at the Transition to Adolescence and Its Relationship to Mental Health: A Participatory Methods Research Study. *JCPP Advances 4*(4). https://doi.org/10.1002/jcv2.12294

McPherson, C., Bayrakdar, S., Gewirtz, S., Laczik, A., Maguire, M., Newton, O., O'Brien, S., Weavers, A., Winch, C. & Wolf, A. (2023). Schools for All? Young

people's experiences of alienation in the English secondary school system. *Young Lives, Young Futures*. https://www.edge.co.uk/documents/346/DD0940_-_Young_Futures_Young_Lives_FINAL.pdf

Melin, J., Jansson-Fröjmark, M., & Olsson, N. C. (2022). Clinical practitioners' experiences of psychological treatment for autistic children and adolescents with school attendance problems: A qualitative study. *BMC Psychiatry*, *22*. (2022-49443-001). https://doi.org/10.1186/s12888-022-03861-y

Miller, A. (1995). Building grounded theory within educational psychology practice. *Educational and Child Psychology, 12*(2), 5–14.

Moon, K. & Blackman, D. (2014). A Guide to Understanding Social Science Research for Natural Scientists. *Conservation Biology, 28*(5), 1167–77.

Mullally, S. & Connolly S. (2025). "I felt shamed and blamed": an exploration of the parental lived experience of school distress. *Frontiers in Psychiatry,* 16. https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsyt.2025.1489316/full

National Association of Principal Educational Psychologists. (2026). *National Guidance forEducational Psychologists Supporting School Attendance*. www.napep.info

National Institute for Health and Care Excellence. (2017). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis, clinical guideline*. https://www.nice.org.uk/guidance/cg128

Nelson, T. & Lichwa, H. (2025). The lived experiences of masking black Autistic girls in UK education: "before people see the autism, they see my

race.”. *Educational Psychology in Practice, 41*(4), 417-438. DOI https://doi.org/10.1080/02667363.2025.2541211

Nordin, V., Palmgren, M., Lindbladh, A., Bolte, S. & Jonsson, U. (2024). School absenteeism in autistic children and adolescents: A scoping review. *Autism, 28* (7), 1622-1637.

O’Hagan, S., Bond ,Caroline, & Hebron, J. (2024). Autistic girls and emotionally based school avoidance: Supportive factors for successful re-engagement in mainstream high school. *International Journal of Inclusive Education*, *28*(9), 1919–1935. https://doi.org/10.1080/13603116.2022.2049378

Oliver, C. (2012). Critical Realist Grounded Theory: A New Approach for Social Work Research. *The British Journal of Social Work*, *42*(2), 371–387.

Pearson, E., Sharp, L., & Hampton, L. (2025). Resilience in context: A synthesis of theories and practices for educational psychologists. *Educational Psychology in Practice, 41*(4), 439–456. https://doi.org/10.1080/02667363.2025.2518990

Powell, J. (2016). *What works? A grounded theory of effective peer mentoring in secondary schools.* [Doctoral Thesis]. Tavistock and Portman NHS Foundation Trust / University of Essex. https://repository.essex.ac.uk/15776/1/J%20E%20Powell%20Doctorate%20Thesis.pdf

Prosser, R. & Birchwood, J. (2024). A Systematic Review Identifying Factors Associated with Emotionally Based School Non-Attendance in Autistic Children and Young People. *Educational & Child Psychology, 41(*1), 31–54. https://doi.org/10.53841/bpsecp.2024.41.1.31.

Reinke, W. M., Herman, K. C., Thompson, A., & Owens, S. (2025). A Comprehensive School-Based Mental Health Model: A Decade in the Making. *Behavioral Sciences, 15*(10), 1428. https://doi.org/10.3390/ bs15101428

Ripley, K. (2015). *Autism from Diagnostic Pathway to Intervention.* Jessica Kingsley publishers.

Robson, C. & McCartan, K. (2016). *Real World Research (4th ed).* Wiley.

Rustin, M. (2016) Grounded Theory methods in child psychotherapy research. *Journal of Child Psychotherapy, 42(*2), 179-197, DOI:10.1080/0075417X.2016.1191205

Sampson, A. C. & Sampson, S. A. (2026). Cultivating Mental Health and Well-being in the School Ecosystem: A Multisystem Framework for School Counselor Advocacy. In *Education as an Ecosystem: A Global Dialogue*. BCES Conference Books, Vol. 24 (pp. 166-176). Sofia: BCES. https://files.eric.ed.gov/fulltext/ED681995.pdf

Samsonsen, V. & Heggdalsvik, I. (2024). Critical realism as a fruitful approach to social work research as illustrated by two studies from the field of child and family welfare. *Journal of Critical Realism, 23*(1), 18-32, DOI: 10.1080/14767430.2023.2251238

Sarfo, J., Debrah, T., Gbordzoe, N., Afful W. & Obeng, P. (2021) Qualitative research designs, sample size and saturation: Is enough always enough?. *Journal of Advocacy, Research and Education, 8*(3), 60-65. DOI: 10.13187/jare.2021.3.60

Schachter, S. (1964). The interaction of cognitive and physiological determinants of emotional state. In: Berkowitz, L. (Ed.) *Advances in Experimental Social Psychology*, Academic Press, New York, pp. 48-81.

Simcoe, S., Gilmour, J., Garnett, M., Attwood, T., Donovan, C. & Kelly, A. (2023). Are There Gender-Based Variations in the Presentation of Autism amongst Female and Male Children? *Journal of Autism and Developmental Disorders 53*(9), 3627–35. https://doi.org/10.1007/s10803-022-05552-9.

Smart, R., Adams, D. & Simpson, K. (2024). Parent experiences of school distress or school refusal in their autistic child. *Educational & Child Psychology, 41*(1), 93-110. https://doi.org/10.53841/bpsecp.2024.41.1.93

Square Peg & Not Fine In School. (2022). *Submission of evidence to attendance consultation.* https://www.teamsquarepeg.co.uk/publications-1

Sturrock, A., Adams, C. & Freed, J. (2021). A Subtle Profile With a Significant Impact: Language and Communication Difficulties for Autistic Females Without Intellectual Disability. *Frontiers in Psychology*. 12. https://www.researchgate.net/publication/353772141_A_Subtle_Profile_With_a_Significant_Impact_Language_and_Communication_Difficulties_for_Autistic_Females_Without_Intellectual_Disability

Sutcliffe, A. (2016). Grounded Theory: A Method for Practitioner Research by Educational Psychologists. *Educational & Child Psychology, 33*(3), 44–54. https://doi.org/10.53841/bpsecp.2016.33.3.44.

Thambirajah, M., Grandison, K. and De-Hayes, L. (2008). *Understanding School Refusal: A Handbook for Professionals in Education, Health and Social Care*. Jessica Kingsley Publishers.

Thomas, J. & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8 (45)*. https://doi.org/10.1186/1471-2288-8-45

Thornberg, R. (2012). Informed Grounded Theory. *Scandinavian Journal of Educational Research*, *56*(3), 243–259. https://doi.org/10.1080/00313831.2011.581686

Tomlinson, C., Bond ,Caroline, & Hebron, J. (2022). The mainstream school experiences of adolescent autistic girls. *European Journal of Special Needs Education*, *37*(2), 323–339. https://doi.org/10.1080/08856257.2021.1878657

Tong, P and An, I,S. (2024). Review of studies applying Bronfenbrenner's bioecological theory in international and intercultural education research. *Frontiers in Psychology, 14.* https://pmc.ncbi.nlm.nih.gov/articles/PMC10801006/#B14

Totsika, V., Hastings, R., Dutton, Y., Worsley, A., Melvin, G., Fray, K., Tongue, B. & Heyne, D. (2020). Types and Correlates of School Non-Attendance in Students with Autism Spectrum Disorders. *Autism 24*(7), 1639–49. https://doi.org/10.1177/1362361320916967

Trafford Council. (2021). *Trafford Council Emotionally Based School Non-Attendance (EBSNA) Early Identification of Needs Tool (EINT).* https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fsearch3.openobjects.com%2Fmediamanager%2Ftrafford%2Ffsd%2Ffiles%2Febsna_early_idenification_of_needs_tool_eint_nov21lk_rbcover_sheetv2_002_.docx&wdOrigin=BROWSELINK

Tsou, Y-T., Kovács, L., Louloumari, A., Stockman, L., Blijd-Hoogewys, M., Koutamanis, A & Rieffe, C. (2024). School-Based Interventions for Increasing Autistic Pupils' Social Inclusion in Mainstream Schools: A Systematic Review. *Review Journal of Autism and Developmental Disorders, ahead of print*. https://doi.org/10.1007/s40489-024-00429-2

Van Breda, A. (2018). A Critical Review of Resilience Theory and its Relevance for Social Work. *Social Work/Maatskaplike Werk, 54*(1), 1–18. https://doi.org/10.15270/54-1-611

Walker, S. (2019). *A Constructivist Grounded Theory of the influences and practices that are thought to promote a sense of belonging in a primary school context.* [Unpublished doctoral thesis]. University of Essex. https://repository.tavistockandportman.ac.uk/2083/

Want, H., & Gulliford, A. (2024). Barriers to School Attendance as Experienced by Young People and Their Parents: A Narrative Oriented Inquiry. *Educational & Child Psychology 41*(1), 9–30. https://doi.org/10.53841/bpsecp.2024.41.1.9

Ward, S. & Kelly, C. (2024). Exploring the implementation of whole school emotionally based school non-attendance (EBSNA) guidance in a secondary school. *Educational and Child Psychology 41*(1) 111-123.

West Sussex. (2022). *Emotionally Based School Avoidance*. https://schools.westsussex.gov.uk/Page/10483

Wing, L & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and Classification. *Journal of Autism and Childhood Schizophrenia, 9,* 11-29.

Wood-Downie, H., Wong, B., Kovshoff, H., Mandy, W., Hull, L., & Hadwin, J. A. (2021). Sex/Gender Differences in Camouflaging in Children and Adolescents with Autism. *Journal of Autism and Developmental Disorders*, *51*(4), 1353–1364. https://doi.org/10.1007/s10803-020-04615-z

World Health Organization [WHO]. (2022). *ICD-11: International classification of diseases (11th revision)*. WHO. https://icd.who.int/ .

9. Appendices

Contents

APPENDIX 1- INITIAL SCOPING REVIEW SEARCH TERMS 317

APPENDIX 2- LITERATURE APPRAISAL TOOL EXAMPLES 318

APPENDIX 3- EXCLUDED LITERATURE MAPPING TABLE 346

APPENDIX 4- CRITICAL APPRAISAL FINDINGS PER PAPER 352

APPENDIX 5- EXAMPLE THEMES FROM WRITING HELPER- NB ALL ARE DIRECT QUOTES FROM THE PAPERS 362

APPENDIX 6- LITERATURE METHODOLOGICAL APPROACH MATRIX 366

APPENDIX 7- HISTORICAL OVERVIEW OF GROUNDED THEORY 386

APPENDIX 8- RECRUITMENT FLYER 387

APPENDIX 9- PARTICIPANT INCLUSION AND EXCLUSION CRITERIA 388

APPENDIX 10- ETHICS APPROVAL AMENDMENT 390

APPENDIX 11- ADDITIONAL MEASURES FOR THOSE WITH ADDITIONAL MENTAL HEALTH NEEDS 395

APPENDIX 12- EMAIL FOR PARTICIPANTS WITH ADDITIONAL MENTAL HEALTH NEEDS 396

APPENDIX 13- COLLEGE EMAIL 397

APPENDIX 14- INTRODUCTORY EMAIL TO PARTICIPANTS 398

APPENDIX 15- PARTICIPANT INFORMATION SHEETS STANDARD 400

APPENDIX 16- CONSENT TO PARTICIPATE STANDARD 403

APPENDIX 17- PARTICIPANT INFORMATION SHEET ACCESSIBLE 405

APPENDIX 18- PARTICIPANT CONSENT FORM ACCESSIBLE 408

APPENDIX 19- MICROSOFT FORM 410

APPENDIX 20- EMAIL CONFIRMATION 415

APPENDIX 20- REMINDER EMAIL 416

APPENDIX 22- APPOINTMENT REMINDER EMAIL 417

APPENDIX 23- EMAIL RESPONSES TO PARENTS 418

APPENDIX 24- ADDITIONAL PROCEDURES FOR VULNERABLE PARTICIPANTS 419

APPENDIX 25- INTERVIEW POWERPOINT AND SCRIPT 420

APPENDIX 26- CARD SORTING TOOLS 428

APPENDIX 27- CARD SORT TOOL RESPONSES 431

APPENDIX 28- REFLECTIVE DIARY EXAMPLES 433

APPENDIX 29- ADDED INTERVIEW QUESTIONS 438

APPENDIX 30- EXAMPLES OF INITIAL CODES AND MEMOS 439

APPENDIX 31- EXAMPLES OF LINE BY LINE CODING 441

APPENDIX 32- EXAMPLES OF INITIAL CODES SPLIT INTO EARLY FOCUSED CODES 445

APPENDIX 33- EARLY FOCUSED CODES, INITIAL CODES AND DATA SELECTION 448

APPENDIX 34- FINAL FOCUSED CODES, INITIAL CODES AND QUOTES 450

APPENDIX 35- EARLY CONCEPTUAL CODE DIAGRAMS 457

APPENDIX 36- EARLY THEORETICAL FRAMEWORK DIAGRAMS..... 459

APPENDIX 37- ETHICAL APPROVAL..... 461

APPENDIX 38- DISTRESS PROTOCOL..... 462

APPENDIX 39- FOLLOW UP THANK YOU EMAIL 463

APPENDIX 40- RESEARCHER RISK ASSESSMENT 464

APPENDIX 41- THEORETICAL CODE ORDER AND RELATED MEMOS 465

APPENDIX 42- EXAMPLE RESPONSE PATHWAY FOR SCHOOLS 467

APPENDIX 43- GRADUATED RESPONSE..... 469

APPENDIX 44- EARLY IDENTIFICATION SCREENING TOOL 470

Appendix 1- Initial scoping review search terms

Literature Search Parameters

The keywords identified to ascertain search terms for the literature review were ‘autism', ‘emotionally based school non-attendance' and ‘girls’. The EBSCO platform was used to search the PsychInfo database. Publication years between 2000 and 2024, limiters 'peer-reviewed journals' and 'linked full text' were selected to limit matches to the most relevant. The * wildcard accounted for variations in certain words, including plurals and tense differences (e.g., autis* for autism, and autistic).

Reviewing the references of the papers identified, legislation, and other relevant literature recommended or known to the researcher revealed additional relevant literature.

Appendix 2- Literature appraisal tool examples



CASP Checklist:

For Qualitative Research

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Reviewer Name:	Louise Brackpool
Paper Title:	Autistic girls and emotionally based school avoidance: supportive factors for successful re-engagement in mainstream high school
Author:	Siobhan O'Hagan, Caroline Bond and Judith Hebron
Web Link:	
Appraisal Date:	16/04/25

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research? 'To identify the supportive factors that help autistic girls who experience EBSA re-engage and maintain their attendance in mainstream high school' lack of flexible and inclusive practice, school exclusion, social exclusion and the child's subsequent poor mental health are risk factors for autistic girls avoiding school	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate? 'The present study, therefore, consulted with autistic girls who have experienced EBSA, their parents and educators to answer the question. A qualitative exploratory multiple case study design was selected to address the research question.'	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research? Yes although it doesn't justify why casestudy design was used over another e.g. IPA.	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research? 'Schools were recruited to take part in the study through the researchers' contacts in local authority educational psychology services and specialist autism services. The participants were selected by the schools' SENCo based	☒ Yes ☐ No ☐ Can't Tell

on the following inclusion criteria: (1) must have a diagnosis of autism from a recognised medical practitioner; (2) attend a mainstream high school; (3) female; (4) must have had a period of EBSA with a decrease in attendance followed by an increase in school attendance.'	
CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	
5. Was the data collected in a way that addressed the research issue? Semi-structured interviews and one participant completed questionnaire instead (limitations noted). 'The interview format was influenced by the interview schedules utilised by Nuttall and Woods (2013), the bio-ecological systems outlined by Bronfen brenner (1979), and the researcher's exploratory study' 'Each interview schedule (see Appendix 1) was adapted to the participant group but all primarily focused on school attendance experiences and factors which supported re-engagement with school.' Explanation of each interview and who with	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered? Nothing mentioned relating to this	☐ Yes ☒ No ☐ Can't Tell

CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration? Not explained in detail other than to explain that consent and assent was gathered, but not how. However, they state that ethical approval granted from UoManchester so I have made an assumption that all ethical issues have been taken into consideration.	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	
8. Was the data analysis sufficiently rigorous? 'Inductive thematic analysis was utilised to suit the research purpose of exploring the interacting systems that support re-engagement in education' 'NVivo was used as a tool to code the transcripts. The 15-point checklist of criteria for good thematic analysis and the six-phase guidelines for conducting thematic analysis described by Braun and Clarke (2006) were followed. a collaborative and reflexive approach was taken between the authors to make meaning from the analysis. Cross-case analysis was conducted to enable an in-depth exploration of the supportive factors and barriers to re-engagement in mainstream education.'	☒ Yes ☐ No ☐ Can't Tell

Multiple direct quotes used to support the themes generated. However, Own role and potential bias not discussed	
CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings? 'The findings tentatively demonstrate that trusting relationships are the foundation for autistic girls to re-integrate into the school community and this begins with establishing trust between the child and key adult.' 'The relational aspects of education are at the core of autistic girls feeling a sense of belonging and acceptance. This is underpinned by educators having a good understanding of female autism, an ethos of flexibility based on individual need and the resources to provide safe spaces and person-centred intervention.'	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	
Section C: Will the results help locally?	
10. How valuable is the research? Identified further research	☒ Yes ☐ No ☐ Can't Tell

'This is the first study to explore the supportive factors for autistic girls who have success fully re-engaged with mainstream education following EBSA. A shift of research focus onto autistic girls who have overcome barriers to education and who are thriving in high school has highlighted supportive factors to successful re-engagement.' Considers how to involved other autistic CYP to illicit their voices too. Very important/valuable in terms of experiences of those who have successfully reintegrated. Also very relevant to my own research.	
CONSIDER: • *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature* • *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*		
Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**
Good level of detail around methodology and all but one criteria met.	Relationships and biases not discussed so can't tell if this has been considered. Extensive detail not given for ethical issues, but it gained university ethical approval so would make the assumption it	Biases not acknowledged or considered within the paper so not sure if this was mitigated for.

	has. It includes a typical level of detail for journal articles.	

Referencing recommendation:

CASP recommends using the Harvard style referencing, which is an author/date method. Sources are cited within the body of your assignment by giving the name of the author(s) followed by the date of publication. All other details about the publication are given in the list of references or bibliography at the end.

Example:

Critical Appraisal Skills Programme (2024). CASP (insert name of checklist i.e. systematic reviews with meta-analysis of randomised controlled trials (RCTs) Checklist.) [online] Available at: insert URL. Accessed: insert date accessed.

Creative Commons

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial- Share A like. To view a copy of this licence, visit https://creativecommons.org/licenses/by-nc-sa/4.0/



Critical Appraisal Skills Programme

CASP Checklist:

For Descriptive/Cross-Sectional Studies

Reviewer Name:	Louise Brackpool
Paper Title:	Types and correlates of school non attendance in students with autism spectrum disorders
Author:	Totsika et al
Web Link:	
Appraisal Date:	20/06/25

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A: Are the results valid?			
11. Did the study address a clearly focused issue?	☒ Yes	☐ No	☐ Can't Tell

'The aim of this study was to provide a more comprehensive description of the school non-attendance of children with ASD...we aimed to describe non-attendance at the broader level of school absence and investigate a wide range of potential correlates of non-attendance across dif ferent levels of influence (cf. Melvin et al., 2019). In addi tion, for the first time, we used a systematic typology to describe the types of non-attendance in children with ASD '	
CONSIDER: *A question can be 'focused' in terms of* • *the population studied* • *the risk factors studied* • *is it clear whether the study tried to detect a beneficial or harmful effect* • *the outcomes considered*	
12. Did the authors use an appropriate method to answer their question?	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *Is a descriptive/cross-sectional study an appropriate way of answering the question* • *did it address the study question*	
13. Were the subjects recruited in an acceptable way? Parents recruited nationally via social media and mailing list held by an autism charity. Parents self-selected to take part in an online survey Using two approaches reduces bias of those active on social media	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: *We are looking for selection bias which might compromise the generalisability of the findings:* • *Was the sample representative of a defined population* • *Was everybody included who should have been included*	
14. Were the measures accurately measured to reduce bias? Subjective checklists used (SNACK) and where an 'other' category was included, parents were required to explain the reason- this was then reviewed by the researchers to see if it could fit into a pre-existing category, or to code it to another. Demographic data gathered and other data (attendance) was subjective- attended the day or did not.	☒ Yes ☐ No ☐ Can't Tell

Descriptive statistics used for some questions, so not as reliable as data analysis. Regression model (generalised linear model-GLM) used to consider factors involved in non-attendance. On the whole yes, but there is an element of subjectivity as with any self-report measures.	
CONSIDER: *Look for measurement or classification bias:* • *did they use subjective or objective measurements* • *do the measurements truly reflect what you want them to (have they been validated)*	
15. Were the data collected in a way that addressed the research issue? Looked at reasons for absence alongside demographic information and days attended so yes, this addresses the research aims. Data collection methods clearly described.	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the setting for data collection was justified* • *if it is clear how data were collected (e.g., interview, questionnaire, chart review)* • *if the researcher has justified the methods chosen* • *if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted?)*	
16. Did the study have enough participants to minimise the play of chance? 486 participants included in study which seems large sample, but G power not used.	☐ Yes ☐ No ☒ Can't Tell
CONSIDER: • *if the result is precise enough to make a decision* • *if there is a power calculation. This will estimate how many subjects are needed to produce a reliable estimate of the measure(s) of interest.*	
17. How are the results presented and what is the main result? Results presented as likelihoods and proportions of participants in different categories/experiences School non-attendance is common in autistic students, with older students and those in single parent households being particularly susceptible to reduced attendance.	☒ Yes ☐ No ☐ Can't Tell

CONSIDER: • *if, for example, the results are presented as a proportion of people experiencing an outcome, such as risks, or as a measurement, such as mean or median differences, or as survival curves and hazards* • *how large this size of result is and how meaningful it is* • *how you would sum up the bottom-line result of the trial in one sentence*	
18. Was the data analysis sufficiently rigorous?	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *if there is an in-depth description of the analysis process* • *if sufficient data are presented to support the findings*	
19. Is there a clear statement of findings? 'This study suggests that school non-attendance is common among students with ASD, and levels of persistent non attendance are concerning. Older students from mainstream schools living in households with single or unemployed 1648 Autism 24(7) parents are more likely to miss school. Approximately 4 in 10 missed days were due to school refusal' However, multiple factors were explored and so there are lots of findings for each aspect explored rather than one overall finding.	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the findings are explicit* • *if there is adequate discussion of the evidence both for and against the researchers' arguments* • *if the researchers have discussed the credibility of their findings* • *if the findings are discussed in relation to the original research questions*	
20. Can the results be applied to the local population? Yes as autistic girls are included in the study, as is secondary age CYP. However, the lack of comparison between the sexes makes it less relevant and would have been very helpful to my study if this was included.	☒ Yes ☐ No ☐ Can't Tell
CONSIDER: • *the subjects covered in the study could be sufficiently different from your population to cause concern.* • *your local setting is likely to differ much from that of the study*	
21. How valuable is the research?	☒ Yes ☐ No ☐ Can't Tell

Linked to other findings in other studies and discrepancies in findings with other studies is also noted. Very valuable to current research in terms of autism and EBSNA, however it would have been even more relevant if it had compared male and female data. Decided to include as still highly relevant.	

CONSIDER:

- *one descriptive/cross-sectional study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making*
- *if the researcher discusses the contribution the study makes to existing knowledge (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
- *if the researchers have discussed whether or how the findings can be transferred to other populations*

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**
Large sample size Subjective measures used and controls in place for bias Regression model used to explore variables National recruitment and demographic data gathered which will support generalisability	Recruitment method used could bias sample towards those whose children are already experiencing reduced attendance, and not necessarily those at an early stage of barriers to attendance.	G-power analysis not included due to statistical analysis used so not sure if sample size is enough for the data and comparisons generated- although it does seem to be a large sample

Referencing recommendation:

CASP recommends using the Harvard style referencing, which is an author/date method. Sources are cited within the body of your assignment by giving the name of the author(s) followed by the date of publication. All other details about the publication are given in the list of references or bibliography at the end.

Example:

Critical Appraisal Skills Programme (2024). CASP (insert name of checklist i.e. cross sectional Checklist.)

[online] Available at: insert URL. Accessed: insert date accessed.

Creative Commons

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial- Share A like. To view a copy of this licence, visit https://creativecommons.org/licenses/by-nc-sa/4.0/

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?			X	*Not discussed*

	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	X			

CASP Checklist: 10 questions to help you make sense of a Systematic Review

How to use this appraisal tool: Three broad issues need to be considered when appraising a systematic review study:

- **Are the results of the study valid? (Section A)**
- **What are the results? (Section B)**
- **Will the results help locally? (Section C)**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Systematic Review) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Paper for appraisal and reference:... Camouflaging in autism: A systematic review

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?	**Yes** **Can't Tell** **No**	**X**	**HINT: An issue can be 'focused' In terms of** **• the population studied** **• the intervention given** **• the outcome considered**

Comments:

Is camouflaging associated with having high autistic traits or an autism diagnosis?

Are there sex or gender differences in camouflaging behaviours?

Are particular cognitive abilities or processes associated with camouflaging?

Is camouflaging related to current age or age at diagnosis?

What is the relationship between camouflaging and mental health or wellbeing outcomes?

We examine and summarise study findings based on the five aforementioned research questions.

2. Did the authors look for the right type of papers?	**Yes** **Can't Tell** **No**	**Y**	**HINT: 'The best sort of studies' would** • **address the review's question** • **have an appropriate study design (usually RCTs for papers evaluating interventions)**

Comments:

Lots of search terms and databases searched and outlined within Appendix A

Is it worth continuing?

	Yes	**X**	**HINT: Look for**

3. Do you think all the important, relevant studies were included?	**Can't Tell** **No**		**• which bibliographic databases were used** **• follow up from reference lists** **• personal contact with experts** **• unpublished as well as published studies** **• non-English language studies**

Comments: **Exclusion quite broad so think likely to include most relevant articles.**

4. Did the review's authors do enough to assess quality of the included studies?	**Yes** **Can't Tell** **No**	**X**	**HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)**

Comments: **MMAT used, independently rated by two reviewers and did not rate any studies that were their own. Discrepancies in ratings were discussed and resolved by consensus.**

5. If the results of the review have been combined, was it reasonable to do so?	**Yes** **Can't Tell** **No**	**X**	**HINT: Consider whether** **• results were similar from study to study** **• results of all the included studies are clearly displayed** **• results of different studies are similar**

- reasons for any variations in results are discussed

Comments:

Yes because they were looking at a set of different questions and so each article providing evidence relating to that question is summarised in table and discussed in discussion section.

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider

- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:

Three preliminary conclusions about the nature of autistic camouflaging emerged: (1) adults with more self- reported autistic traits report greater engagement in camouflaging; (2) autistic females and girls/women appear to demonstrate more camou f laging than autistic males and boys/men; and (3) higher self-reported camouflaging is associated with increased mental health difficulties. However, the evidence base was limited regarding participant charac terisation and representativeness, suggesting that conclusions cannot be applied to the autistic community as a whole.

7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments:

N/A

Section C: Will the results help locally?

8. Can the results be applied to the local population?	**Yes**	**X**	**HINT: Consider whether** • **the patients covered by the review could be sufficiently different to your population to cause concern** • **your local setting is likely to differ much from that of the review**
	Can't Tell		
	No		

Comments:

Yes, the combined sample included 60% adult females (29% adult Male) and 36.9% female (62.9% Male) with an average age of 11.9 years. With the inclusion of information from adult females and the comparison between sexes this study is quite relevant.

9. Were all important outcomes considered?	**Yes**		**HINT: Consider whether** • **there is other information you would like to have seen**
	Can't Tell	**X**	
	No		

Comments:

10. Are the benefits worth the harms and costs?	**Yes**	**X**	**HINT: Consider** • **even if this is not addressed by the review, what do you think?**
	Can't Tell		
	No		

Comments:

Review of literature which has already been undertaken so limited scope for harm.

Scale for the Assessment of Narrative Review Articles – SANRA

Please rate the quality of the narrative review article in question, using categories 0–2 on the following scale. For each aspect of quality, please choose the option which best fits your evaluation, using categories 0 and 2 freely to imply general low and high quality.

These are not intended to imply the worst or best imaginable quality.

1) Justification of the article's importance for the readership		Number
The importance is not justified.	0	
The importance is alluded to, but not explicitly justified.	1	__2____
The importance is explicitly justified.	2	

2) Statement of concrete aims or formulation of questions		
No aims or questions are formulated.		0
Aims are formulated generally but not concretely or in terms of clear questions.	1	__1_____
One or more concrete aims or questions are formulated.	2	

3) Description of the literature search		
The search strategy is not presented.	0	
The literature search is described briefly.	1	___0_____
The literature search is described in detail, including search terms and inclusion criteria.	2	

4) Referencing		
Key statements are not supported by references.	0	
The referencing of key statements is inconsistent.	1	___2_____
Key statements are supported by references.		2

5) Scientific reasoning		
(e.g., incorporation of appropriate evidence, such as RCTs in clinical medicine)		
The article's point is not based on appropriate arguments.	0	
Appropriate evidence is introduced selectively.	1	___2___
Appropriate evidence is generally present.	2	

6) Appropriate presentation of data/findings

(e.g., absolute vs relative risk; effect sizes without confidence intervals)		
Data /findings are presented inadequately.	0	
Data /findings are often not presented in the most appropriate way.	1	2_
Relevant findings are generally presented appropriately.	2	

Total __9_____

SANRA – explanations and instructions

This scale is intended to help editors assess the quality of a narrative review article based on formal criteria accessible to the reader. It cannot cover other elements of editorial decision making such as degree of originality, topicality, conflicts of interest or the plausibility, correctness or completeness of the content itself. SANRA is an instrument for editors, authors, and reviewers evaluating individual manuscripts. It may also help editors to document average manuscript quality within their journal and researchers to document the manuscript quality, for example in peer review research.

Using only three scoring options, 0, 1 and 2, SANRA is intended to provide a swift and pragmatic sum score for quality, for everyday use with real manuscripts, in a field where established quality standards have previously been lacking. It is not designed as an exact measurement of the quality of all theoretically possible manuscripts. For this reason, the extreme values (0 and 2) should be used relatively freely and not reserved only for perfect or hopeless articles.

We recommend that users test-rate a few manuscripts to familiarize themselves with the scale, before using it on the intended group of manuscripts. Ratings should assess the totality of a manuscript, including the abstract. The following comments clarify how each question is designed to be used.

Item 1 – Justification of the article's importance for the readership

Justification of importance for the readership must be seen in the context of each journal's readership. Consider how well the manuscript outlines the clinical problem and highlights unanswered questions or evidence gaps – thoroughly (2), superficially (1), or not at all (0).

Item 2 – Statement of concrete/specific aims or formulation of questions

A good paper will propose one or more specific aims or questions which will be dealt with or topics which will be reviewed. Please rate whether this has been done thoroughly and clearly (2), vaguely or unclearly (1), or not at all (0).

Item 3 – Description of the literature search

A convincing narrative review will be transparent about the sources of information on which the text is based. Please rate the degree to which you think this has been achieved. To achieve a rating of 2, it is not necessary to describe the literature search in as much detail as for a systematic review (searching multiple databases, including exact descriptions of search history, flowcharts, etc.), but it is necessary to specify search terms, and the types of literature included. A manuscript which only refers briefly to its literature search would score 1, while one not mentioning its methods would score 0.

Item 4 – Referencing

No manuscript references all statements. However, those that are essential for the arguments of the manuscript – "key statements" – should be backed by references in all or almost all cases. Exceptions could reasonably be made for rating purposes where a key statement has uncontroversial face-validity, such as "Diabetes is among the commonest causes of chronic morbidity worldwide." Please rate the completeness of referencing: for most or all relevant key statements (2), inconsistently (1), sporadically (0).

Item 5 – Scientific reasoning

The item describes the quality of the point made in relation to the aims and review question. A convincing narrative review presents evidence for key arguments. It should mention study design (randomized controlled trial, qualitative study, etc), and where available, levels of evidence.

Please rate whether you feel this has been done thoroughly (2), superficially (1), or hardly at all (0). Unlike item 6, which is concerned with the selection and presentation of concrete outcome data, this item relates to the use of evidence and of types of evidence in the manuscript's arguments.

Item 6 – Appropriate presentation of data:

This item describes the correct presentation of data/findings central to the article's argument. Which data/findings are considered relevant varies from field to field. In some areas relevant data/findings could be more generalizable than others depending on type of study and methods (e.g. large scale quantative studies). These outcomes must be presented correctly. For example, it is appropriate that effect sizes are accompanied by confidence intervals. Please rate how far the paper achieves this – thoroughly (2), partially (1), or hardly at all (0). Unlike item 5, which

relates to the use of evidence and of types of evidence in the manuscript's arguments, this item is concerned with the selection and presentation of concrete outcome data.

Reference

Baethge C, Goldbeck-Wood S, Mertens S: SANRA—a scale for the quality assessment of narrative review articles. Research Integrity and Peer Review (2019) 4:5

https://doi.org/10.1186/s41073-019-0064-

SANRA with amendments made by current researcher and justification.

Scale for the Assessment of Narrative Review Articles – SANRA

Please rate the quality of the narrative review article in question, using categories 0–2 on the following scale. For each aspect of quality, please choose the option which best fits your evaluation, using categories 0 and 2 freely to imply general low and high quality.

These are not intended to imply the worst or best imaginable quality.

	Number
1) Justification of the article's importance for the readership	
The importance is not justified ____ 0	
The importance is alluded to, but not explicitly justified ____ 1	
The importance is explicitly justified ____ 2	
2) Statement of concrete aims or formulation of questions	
No aims or questions are formulated ____ 0	
Aims are formulated generally but not concretely or in terms of clear questions ____ 1	
One or more concrete aims or questions are formulated ____ 2	
3) Description of the literature search	
The search strategy is not presented ____ 0	
The literature search is described briefly ____ 1	
The literature search is described in detail, including search terms and inclusion criteria ____ 2	
4) Referencing	
Key statements are not supported by references ____ 0	
The referencing of key statements is inconsistent ____ 1	
Key statements are supported by references ____ 2	
5) Evidence referenced [amended from 'scientific reasoning']	
(e.g., incorporation of appropriate evidence, such as RCTs ~~in clinical medicine~~)	
The article's point is not based on appropriate arguments ____ 0	
Appropriate evidence is introduced selectively ____ 1	
Appropriate evidence is generally present ____ 2	
6) Appropriate presentation of data	
(e.g., absolute vs relative risk; effect sizes without confidence intervals)	
Data are presented inadequately ____ 0	
Data are often not presented in the most appropriate way ____ 1	
Relevant outcome data are generally presented appropriately ____ 2	
Total	

SANRA – explanations and instructions

This scale is intended to help editors assess the quality of a narrative review article based on formal criteria accessible to the reader. It cannot cover other elements of editorial decision making such as degree of originality, topicality, conflicts of interest or the plausibility, correctness or completeness of the content itself. SANRA is an instrument for editors, authors, and reviewers evaluating individual manuscripts. It may also help editors to document average manuscript quality within their journal and researchers to document the manuscript quality, for example in peer review research.

Using only three scoring options, 0, 1 and 2, SANRA is intended to provide a swift and pragmatic sum score for quality, for everyday use with real manuscripts, in a field where established quality standards have previously been lacking. It is not designed as an exact measurement of the quality of all theoretically possible manuscripts. For this reason, the extreme values (0 and 2) should be used relatively freely and not reserved only for perfect or hopeless articles.

We recommend that users test-rate a few manuscripts to familiarize themselves with the scale, before using it on the intended group of manuscripts. Ratings should assess the totality of a manuscript, including the abstract. The following comments clarify how each question is designed to be used.

Item 1 – Justification of the article's importance for the readership

Justification of importance for the readership must be seen in the context of each journal's readership. Consider how well the manuscript outlines the clinical problem and highlights unanswered questions or evidence gaps – thoroughly (2), superficially (1), or not at all (0).

Item 2 – Statement of concrete/specific aims or formulation of questions

A good paper will propose one or more specific aims or questions which will be dealt with or topics which will be reviewed. Please rate whether this has been done thoroughly and clearly (2), vaguely or unclearly (1), or not at all (0).

Item 3 – Description of the literature search

A convincing narrative review will be transparent about the sources of information on which the text is based. Please rate the degree to which you think this has been achieved. To achieve a rating of 2, it is not necessary to describe the literature search in as much detail as for a systematic review (searching multiple databases, including exact descriptions of search history, flowcharts, etc.), but it is necessary to specify search terms, and the types of literature included. A manuscript which only refers briefly to its literature search would score 1, while one not mentioning its methods would score 0.

Item 4 – Referencing

No manuscript references all statements. However, those that are essential for the arguments of the manuscript – "key statements" – should be backed by references in all or almost all cases. Exceptions could reasonably be made for rating purposes where a key statement has uncontroversial face-validity, such as "Diabetes is among the commonest causes of chronic morbidity worldwide." Please rate the completeness of referencing: for most or all relevant key statements (2), inconsistently (1), sporadically (0).

Item 5 – Evidence referenced [amended from 'scientific reasoning']

The item describes the quality of the point made in relation to the aims and review question [Amended from 'The item describes the quality of the scientific point made.']. A convincing narrative review presents evidence for key arguments. It should mention study design (randomized controlled trial, qualitative study, etc), and where available, levels of evidence.
Please rate whether you feel this has been done thoroughly (2), superficially (1), or hardly at all (0). Unlike item 6, which is concerned with the selection and presentation of concrete outcome data, this item relates to the use of evidence and of types of evidence in the manuscript's arguments.

- Rationale for change to item 5 descriptor- To reflect the different types of studies reviewed in social and educational research from purely scientific- reflecting a shift from positivist research studies to a wider range of positions.

Item 6 – Appropriate presentation of data

This item describes the correct presentation of data/findings central to the article's argument. Which data/findings are considered relevant varies from field to field. In some areas relevant data/findings could be more transferable/generalisable than others depending on type of study and methods (e.g. large scale quantative studies). These outcomes must be presented correctly. For example, it is appropriate that effect sizes are accompanied by confidence intervals. Please rate how far the paper achieves this – thoroughly (2), partially (1), or hardly at all (0). Unlike item 5, which relates to the use of evidence and of types of evidence in the manuscript's arguments, this item is concerned with the selection and presentation of concrete outcome data.

Item 6 original descriptor:
This item describes the correct presentation of data central to the article's argument. Which data are considered relevant varies from field to field. In some areas relevant data would be absolute rather than relative risks or clinical versus surrogate or intermediate end points. These outcomes must be presented correctly. For example, it is appropriate that effect sizes are accompanied by confidence intervals. Please rate how far the paper achieves this – thoroughgoingly (2), partially (1), or hardly at all (0). Unlike item 5, which relates to the use of evidence and of types of evidence in the manuscript's arguments, this item is concerned with the selection and presen tation of concrete outcome data.

- Rationale for change to item 6 descriptor- Similar to item 5, changes made to reflect the information contained within the different types of studies that may of may not include findings (e.g. purely qualitative studies included within the review). Also changing language on the medical/scientific language used.

Reference

Baethge C, Goldbeck-Wood S, Mertens S: SANRA—a scale for the quality assessment of narrative review articles. Research Integrity and Peer Review (2019) 4:5
https://doi.org/10.1186/s41073-019-0064-8

Appendix 3- Excluded literature mapping table

Excluded literature N= 33

Papers excluded at full text review stage= 28

Title	Author	Date	Exclusion reason
School distress and the school attendance crisis: a story dominated by neurodivergence and unmet need	Connolly, S., Constable, H. and Mullally, S	2023	Male focus/no sex comparison
Characteristics of restricted interests in girls with ASD compared to boys: a systematic review of the literature	Bourson, L and Prevost, C,	2024	Non-UK (France)
A brief neuro-affirming resource to support school absences for autistic learners: development and program description	Johnston, L., Maciver, D., Rutherford, M., Gray, A., Curnow, E. and Utley	2024	Male focus/no sex comparison
Drowning, Not Waving: Autism in Women and Girls.	Evanko, R.	2024	Non-UK (US)
Behavioral gender differences in school-age children with autism	Sanchez, M., Bullen, J., Zajic, M., McIntyre, N. and Mundy, P.	2024	Non-UK (US)
Perspectives of autistic adolescent girls and women on the determinants of their mental health and social and emotional well-being: A systematic review and	O'Connor, R., Doherty, M., Ryan-Enright, T and Gaynor, K	2023	Non-UK (Ire)

Title	Author	Date	Exclusion reason
thematic synthesis of lived experience.			
Issues in persistent non-attendance at school of autistic pupils and recommendations following the reintegration of 11 autistic pupils	Lowri, C.	2021	Male focus/no sex comparison
Friend matters: sex differences in social language during autism diagnostic interviews	Cola, M, Yankowitz, L., Tena, K., Russell, A., Bateman, L., Knox, A., Plate, S., Cubit, L., Zampella, C., Pandey, J., Schultz, R. & Parish-Morris, J.	2022	Non-UK (US)
Sex differences in the first impressions made by girls and boys with autism	Cola, M, Yankowitz, L., Tena, K., Petrulla, V., Bateman, L., Knox, A., Plate, S., Zampella, C., de Marchena, A., Pandey, J., Schultz, R. & Parish-Morris, J.	2020	Non-UK (US)
Camouflaging in Autism: Examining Sex-Based and Compensatory Models in Social Cognition and Communication.	Corbett, B. A., Schwartzman, J. M., Libsack, E. J., Muscatello, R. A., Lerner, M. D.,	2021	Non-UK (US)

Title	Author	Date	Exclusion reason
	Simmons, G. L., & White, S. W.		
The school experiences of autistic girls and adolescents: a systematic review	Tomlinson, C., Bond, C. & Hebron, J.	2019	Pre-2020
Recognition of Girls on the Autism Spectrum by Primary School Educators: An Experimental Study.	Whitlock, A., Fulton, K., Lai, M-C., Pellicano, E & Mandy, W.	2020	Participant age (primary)
'Sea- glass survivors': Autistic testimonies about education experiences	Shepherd, J., Sutton, B., Smith, S & Szlenkier, M.	2024	Participant age (adults)
Pubertal Timing During Early Adolescence: Advanced Pubertal Onset in Females with Autism Spectrum Disorder	Corbett, B., Vandekar, S., Muscatello, R. & Tanguturi, Y.	2020	Non-UK (US)
Sex differences in automatic emotion regulation in adolescents with autism spectrum disorder.	Key, A., Jones, D. & Corbett, B.	2022	Non-UK (US)
Sex Differences in an Autism Spectrum Disorder Diagnosis: Are Restricted Repetitive Behaviors and Interests the Key?	McFayden, T., Antezana, L., Albright, J., Muskett, A, & Scarpa, A.	2020	Non-UK (US)

Title	Author	Date	Exclusion reason
School absenteeism in autistic children and adolescents: A scoping review	Nordin, V., Palmgren, M., Lindbladh, A., Bölte, S & Jonsson, U.	2024	Non-UK
What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills	Ratto, A., Kenworthy, L., Yerys, B., Bascom, J., Wieckowski, A., White, S., Wallace, G., Pugliese, C., Schultz, R., Ollendick, T., Scarpa, A., Seese, S., Register-Brown, K., Martin, A. & Gutermuth Anthony, L.	2017	Pre 2020
“You Must Become a Chameleon to Survive”: Adolescent Experiences of Camouflaging	Bernardin, C., Mason, E., Lewis, T. & Kanne, S.	2021	Non-UK (US)
Associations between social camouflaging and internalizing symptoms in autistic and non-autistic adolescents	Bernardin, C. & Kanne, S.	2021	Non-UK (US)
Barriers to school attendance as experienced by young people and their parents: A Narrative Oriented Inquiry	Want, H. & Gulliford, A.	2024	Male focus/no sex comparison

Title	Author	Date	Exclusion reason
School non-attendance-editorial	Bond, C., Kelly, C., Atkinson, C. & Gulliford, A.	2024	Male focus/no sex comparison
Towards understanding the under-recognition of girls and women on the autism spectrum	Gould, J.	2017	Pre 2020
Sex Differences in Mental Health Problems And Psychiatric Hospitalization in Autistic Young Adults	Martini, M., Kuja-Halkola, R., Butwicka, A., DuRietz, E., D'Onofrio, B., Happé, F., Kanina, A., Larsson, H., Lundström, S., Martin, J., Rosenqvist, M., Lichtenstein, P & Taylor, M.	2022	Non-UK (Sweden)
Measuring the function of school refusal behaviour	Kearney, C. & Silverman, W.	1993	Pre-2020
Parent experiences of school distress or school refusal in their autistic child	Smart, R., Adams, D. & Simson, K.	2024	Non-UK (Australian)
Shining a Light on a Hidden Population: Social Functioning and Mental Health in Women Reporting Autistic Traits But Lacking Diagnosis	Belcher, H, Morein-Zamir, S., Stagg, S. & Ford, R.	2023	Participant age (adults)
What about my voice? Autistic young girls'	Goodall, C. & MacKenzie, A.	2017	Pre-2020

Title	Author	Date	Exclusion reason
experiences of mainstream school			

Papers excluded at critical appraisal stage= 5

Title	Author	Date	Exclusion reason
A systematic review identifying factors associated with emotionally based school non-attendance in autistic children and young people	Prosser, R. & Birchwood, B.	2024	Highly relevant so considered further to critical appraisal, but excluded as male focus/no sex comparison
Differently different?: A commentary on the emerging social cognitive neuroscience of female autism.	Rippon, G.	2024	Did not meet first two criteria on CASP systematic review checklist- no research question or information on literature search undertaken.
Is androcentrism causing harm to autistic girls? – An ethical consideration for educational psychologists	Davies, E.	2022	Position paper- no literature review information or research element. Literature used to back up authors position.
A Subtle Profile With a Significant Impact: Language and Communication Difficulties for Autistic Females Without Intellectual Disability.	Sturrock, A., Adams, C. & Freed, J.	2021	Literature review paper- relevant studies were included but papers included were all the author's own research. No information of the literature searches undertaken. Potentially biased literature review.
DSM-5 and Challenges to Female Autism Identification	Suckle, E.	2021	Open letter/position paper. Relevant paper, but literature used to support authors position and recommendations so excluded for literature review purposes.

Appendix 4- Critical Appraisal Findings per Paper

CASP Checklist for Qualitative Research

Question	O'Hagan et al. (2024)	Halsall et al. (2021)	Gaffney (2020)	Tomlinson et al. (2022)	Anderson et al. 2020)
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Can't tell
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes

Question	O'Hagan et al. (2024)	Halsall et al. (2021)	Gaffney (2020)	Tomlinson et al. (2022)	Anderson et al. 2020)
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	No	No	Yes	No	Yes
Have ethical issues been taken into consideration?	Yes	Yes	Yes	Can't tell (but ethical approval received)	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes

Question	O'Hagan et al. (2024)	Halsall et al. (2021)	Gaffney (2020)	Tomlinson et al. (2022)	Anderson et al. 2020)
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	Yes	Yes	Yes	Yes	Yes
Total with 2 or yes responses	**9/10**	**9/10**	**10/10**	**9/10**	**9/10**

Answers are yes, no or can't tell

CASP Checklist for Descriptive/Cross-Sectional Studies (Quantitative)

Question	McKinney et al. (2024)	Wood Downie et al. (2021)	Totsika et al. (2020)
Did the study address a clearly focused issue?	Yes	Yes	Yes
Did the authors use an appropriate method to answer their question?	Yes	Yes	Yes

Question	McKinney et al. (2024)	Wood Downie et al. (2021)	Totsika et al. (2020)
Were the subjects recruited in an acceptable way?	Yes	Yes	Yes
Were the measures accurately measured to reduce bias?	Yes	Yes	Yes
Were the data collected in a way that addressed the research issue?	Yes	Yes	Yes
Did the study have enough participants to minimise the play of chance?	No	Yes	Can’t tell
How are the results presented and what is the main result?	Presented as autistic girls being more likely to display	Presented in terms of likelihood.	Results presented as likelihoods and proportions of

Question	McKinney et al. (2024)	Wood Downie et al. (2021)	Totsika et al. (2020)
	a specific element of camouflaging than NT girls, but being equal in other aspects. Older age also increased camouflaging scores in both groups. Higher camouflaging scores significantly predicted anxiety and depression symptoms.	Findings suggests that camouflaging is a key part of the female autism phenotype, and that it is more prevalent in autistic females than males. Also argued that individuals who mask and hide their needs are less likely to receive a diagnosis.	participants in different categories/experiences Found that school non-attendance is common in autistic students, with older students and those in single parent households being particularly susceptible to reduced attendance.

Question	McKinney et al. (2024)	Wood Downie et al. (2021)	Totsika et al. (2020)
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes
Can the results be applied to the local population?	Yes	Yes	Yes
How valuable is the research?	Yes	Yes	Yes
Total with 2 or yes responses	**10/11**	**11/11**	

Answers are yes, no or can't tell

Mixed Methods Appraisal Tool

Question	Gray et al. (2021)
Are there clear research questions?	Yes
Do the collected data allow to address the research questions?	Yes

Question	Gray et al. (2021)
Is there an adequate rationale for using a mixed methods design to address the research question?	Can't tell
Are the different components of the study effectively integrated to answer the research question?	Yes
Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes
Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes
Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes
Total with 2 or yes responses	**6/7**

CASP Checklist for Systematic review

Question	Cook et al. (2021)	Ayirebi & Thomas (2023)
Did the review address a clearly focused question?	Yes	Yes
Did the authors look for the right type of papers?	Yes	Yes

Question	Cook et al. (2021)	Ayirebi & Thomas (2023)
Do you think all the important, relevant studies were included?	Yes	Can't tell
Did the review's authors do enough to assess quality of the included studies?	Yes	Yes
If the results of the review have been combined, was it reasonable to do so?	Yes	Yes
What are the overall results of the review?	Three primary conclusions Adults reported more autistic traits also reported greater camouflaging; Autistic girls/women demonstrated more camouflaging than autistic boys/men; Association between higher self-reported camouflaging and increased mental health difficulties.	Findings revealed that supporting the social, emotional and mental health needs of autistic girls of primary importance.

Question	Cook et al. (2021)	Ayirebi & Thomas (2023)
How precise are the results? (relating to CIs if relevant)	N/A	N/A
Can the results be applied to the local population?	Yes	Yes
Were all important outcomes considered?	Can't tell	Yes
Are the benefits worth the harms and costs?	Yes	Yes
Total with 2 or yes responses	**8/10**	**9/10**

Answers are yes, no or can't tell. Questions asking 'what are the findings' have been answered 'yes' if there is a clear statement.

Scale for the Assessment of Narrative Review Articles – SANRA

Question	Hamilton (2024)	Hull et al. (2020)
Justification of the article's importance for the readership	2	2
Statement of concrete aims or formulation of questions	2	1
Description of the literature search	0	0
Referencing	2	2
Scientific reasoning	2	2
Appropriate presentation of data/findings	2	2

Question	Hamilton (2024)	Hull et al. (2020)
Total with 2 or yes responses	**5/6**	**4/6**

Answers are 0, 1 or 2 with 0 being that the criteria is not met and two being that the criteria is explicitly and clearly met.

Appendix 5- Example themes from writing helper- NB all are direct quotes from the papers

Diagnosis + females

Male bias

Needs Rewording - Autism could therefore be regarded as a predominantly male ‘disorder’ or ‘condition’. Females who are diagnosed with autism experience a dual difference: Difference from their ‘typical’ peer group and being in a female minority of people ‘diagnosed’ with autism (Davidson, 2007) (Gaffney)

Needs Rewording - Factors thought to influence the higher incidence in autism diagnosis in males are research studies which include more boys than girls, the ability of current assessment tools to detect the disorder in girls and the different ‘symptom’ presentations in males versus females (Atwood, 2007; Gould & Ashton-Smith, 2011; Wing et al., 2011). (Gaffney)

Needs Rewording - Research within the field has attempted to disentangle this sex discrepancy and male biased aetiology in the core symptomology of ASD. This historical male bias could be explained by a lack of recognition of a female phenotype of ASD (Kopp & Gillberg, 1992). (Gray, Ella Bownas, Lucy hicks, Emma Hutcheson-Galbraith and Sandra Harrison)

Needs Rewording - Similarly, literature has attested to boys with ASD being more likely to display externalising types of behaviour compared to their female peers (Gould & Ashton-Smith, 2011; Hiller et al., 2014); this could be a result of girls’ efforts to mask their difficulties in order to fit in (Sutherland et al., 2017). Ta (Gray, Ella Bownas, Lucy hicks, Emma Hutcheson-Galbraith and Sandra Harrison)

Needs Rewording - Empirical research has found that boys with ASD displayed significantly higher levels of behavioural problems and difficult interactions within a school context than girls with ASD (Hsiao et al., 2013), a finding which does not generalise to home contexts (Kozlowski et al., 2012). (Gray, Ella Bownas, Lucy hicks, Emma Hutcheson-Galbraith and Sandra Harrison)

Needs Rewording - Autism has historically been considered a predominantly male condition but in recent years, awareness of autism in girls has increased (Mandy and Lai 2017). Autistic girls may be less easily identified as they tend to internalise or mask their difficulties and have more surface-level social skills (Hebron and Bond 2019). (Tomlinson)

Needs Rewording - There are many more males diagnosed with autism than females (Dworzynski et al., 2012). (Gaffney)

Needs Rewording - It has long been considered that there is a sex dis crepancy in the prevalence of ASD, with a ratio of 4:1, in favour of males (Baird et al., 2006; Rivet & Matson, 2011). However, some literature suggests that the actual ratio of Autism diagnoses is closer to 2:1 (Dworzynski et al., 2012) and other studies report equal rates of prevalence between males and females (Matheis et al., 2019). This suggests that girls with ASD may be going under-recognised. (Gray, Ella Bownas, Lucy hicks, Emma Hutcheson-Galbraith and Sandra Harrison)

Needs Rewording - Earlier estimates put differential rates of male to female diagnosis at 4:1 (Mandy et al. 2012), but more recent figures suggest the ratio is closer to 2:1 (Kirkovski, Enticott, and Fitzgerald 2013). (Tomlinson)

Needs Rewording - Furthermore, parental participants raised concerns around some inter ventions being tailored for autistic males, suggesting the need for schools to

develop specific groups for autistic females (Cridland et al., 2014; Jamison & Schuttler, 2017). (Ayirebi and George Thomas)

Masking or camouflaging

Needs Rewording - Camouflaging may enable an individual to, consciously or uncon sciously, present a non-autistic social style, hide autistic characteristics, and/or minimise the visibility of social difficulties (Hull et al., 2017; Lawson, 2020). (Cook, Laura Hull, Laura Crane and William Mandy)

Needs Rewording - Camouflaging has been seen to comprise the distinct coping strategy named masking (Hull et al., 2017). Masking has been defined as a conscious or unconscious effort to hide ASD characteristics through the use of strategies that result in a more conforming behavioural presentation (Lai et al., 2017; Livingston & Happé, 2017), driven by the desire to fit in (Hull et al., 2017). (Gray, Ella Bownas, Lucy hicks, Emma Hutcheson-Galbraith and Sandra Harrison)

Needs Rewording - Camouflaging2 is the conscious or subconscious suppression of socially unacceptable behaviour and the compensation of difficulties in social interaction with the goal of being perceived as neurotypical (Hull et al., 2017; Pearson & Rose, 2023). (McKinney, SarahO’Brien, Jacqueline A. Maybin, Stella W. Y. Chan, Simone Richer and Sinead Rhodes)

Needs Rewording - Camouflaging can involve suppressing reactions to sensory experiences, imitating social behaviour (without always understanding the social behaviour they are imitating), and developing ways of avoiding situations or perfectionism (Sedgewick et al., 2022; Young, 2020). (McKinney, SarahO’Brien, Jacqueline A. Maybin, Stella W. Y. Chan, Simone Richer and Sinead Rhodes)

Needs Rewording - Camouflaging offers some benefits in a largely neurotypical world, including securing education and employment, and making connections (Zhuang et al., 2023). Although, autistic advocates highlight camou flaging is often a way to stay safe and a reaction to rejection and trauma (Pearson & Rose, 2021). (McKinney, SarahO’Brien, Jacqueline A. Maybin, Stella W. Y. Chan, Simone Richer and Sinead Rhodes)

Factors supporting attendance

Needs Rewording - This research highlights the importance of seeking to listen to the voice of the child or young person. (Gaffney)

Appendix 6- Literature Methodological approach matrix

Approach	Number	Studies
Qualitative	5	Halsall et al (2021) O'Hagan et al (2024) Gaffney (2025) Tomlinson et al (2022) Anderson et al (2020)
Quantitative	3	Totsika et al. (2020) McKinney et al (2024) Wood-Downie et al (2021)
Mixed methods	1	Gray et al. (2021)
Systematic literature review	2	Ayirebi + Thomas (2022) Cook et al (2021)
Narrative review	2	Hull et al (2020) Hamilton (2024)
Total	13	
	Qualitative methods design	
Interpretative Phenomenological Analysis (IPA)	2	Gaffney (2025) Anderson et al (2020)
Reflective Thematic Analysis	2	Halsall et al (2021) O'Hagan et al (2024)
Case study	1	Tomlinson et al (2022)

Synthesis Matrix

Study	Methodology	Sample	Focus	Relevance to Your Study
Anderson et al (2020) When the Mask Comes Off: Mothers' Experiences of Parenting a Daughter with Autism	Qualitative IPA	10 mothers of autistic girls aged 12-18	Masking, diagnostic delay, emotional toll	Retrospective lens; rich maternal insight into pre-diagnosis struggles
Tomlinson et al (2022) – The Mainstream	Qualitative Case study design	3 autistic girls + parents + therapist	Mainstream school experiences,	Strong thematic overlap; similar

Study	Methodology	Sample	Focus	Relevance to Your Study
School Experiences of Adolescent Autistic Girls			masking, inclusion	participant group; qualitative
Gaffney (2025)- "It's Autism, It's Just a Name": Adolescent Girls' Experiences of Receiving an Autism Diagnosis:	Qualitative IPA	6 autistic girls 14-20	Identity and diagnosis, lived experiences female autism	Offers valuable insight into how adolescent girls interpret their autism diagnosis.
O'Hagan et al (2024)- Autistic girls and emotionally based school avoidance: supportive factors for successful re-engagement in mainstream high school	Qualitative Reflexive thematic analysis	3 triads (autistic female, parent, therapist from school)	Camouflaging, inclusion, supportive factors, EBSNA	High relevance looking at correct participant group, themes and qualitative design
Halsall et al (2021)- "Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives	Qualitative Reflexive thematic analysis Multi-informant	8 triads (autistic female, parent and educator) CYP aged 13-15	Camouflaging, inclusion, mental health impact	High relevance looking at correct participant group, themes and qualitative design

Study	Methodology	Sample	Focus	Relevance to Your Study
of girls, their mothers and their educators Totsika et al. (2020) – Types and Correlates of School Non-Attendance in Students with Autism	Quantitative	486 caregivers of autistic children enrolled at school. Age range 2-18, average age 11 69% male	School non-attendance in autism	EBSNA prevalence and correlates; contextual backdrop for qualitative findings
Wood-Downie et al (2021)- Sex/Gender Differences in Camouflaging in Children and Adolescents with Autism	Quantitative	40 children and adolescents with diagnosis or high autistic traits (18 girls, 22 boys) 44 neurotypical controls matched by age and gender (22 males, 22 females) Total= 84 participants 8-14 years	Gender differences in camouflaging and compared to NT peers	Provides empirical evidence for sex/gender differences in camouflaging among autistic CYP compared to NT peers
McKinney et al (2024)- 'Camouflaging in Neurodivergent and Neurotypical Girls at the transition to adolescence and its relationship to mental health:	Quantitative Participatory methods	Participants were 119 girls (70 neurodivergent, 49 neurotypical) aged 11–14 years.	Camouflaging, females, NT comparison groups, mental health correlation, neurodivergent (ADHD + DCD included)	Highly relevant as looking at correlation between camouflaging and mental health. However participant group also included those with ADHD and DCD however

Study	Methodology	Sample	Focus	Relevance to Your Study
A participatory methods research study'				the overlap between conditions is high so felt to still be relevant.
Gray et al. (2021) – Towards a Better Understanding of Girls on the Autism Spectrum	Mixed methods	53 SENCos + 3 parents	Female presentation, Identification, understanding of school staff, masking, support gaps	Qualitative element, CYP overlap; Similar themes: autistic female identification and support
Ayirebi & Thomas (2022) – What Could Be Considered as Effective Support for Autistic Females in high school?	Systematic literature review	12 papers- Secondary sources	Effective support, gendered autism presentation	Very relevant- participant group overlap; similar themes (supportive strategies)
Cook et al (2021)- Camouflaging in Autism: A Systematic Review	Systematic review	29 studies included; Mixed studies; 60% female samples; average age 11.9 years; Mixed neurotypes and age ranges across studies	Camouflaging, age, gender differences, mental health impact	High relevance looking at correct participant group, themes and comparison between genders to give context for this review
Hamilton (2024)- Emotionally Based School Avoidance in	Narrative review	Secondary sources	EBSNA post Covid	Relevant. Synthesizes post-pandemic EBSA challenges and

Study	Methodology	Sample	Focus	Relevance to Your Study
the Aftermath of the Pandemic: Neurodiversity, Agency and Belonging in School				support strategies within current educational pressures and systemic responses.
Hull et al (2020)- The Female Autism Phenotype and Camouflaging: A Narrative Review	Narrative review	Secondary sources	Camouflaging, female autistic phenotype, gender differences, mental health impacts	Foundational piece in the camouflaging literature, especially regarding gendered autism presentation. It's highly relevant, particularly for framing diagnostic challenges and the evolving understanding of the female autism phenotype, but methodological weaknesses in terms of search strategy and details of assessing quality.

Methodological Critique Mapping Table

Category	Details from the Study
Author(s) & Year	O'Hagan, Bond & Hebron (2024)
Study Title / Topic	'Autistic girls and emotionally based school avoidance: supportive factors for re-engagement' The study seeks to explore subjective experiences and contextual factors influencing re-engagement, making qualitative methodology appropriate
Research Question / Aim	To identify supportive factors that help autistic girls with EBSA re-engage and support attendance in mainstream school
Methodology Type	Qualitative
Design & Approach	Exploratory multiple case study design, involving triangulated perspectives from autistic girls, their parents, and school staff.
Sample & Setting	- 3 autistic girls (ages 13–15) - Their parent(s) - A key adult from each school Autistic girls in mainstream high schools; recruited via SENCo from local authority contacts
Data Collection Methods	Semi-structured interviews; one questionnaire completed instead of interview; adapted interview schedules per participant group
Data Analysis Techniques	Inductive thematic analysis using Braun & Clarke's six-phase guide; NVivo used for coding; cross-case analysis conducted.
Strengths of Methodology	Rich qualitative data; adapted tools; collaborative analysis; direct quotes support themes
Limitations / Biases	Lack of justification for case study design; researcher bias not critically examined; Limited detail on ethical procedures beyond approval; small sample size; potential selection bias via SENCo recruitment; one participant's data collected via questionnaire, limiting depth.
Ethical Considerations	Ethical approval from University of Manchester; limited detail on consent procedures
Relevance to Your Topic	Highly relevant—focuses on autistic girls, EBSA, and school re-engagement strategies
Theoretical Framework	Bio-ecological systems (Bronfenbrenner); informed by prior exploratory study

Category	Details from the Study
Critique Summary	Methodologically sound overall; rich data gathered from multiple participants; direct quotes used to support findings. Ethical and reflexive transparency could be improved; small sample size limits generalisability.

Category	Details from the Study
Author(s) & Year	Halsall, Clarke & Crane (2021)
Study Title / Topic	"Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators The study explores subjective experiences of camouflaging among autistic girls, their parents, and educators—making qualitative methodology appropriate.
Research Question / Aim	Do autistic girls use camouflaging strategies, why, and what are the consequences?
Methodology Type	Qualitative
Design & Approach	Multi-informant design using semi-structured interviews with triangulated perspectives.
Sample & Setting	8 autistic girls (12-15), 8 mothers, and 7 educators in a UK resource bases
Data Collection Methods	Semi-structured interviews; modified CAT-Q
Data Analysis Techniques	Reflective thematic analysis
Strengths of Methodology	Piloted tools; triangulated perspectives; detailed coding
Limitations / Biases	Small sample size limits generalizability; Potential bias in eliciting autistic girls' perspectives due to communication demands; possible camouflaging during interviews not fully accounted for; lack of demographic diversity (e.g. ethnicity, SES not recorded); no neurotypical or male comparison group; Researcher positionality noted but not deeply interrogated
Ethical Considerations	Ethical approval granted; piloting with feedback
Relevance to Your Topic	Directly relevant—camouflaging and educational context

Category	Details from the Study
Theoretical Framework	Social constructionist perspective
Critique Summary	Strong design and analysis, rich triangulation of data; reflexivity could be more explicit; limited generalisability. A methodologically sound and insightful study

Category	Details from the Study
Author(s) & Year	Tomlinson, Bond & Hebron (2022)
Study Title / Topic	'The Mainstream School Experiences of Adolescent Autistic Girls'
Research Question / Aim	How do autistic adolescent girls experience mainstream school?
Methodology Type	Qualitative
Design & Approach	Multiple-case study; Interpretive, exploratory
Sample & Setting	3 girls 14-16, their mothers and the school's psychotherapist Girls recruited via SENCo in a large UK secondary school
Data Collection Methods	Participatory- the girls chose their preferred methods. Diaries, drawings, photos, interviews; contextual interviews with mothers
Data Analysis Techniques	Hybrid thematic analysis (Braun & Clarke); member checking
Strengths of Methodology	Participant-led methods; triangulation; member checking; focus on successful placements
Limitations / Biases	Researcher bias not acknowledged; ethical detail limited; small sample size limits generalisability; all participants academically able + verbal; single school context also limits generalisability
Ethical Considerations	Ethical approval granted; consent obtained
Relevance to Your Topic	Highly relevant—school experience, support, identity
Theoretical Framework	Not explicitly stated but includes autistic female phenotype, masking and camouflaging and inclusion

Category	Details from the Study
Critique Summary	Rich data and participatory ethos; reflexivity could be stronger. offers a rare and valuable glimpse into the mainstream school experiences of autistic girls who are thriving in an inclusive setting.

Category	Details from the Study
Author(s) & Year	Anderson, Marley, Gillespie-Smith, Carter & MacMahon (2020)
Study Title / Topic	'When the Mask Comes Off: Mothers' experiences of parenting a daughter with autism spectrum condition'
Research Question / Aim	The main research question was, what are mothers' lived experiences of parenting a daughter with ASC, with a specific focus on female ASC presentation and the diagnostic process.
Methodology Type	Qualitative
Design & Approach	Interpretative Phenomenological Analysis (IPA)
Sample & Setting	10 mothers of autistic girls aged 12-18; recruited via autism organisations
Data Collection Methods	Semi-structured interviews (face-to-face and Skype)
Data Analysis Techniques	IPA six-stage process; triangulation; reflexive diary
Strengths of Methodology	Deep interpretive insight; multiple validation strategies; - IPA well-suited to exploring identity and relational dynamics; Ethical sensitivity and reflexivity well-articulate
Limitations / Biases	Small sample limits generalisability; no triangulation with daughters or professional; SES and education level information not collected
Ethical Considerations	Ethical approval granted; consent and debriefing detailed
Relevance to Your Topic	Highly relevant—female autism presentation and family dynamics. The findings are relevant for mapping diagnostic journeys, relational support, and gendered dynamics in autism recognition. However different in terms that the experiences of the mothers were the focus rather than the autistic daughters'.

Category	Details from the Study
Theoretical Framework	Phenomenological; female phenotype, masking and camouflaging, relational perspectives
Critique Summary	Methodologically sound; strong reflexivity and credibility

Category	Details from the Study
Author(s) & Year	Gaffney (2025)
Study Title / Topic	'It's Autism, It's Just a Name': Exploring the impact of autism spectrum diagnosis with adolescent females using Interpretative Phenomenological Analysis Impact of autism diagnosis on adolescent females' identity
Research Question / Aim	How do adolescent girls make sense of their autism diagnosis? How does the autism diagnosis impact on their sense of self?
Methodology Type	Qualitative
Design & Approach	Interpretative Phenomenological Analysis (IPA)
Sample & Setting	6 Adolescent girls (14-20) recruited via school posters; All participants had received an autism diagnosis within the past 2 years
Data Collection Methods	Semi-structured interviews
Data Analysis Techniques	IPA six-stage process; reflexive diary; respondent validation; Cross-case analysis
Strengths of Methodology	Deep interpretive insight; reflexivity; ethical rigor; rich, in-depth exploration of identity and diagnosis; Strong alignment with IPA principles; Use of respondent validation and reflexivity enhances credibility; Use of verbatim quotes to support interpretation
Limitations / Biases	Small sample; limited generalizability; all participants were verbal and cognitively able—excludes broader autistic profiles; researcher bias acknowledged but not deeply interrogated; no triangulation with other data sources (e.g. parents or educators)
Ethical Considerations	University ethical approval; parental consent for minors
Relevance to Your Topic	Highly relevant—identity, diagnosis, female autism

Category	Details from the Study
Theoretical Framework	Phenomenological
Critique Summary	This is a methodologically robust and emotionally resonant IPA study that offers valuable insight into how adolescent girls interpret their autism diagnosis. While the sample is narrow and reflexivity could be deepened, the study contributes meaningfully to understanding identity, gendered autism presentation, and the personal impact of diagnostic processes.

Category	Details from the Study
Author(s) & Year	McKinney, O'Brien, Maybin, Chan, Richer & Rhodes (2024)
Study Title / Topic	'Camouflaging in Neurodivergent and Neurotypical Girls at the transition to adolescence and its relationship to mental health: A participatory methods research study' Camouflaging and mental health in adolescent girls
Research Question / Aim	The study aims to compare camouflaging behaviours and mental health outcomes between neurodivergent and neurotypical girls.
Methodology Type	Quantitative
Design & Approach	Cross-sectional cohort study with validated assessments, comparative design between two groups: neurodivergent girls (including autistic and ADHD profiles) and neurotypical girls
Sample & Setting	119 girls (neurodivergent n = 70, neurotypical n = 49), aged 11–14
Data Collection Methods	CAT-Q-A, ASC-ASD, RCADS; self-report with researcher support. Recruitment through schools and community networks
Data Analysis Techniques	- Descriptive statistics to profile each group - Inferential statistics (e.g., t-tests, ANOVA) to compare camouflaging and mental health scores - Correlational analysis to explore relationships between camouflaging and anxiety/depression
Strengths of Methodology	Large sample size; validated, age appropriate tools; comparative design; Researcher support during data collection enhances accessibility

Category	Details from the Study
Limitations / Biases	No longitudinal follow-up—limits understanding of developmental trajectory; neurodivergent group includes mixed diagnoses (autism, ADHD), which may confound interpretation; no qualitative data to contextualize findings; cultural and socioeconomic diversity not reported
Ethical Considerations	Ethical approval granted; anonymized responses
Relevance to Your Topic	Highly relevant—camouflaging, gender, mental health
Theoretical Framework	Not explicitly stated
Critique Summary	Robust quantitative snapshot of camouflaging behaviours and their mental health correlates in adolescent girls. Its strengths lie in its validated tools and comparative design, though it would benefit from clearer theoretical grounding and broader demographic reporting.

Category	Details from the Study
Author(s) & Year	Wood-Downie, Wong, Kovshoff, Mandy, Hull & Hadwin (2021)
Study Title / Topic	'Sex/Gender Differences in Camouflaging in Children and Adolescents with Autism' Sex/gender differences in camouflaging among autistic individuals
Research Question / Aim	To examine whether camouflaging differs by sex/gender and its correlates
Methodology Type	Quantitative (non-randomized)
Design & Approach	Cross-sectional survey
Sample & Setting	- 40 children and adolescents with diagnoses or high autistic traits (18 girls, 22 boys) - 44 neurotypical controls matched by age and gender (22 males, 22 females) - 8-14 years Recruitment through schools
Data Collection Methods	WASI-II; Interactive drawing test; Reading the Mind in the Eyes Test + Self-report questionnaires with group comparisons between autistic boys, autistic girls, and neurotypical controls

Category	Details from the Study
Data Analysis Techniques	- Descriptive statistics to profile camouflaging scores - Inferential statistics (ANOVA, regression analysis) to test group differences and predictors - Controlled for age, IQ, and autistic traits
Strengths of Methodology	Balanced gender representation within autistic sample; use of validated camouflaging measures (CAT-Q adapted for children); rigorous statistical controls for confounding variables; clear operational definitions of camouflaging
Limitations / Biases	Reliance on self-report may underrepresent camouflaging in younger or less verbal participants; cultural and socioeconomic diversity not reported; cross-sectional design limits developmental interpretation; theoretical framing of gender could be more nuanced
Ethical Considerations	University ethical approval obtained, informed consent and assent procedures and age appropriate and accessible tools used.
Relevance to Your Topic	Relevant—gendered patterns in camouflaging
Theoretical Framework	Not specified
Critique Summary	This is a well-executed quantitative study that provides empirical evidence for sex/gender differences in camouflaging among autistic youth. Theoretical framing could be more explicit

Category	Details from the Study
Author(s) & Year	Totsika, Hastings, Dutton, Worsley, Melvin, Gray, Tongue & Heyne (2020)
Study Title / Topic	'Types and Correlates of School Non-Attendance in Students with Autism Spectrum Disorders' School non-attendance patterns and predictors in students with SEND
Research Question / Aim	The aim of this study was to provide a more comprehensive description of the school non-attendance of children with ASD.
Methodology Type	Quantitative
Design & Approach	Cross-sectional survey study

Category	Details from the Study
Sample & Setting	486 caregivers of autistic children enrolled at school. Age range 2-18, average age 11 69% male
Data Collection Methods	Structured questionnaires about their child's school attendance, health, and developmental status
Data Analysis Techniques	Statistical analysis: Descriptive statistics for non-attendance Multivariable regression models that included a series of child, family/caregiver characteristics as well as school type and school access as predictors.
Strengths of Methodology	Large sample; Robust statistical controls for confounding variables; Differentiates between types of non-attendance, including EBSA; Highlights systemic inequalities and diagnostic disparities
Limitations / Biases	Autism status based on parental report—not clinical confirmation; No qualitative data to contextualise absence reasons; EBSNA inferred from patterns—not directly measured
Ethical Considerations	Informed consent gathered
Relevance to Your Topic	Relevant—EBSA and SEND intersection highlighting patterns and frequency compared to typically developing peers. Unfortunately, no gender comparison which would have been possible as gender information gathered. Still highly relevant to give context to the incidence of EBSNA in autistic individuals.
Theoretical Framework	Not specified
Critique Summary	Useful data; transparency and demographic detail could improve. This study offers a statistically grounded view of school non-attendance among autistic students, revealing higher rates of both authorised and unauthorised absence. While it lacks qualitative depth, its scale and clarity make it a valuable piece for mapping attendance patterns and policy implications.

Category	Details from the Study
Author(s) & Year	Gray, Bownas, Hicks, Hutcheson-Galbraith & Harrison (2021)
Study Title / Topic	'Towards a Better Understanding of Girls on the Autism Spectrum: educational support and parental perspectives'
Research Question / Aim	Aims to elicit parental voices and school SENCo views, with the hope of disentangling any disparities in understanding of sex- specific symptomology and identifying the specific educational and therapeutic needs of these girls and women.
Methodology Type	Mixed Methods - Quantitative: Cross-sectional survey of 53 SENCos across a UK local authority - Qualitative: Group interview with 3 parents of autistic girls
Design & Approach	GT principles used to guide qualitative questioning. Integrated qualitative and quantitative components
Sample & Setting	53 respondents (SENCos) from early years, primary, and secondary schools 3 mothers of girls aged 7–12 with confirmed autism diagnoses, recruited via EarlyBird programme
Data Collection Methods	Group interviews for mothers; surveys for SENCos
Data Analysis Techniques	Thematic analysis/iterative coding and statistical synthesis (chi Square tests)
Strengths of Methodology	Strong integration; quality criteria met across both traditions; elicits under-represented parental voices; Reveals nuanced understanding of masking and internalised distress which is highly relevant
Limitations / Biases	Rationale for mixed methods not clearly discussed; small parent sample (n=3) limits generalisability; questionnaire not piloted or standardised; self-report ratings may reflect perceived rather than actual competence; focused on one local authority—regional bias possible
Ethical Considerations	Ethical approval assumed; not detailed. BPS code of ethics and conduct referred to.
Relevance to Your Topic	Highly relevant—gendered autism presentation and support

Category	Details from the Study
Theoretical Framework	Not specified but female phenotype and camouflaging concepts presented.
Critique Summary	Robust design; rationale for mixed methods could be clearer. This study underscores the disconnect between school-based identification of autistic girls and parental insight into their daughters' needs which is highly relevant to this study.

Category	Details from the Study
Author(s) & Year	Cook, Hull, Crane & Mandy (2021)
Study Title / Topic	Camouflaging in Autism: A Systematic Review
Research Question / Aim	This review aimed to systematically appraise and synthesise the current evidence base pertaining to autistic camouflaging.
Methodology Type	Systematic Review
Design & Approach	Multi-database search; MMAT quality appraisal to assess study quality
Sample & Setting	29 studies included; Mixed studies; 60% female samples; average age 11.9 years; Mixed neurotypes and age ranges across studies
Data Collection Methods	Literature synthesis
Data Analysis Techniques	Thematic synthesis across five research questions
Strengths of Methodology	Clear inclusion criteria and comprehensive search; quality appraisal; diverse sample
Limitations / Biases	Limited generalizability due to participant characterization consistency issues; overrepresentation of female and Western samples; Variation in how camouflaging is defined and measured; Lack of meta-analytic synthesis—findings are thematic, not statistical
Ethical Considerations	N/A (secondary data)
Relevance to Your Topic	Highly relevant—gender differences and mental health outcomes
Theoretical Framework	Not specified
Critique Summary	Well-conducted and structured review; cautious interpretation due to sample limitations

Category	Details from the Study
Author(s) & Year	Ayirebi & Thomas (2022)
Study Title / Topic	'What Could Be Considered as Effective Support for Autistic Females in high school? A systematic literature review'
Research Question / Aim	The current systematic literature review endeavours to extend these findings in order to provide an account of specific support options that could be considered as effective for autistic females attending high school settings. What specific support could be considered as effective in meeting the needs of autistic females in high school?
Methodology Type	Narrative Literature Review
Design & Approach	WoE-rated synthesis- thematic narrative synthesis
Sample & Setting	Secondary literature- - Includes peer-reviewed studies, No participant data collected. 12 studies included; involving 129 participants including combination of autistic adolescent females and/or parents
Data Collection Methods	Literature-based;
Data Analysis Techniques	Thematic synthesis across seven analytical themes
Strengths of Methodology	Strong referencing; clear aims; quality appraisal used; clear information about literature search and PRISMA included
Limitations / Biases	Small number of papers included; small sample sizes within the included papers therefor limited generalisability.
Ethical Considerations	N/A
Relevance to Your Topic	Highly relevant—school support and gendered needs Synthesis of what autistic girls need to thrive in education. It foregrounds identity, emotional safety, and relational support, while critiquing the diagnostic and systemic blind spots that often exclude or misidentify girls.
Theoretical Framework	Not specified but aligns with person centred models.
Critique Summary	Well-structured review; conceptual clarity and practical relevance make it a useful, especially for

Category	Details from the Study
	framing inclusive strategies and gender-sensitive support.

Category	Details from the Study
Author(s) & Year	Hamilton (2024)
Study Title / Topic	'Emotionally Based School Avoidance in the Aftermath of the Pandemic: Neurodiversity, Agency and Belonging in School' Association between mental health and school attendance in the post COVID-19 context is considered, drawing on research with autistic pupils in mainstream school settings in England as an illustrative example.
Research Question / Aim	To explore how the COVID-19 pandemic has influenced the prevalence, presentation, and support needs associated with emotionally based school avoidance (EBSA), particularly in relation to systemic responses and educational policy.
Methodology Type	Narrative Review
Design & Approach	Narrative review
Sample & Setting	Secondary data; literature-based; Uses policy documents, practitioner reports, and selected academic sources. No participant data.
Data Collection Methods	Literature review (search strategy, inclusion and exclusion criteria and databases searched not detailed)
Data Analysis Techniques	Not specified but in line with thematic reasoning and interpretive synthesis
Strengths of Methodology	Timely and contextually rich—addresses EBSA in the wake of COVID-19; Integrates practitioner insights with academic commentary; Clear structure and coherent argumentation; SANRA score suggests strong scientific reasoning and relevance
Limitations / Biases	No formal search strategy or inclusion criteria; Potential selection bias in source choice; Lack of methodological transparency; No participant voice
Ethical Considerations	N/A (secondary data)

Category	Details from the Study
Relevance to Your Topic	Relevant—contextualizes EBSA in current educational climate
Theoretical Framework	Not specified, but the framing appears to align with ecosystemic thinking (e.g., Bronfenbrenner)
Critique Summary	While it lacks methodological transparency and empirical grounding, its relevance and clarity make it a valuable contextual piece. Useful synthesis but lacks methodological transparency

Category	Details from the Study
Author(s) & Year	Hull, Petrides & Mandy (2020)
Study Title / Topic	'The Female Autism Phenotype and Camouflaging: A Narrative Review' Narrative review of female autism and camouflaging
Research Question / Aim	This review explores evidence for a female-typical autism presentation, the Female Autism Phenotype (FAP) and the component of camouflaging (compensating for and masking autistic characteristics) in particular.
Methodology Type	Narrative Review
Design & Approach	Not specifies but appears to be a thematic narrative synthesis
Sample & Setting	Secondary literature- Draws from empirical studies, theoretical papers, and clinical commentary - No participant data; instead, the review aggregates findings from prior research across disciplines
Data Collection Methods	Literature-based; search strategy not detailed
Data Analysis Techniques	Thematic synthesis
Strengths of Methodology	Strong referencing; sound scientific reasoning; Clarifies conceptual ambiguity around camouflaging; highlights gendered diagnostic disparities and methodological blind spots; integrates empirical and theoretical perspectives
Limitations / Biases	No search strategy and number of papers included not specified; aims not concretely stated; lack of critical engagement with intersectionality (e.g. race, class, culture)
Ethical Considerations	N/A

Category	Details from the Study
Relevance to Your Topic	Highly relevant—focus on gendered autism presentation
Theoretical Framework	Not specified
Critique Summary	Useful synthesis; moderate SANRA score (9/12)

Appendix 7- Historical Overview of Grounded Theory

GT was a new method of analysis when it was first developed in 1967 by Glaser and Strauss (Corbin & Strauss, 2015), and it led to a growing interest in qualitative approaches at a time when research was dominated by positivist, quantitative methods and philosophies (Charmaz, 2014). Aside from developing a theory from the data, which was only considered possible through quantitative approaches, GT is also unique in that the theory is generated from the data collected, not chosen prior to the start of the research, with data collection and analysis being carried out simultaneously in an ongoing cycle (Corbin & Strauss, 2015). This original version of the methodology required the researcher to 'abandon' their preconceptions (Oliver, 2012) and delay their literature review until after the data had been gathered and analysed, to prevent preconceived theories and ideas influencing the data collected. Whilst it was not developed with philosophical paradigms in mind (Corbin & Strauss, 2015), it combined the paradigms of positivism and pragmatism (Charmaz, 2014), in as much as concepts to be studied exist and can be observed, but that the world is a complex place with multiple and equally complex explanations for them (Corbin & Strauss, 2015), aligning with the CR perspective. The original principles of GT are linked with empiricism and include rigorous methods for coding, an emphasis on emergent concepts, and language similar to that found in quantitative methods (Charmaz, 2014).

GT has evolved in various forms since its inception, and Corbin & Strauss (2015) explain that Strauss continued to develop the GT approach after his work with Glaser, adopting slightly different ways of thinking about the data. They explain that Strauss's focus was on process rather than structures, and he believed that the meanings derived from social experiences depended on language, aligning more closely with pragmatist and interactionist philosophies (Corbin & Strauss, 2015; Charmaz, 2014). As a result of Strauss's view that the world is complex and that events result from multiple factors interacting, he recognised the importance of considering human experience from multiple perspectives and incorporating variation into the analysis, while positioning it within the current personal, social, and societal contexts (Corbin & Strauss, 2015). His approach became more flexible but still emphasised inductive and iterative processes (Charmaz, 2014). While Glaser regards GT as a method of discovery, Strauss added comparative methods to data analysis and viewed it as a means of verification (Charmaz, 2014).

Appendix 8- Recruitment flyer

The Tavistock and Portman NHS
NHS Foundation Trust

DOCTORAL RESEARCH OPPORTUNITY

Unidentified autism and school non-attendance in teenage girls.

EXPLORING AUTISTIC YOUNG PEOPLE'S VIEWS



I am exploring factors impacting school attendance for teenage girls who had undiagnosed autism. The study will look back to school non-attendance experiences before a diagnosis was received. If you are interested in being part of this study, please continue reading!



If you tick yes to all of the following, then you may be able to participate. You:

- Are female (assigned at birth), aged 16-25, and can think back to your time at school
- Had less than 90% attendance (e.g. missed at least one day a fortnight) for more than a term before receiving your diagnosis of autism
- These difficulties attending were not due to Covid-19 restrictions, illness or medical appointments
- Are able to talk about previous school experiences and engage online for about an hour



About me:
My name is Louise. I am a Trainee Educational Psychologist studying with the Tavistock and Portman NHS Trust. I have worked with people with autism for over 20 years and it is a passion of mine to work to improve outcomes for those currently under recognised within the current system.



How to find out more:
If you think you might like to take part in this study and want to learn more, please email me. I will send you additional information about the study and what it will entail. There is no pressure at any point to participate and you can withdraw at any time without giving a reason.
lbrackpool@tavi-port.nhs.uk

Appendix 9- Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria	Justification
Female (assigned at birth)	Male, Transgender	The study focuses on females because this is a group of CYP whose needs are overlooked. Restricting to 'gender assigned at birth' reduces the variables that could impact school experience and attendance.
Currently aged 16-25	Currently are 15 or younger, or older than 25	From 16 was chosen to give opportunities for more recent educational experiences. Up to 25 was chosen as the work of an EP can include YP up to 25.
School attendance of less than 90% for one term or more	School attendance did not fall below 90% during secondary school	This aligns with the Department for Education's (DfE) definition of persistent school absence and ensures consistency. The flyer and initial email quantifies this in everyday terms e.g. more than one day absent a fortnight, or 1-2 weeks per term.
Reduced attendance a result of emotionally based factors and anxiety relating to the school environment.	Reduced attendance a result of COVID-19 restrictions, illness, or medical needs (e.g. medical needs/illness that requires or directly causes absence from school such as undergoing treatment for cancer, operation, chronic illness e.g. asthma, epilepsy)	To focus on non-attendance resulting from EBSNA specifically.
Received their diagnosis of autism <u>after</u> their attendance reduced.	Either; they still do not have a diagnosis or their diagnosis was received before their attendance reduced.	This ensures that all participants have met the criteria for a diagnosis providing robustness to the study and to explore the impact of unidentified autism and associated

Inclusion Criteria	Exclusion Criteria	Justification
		unmet needs on school attendance.
Support in school (such as SEN support as outlined in the Code of Practice) not received until school attendance reduced	Were received SEN or other support in school prior to their reduced attendance.	To understand the impact of needs being unidentified on EBSNA risk factors.
If participant has additional mental health needs, they do not feel that this will be impacted by discussing possibly difficult previous experiences.	Participant has significant and current mental health needs and on discussion with participant it is felt that it would not be suitable for them to join the study at this time.	To protect the well-being of the participants, some of whom may have co-morbid conditions and still be too impacted to safely discuss their experiences in this context.
Participant identifies as having language skills that will enable them to participate in a to and fro conversation with the researcher and answer questions	Participant has difficulties communicating either in person or online at a conversational level	This is necessary for the interview method, however adaptations and supports will be in place to support understanding.
Able to participate online	Does not have the ability to participate online	Ensures all participants can join the study remotely and allows for national recruitment to increase uptake

Appendix 10- Ethics Approval Amendment

Notification of Amendment to Approved Ethics Application

To apply for an amendment to an existing study please complete the form, attach all appendices (track changes where appropriate) and send application including all appendices to academicquality@tavi-port.nhs.uk – ensuring that your supervisor is copied into the email.

1. Details of Researcher/Principal Investigator and Supervisor

Student name	Louise Brackpool
Doctoral Programme	M4 Professional Doctorate in Child, Educational and Community Psychology
Supervisor(s)	Kate Farmer

2. Details of Research Project

Project Title:	A grounded theory study exploring factors influencing emotionally based school non-attendance in adolescent girls prior to their autism diagnosis.
Original Date of Approval:	17/04/2025
Date Project Commenced (if applicable):	??

3. Details of Amendments

(*Please delete as appropriate)*

Does the amendment involve changes to information supplied in the original ethical application to TREC? (*If yes, please detail the changes in Section 4 below)*	**Yes**	**No**
	X	

Does the information involve changes to the consent form, information sheet or other supporting materials for the study? (*If yes, please ensure all amended materials are appended to this application)*	**Yes**		**No**
	X		
If your project has the approval/consent of external/commissioning organisations 'external organisations', please confirm that they have been consulted/consent to the changes	**Yes**	**No**	**NA**
			X

4. **Summary of Amendments -** Please state clearly and simply the proposed changes to your project (methods of data gathering, changes to design etc)

Please explain the reason for the change(s) and their implications for the study. *If the amendment substantially changes the research design, methodology, data gathering or may otherwise affect the value of the study, please indicate if additional and appropriate critique has been obtained.*
Addition to initial data gathered Addition of geographical location and how participant became aware of study *Rationale- to provide information for the researcher in order to ascertain the 'spread' of participants in terms of area of the UK and source which could lead to either strengths or limitations of the study. Specific participants will not be linked to their locations or where they heard about the study directly within the thesis. The researcher will just indicate either a broad or limited range of areas/sources.* Please see attached amended Microsoft form, added questions Q3 (location) and Q4 (source). **Change to exclusion criteria** • <u>Additional diagnoses (e.g., ADHD, learning difficulty) or current diagnosable mental health conditions (e.g., clinical depression, bipolar disorder):</u> Whilst it is acknowledged that some participants may have undiagnosed mental health conditions and additional diagnoses, where a diagnosis is known this is added as an exclusion criteria to reduce the possibility of triggering more significant mental health conditions and to *reduce* confounding variables.

This has proved to be too restrictive and I have received feedback from potential participants that this actually removes a high number of females with autism due to the co-existence of many additional mental health conditions. I think in part this is due to a difference in understanding of what constitutes a mental health condition and whilst I did give some examples to minimise this, feedback suggests this has still not been effective and may be limiting potential participants coming forward. One participant who is interested in participating but has an additional (but related) condition replied:

'You raise a good point, as I think you may struggle to find many other late-diagnosed autistic females who haven't picked up a few other diagnoses along the way, due to the trauma of being undiagnosed/not accommodated or due to misdiagnosis.'

Further feedback from a potential participant also says that she feels her eating disorder arose as a coping strategy as a result of her undiagnosed and unsupported autism and is very keen to participate.

'Yes I think I would be able to separate it out because I believe (and my parents believe) that my eating disorder was a coping mechanism because I found the school environment overwhelming and not eating made me feel numb/less sensitised to things.'

Experiences such as these are exactly the type of views I would like to capture and as such feel that in order to hear the voices, I need to slightly amend the criteria.

Amendment

- Some additional diagnoses (e.g., ADHD, learning difficulty) or current diagnosable mental health conditions (including personality disorders, bipolar disorder, clinical depression, psychosis): Whilst it is acknowledged that some participants may have undiagnosed mental health conditions and additional diagnoses, some more serious conditions are added as an exclusion criteria to reduce the possibility of triggering more significant mental health conditions and to *reduce* confounding variables. If potential participants are interested in participating but have additional conditions, they will be encouraged to email the researcher to discuss and at this point, ethical considerations will be made in conjunction with the young person.

Please see amended research flyer, additional email contact for those who declare a mental health condition, amended initial email to include a request for participant to let researcher know about additional mental health conditions and amended Microsoft form (Q2 amended, ones in bold).

5. Additional Information

Applicants may indicate any specific ethical issues relating to the proposed changes, on which the opinion of TREC is sought.
Wellbeing One of the primary reasons for the original inclusion of this was to mitigate for adverse impact on current mental wellbeing for the participants in discussing potentially traumatic experiences. However, based on feedback from others this is restricting my pool of participants and is also possible that excluding them from participation because they were 'too' impacted by their school experiences, could have a similar effect. If the participant raises a co-existing mental health condition, but expresses that they would like to take part, the researcher will explore suitability on a case by case basis. She will: Explain to them the reasons for this as a criteria and will ask them (see email 1 in attached document), if they are happy to answer, whether: • In their view, this condition arose from or is part of their autism, or is separate to their autism whilst also acknowledging this can be hard to unpick. • They believe that discussing potentially difficult school experiences would feel ok for them and not have a significant impact on their current wellbeing. If the answers are clear cut they will be sent email 2 in the attached document for them to review the participant information in order to make an informed decision and consent to the study. If the researcher is uncertain, she will discuss with her supervisor to make a joint decision. If it is felt that the risk could be too high, or they have one of the more serious mental health conditions, the Please see attached email. The research protocol remains in place and is unchanged (attached for information). The other approaches taken during the interviews and the support information is the same and remains unchanged.

6. List of enclosed documents

Document	*Date*
Amended research flyer (amended part in bold)	13/06/25
Amended Microsoft form (added questions identified above, amended part in bold)	13/06/25
Email responses for those with MH needs (new)	13/06/25
Amended initial email (amendments highlighted)	13/06/25

7. Declaration

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for the details herein.
- It is my belief that it would be practical for the proposed amendment to be implemented.
- I have discussed the changes with my supervisor(s) and I can confirm that they are in agreement with my changes and have approved my changes (please copy your supervisor into the email request)

Signature of Student: _____

*Print name: _Louise Brackpool*_____

*Date of submission:___20/06/2025*_____

Please return this form as directed by your supervisor or course lead to academicquality@tavi-port.nhs.uk

You **must** ensure any changes are also approved by the ethical approval body before you start work

Appendix 11- Additional Measures for those with Additional Mental Health Needs

- Participants were asked to disclose additional mental health needs to the researcher
- Participants asked to confirm on the Microsoft from that they did not believe participation would negatively affect their condition.
- A phone call was offered to discuss any concerns in more depth.
- Participants were encouraged to inform a trusted person of their involvement and to contact that person after the interview in case of any unforeseen emotional impact.

Appendix 12- Email for Participants with Additional Mental Health Needs

Dear XX,

Thank you for returning the consent form to me and completing the online form. I have completed the researcher part and am sending it back for your information.

I have scheduled you in **for XX at XX**. I'll send you a Teams invite shortly, but it will come from my University of Essex email account (copied in here) as the data generated from our meeting has to be stored on to that Onedrive account.

Thank you also for alerting me to your additional mental health needs. Because you feel confident that your wellbeing is unlikely to be significantly impacted by this study, and that you feel your conditions are either a part of or due to your autism, you would be able to participate in this study. To further support your wellbeing, should you choose to take part in this study, I would ask you to let a trusted person know when you are taking part, and check in with them afterwards, just in case it does impact you more than was anticipated.

I am really grateful to have the opportunity to speak with you and hope that by working together we can begin to make a difference for others who may find themselves in similar experiences.

If you have any other questions then please do let me know.

Thank you for your interest!

Kind regards,

Appendix 13- College Email

Dear Sir/Madame,

My name is Louise Brackpool, and I am a Trainee Educational Psychologist studying at the Tavistock and Portman NHS trust. I am starting to recruit for my thesis, which explores school non-attendance experiences for adolescent girls prior to receiving a diagnosis of autism.

In order to be eligible for participation in the study, they must be female, aged 16-25, have experienced emotionally based school non-attendance (EBSNA/EBSA), reducing attendance by at least 10%, for a term or more (i.e. one or more termly attendance rates of 90% or lower). Crucially, their autism diagnosis needs to have been received after their attendance reduced in order to explore any potential impact of unidentified needs on school experiences, and supportive factors for re-engagement. They would also need to be able to have a conversation/answer questions with me for around an hour online- visuals will be used to support this process.

I would be grateful if you could pass this on to the relevant department within your organisation (e.g. SEN/learning support team). If you believe you have any students who may fit the criteria and would be willing to take part, I'd be grateful if you could share the attached flyer with them which contains additional information about me, the study and the inclusion criteria.

Please do contact me if you would like any additional information or have any questions.

Kind regards,

Appendix 14- Introductory email to participants

Initial email to participants

Dear XX,

Thank you for your interest in this research study.

Important documents
I've attached two important documents for you to look at to help you decide whether you are eligible to and would like to take part:

1. A participant information sheet with detailed study information
2. A consent form

Support for Reviewing Documents
I know that these documents might look a bit complicated. You can:

- Ask someone you trust to go through them with you
- Contact me to arrange a time to talk them through

You are also welcome to bring a support person with you to your interview.

Who can participate in this study?

- *About you*
    - You're a girl (assigned female at birth)
    - You're between 16-25 years old
    - You can have a conversation and answer questions
    - You can join online sessions

- *About your attendance at school*
    - You missed more than 10% of school during at least one term (for example, missed roughly one day every two weeks or 1-2 weeks in a term)
    - Your attendance issues weren't because of COVID restrictions, a physical illness or attending appointments during the school day (e.g. going to the dentist)
    - If you had extra support at school, this didn’t start until after your attendance dropped

- *About your medical diagnoses*

- You got an autism diagnosis AFTER your school attendance difficulties started.
- You do not have other diagnoses like learning difficulties, personality disorders, bipolar disorder, clinical depression, or psychosis.
- If you have a mental health condition (e.g. eating disorder, anxiety), you feel that this would not be significantly impacted through talking about potentially difficult previous school experiences.

If you are unsure whether a medical condition/diagnoses may mean you are not eligible, please make contact if you would still like to participate having read the information. I will ask a couple of questions and decide with you whether it would be suitable for you to participate.

Next steps:
If you have read the attached documents and you're interested in taking part, please:

1. fill out the attached consent form and send it back to me,
2. complete the Microsoft form in the link below.

XXXXXXXXXXXXXX

I'll then email you to confirm your interview date and time.

If you have any other questions then please do let me know.

Thank you for your interest!

Kind regards,

Appendix 15- Participant information sheets standard

NHS
The Tavistock and Portman
NHS Foundation Trust

Tavistock and Portman Trust Research Ethics Committee
Participant Information Sheet

(Accessible version also available)

Contact Information:

- **Head of Academic Registry:** academicquality@tavi-port.nhs.uk
- **Researchers:**
  - Louise Brackpool (Trainee Educational Psychologist): LBrackpool@tavi-port.nhs.uk
  - Kate Farmer (Research Supervisor, Educational Psychologist): kfarmer@tavi-port.nhs.uk

---

Consent to Participate in a Research Study
The purpose of this letter is to provide you with the information that you need to consider when deciding whether to participate in this study.

Who is doing this research?

My name is Louise Brackpool and I am a Trainee Educational Psychologist. This piece of research is part of my course and will be supervised by Dr. Kate Farmer.

Study Overview

Title: Exploring School Attendance for Teenage Girls Before an Autism Diagnosis
Purpose: This study aims to understand the school experiences of teenage girls before they were diagnosed with autism. We want to know how not recognising autism early might have affected school attendance.

Why this study is important:

- To help educational professionals understand potential connections between unidentified autism and reduced school attendance.
- To highlight the importance of early recognition of needs consistent with autism and how it could be impacting school attendance.
- To improve recognition and school attendance.

What Participation Involves

1. **Pre-Interview Questionnaire:** A short questionnaire to complete before the interview plus consent form.
2. **Online Interview:** A semi-structured interview via Teams lasting between an hour and an hour and a half (60-90 minutes). Visual aids and chat functions can be used to support this as required. Please ensure you are in a private space where your answers cannot be overheard. You will also need to join on a laptop, PC or tablet in order to use some of the online tools.

Preparation:

- Optional pre-interview call to meet researcher and discuss the questions, format and visuals.

Topics:

- Your school experiences before your diagnosis of autism and factors affecting your attendance.

It is possible that discussing previous school experiences could cause some discomfort or anxiety. Participants will be signposted to organisations who can provide support and the researcher will be ensuring consent and checking on wellbeing during the interview and will end this early if distress does occur. You are welcome to have a familiar person join you for the interview. However, it is important that they do not support you to answer the questions to ensure the views are in your own words.

Additional Steps (Optional):

- A follow-up meeting to review your individual findings.
- A summary of the study's overall findings.

Participant Details

- **Number of Participants:** 6-10.
- **Selection:** Participants who meet the criteria described in the consent form will be selected for the research. In the event that more participants than this come forward, participants will be selected on a first come first serve basis and recruitment will close. However, potential participants may be contacted if a place becomes available, or if additional data is required.

Confidentiality and Data Protection

- **Confidentiality:** Once transcribed, your recording will be deleted, data will be anonymised 4 weeks after your interview. Only the researcher will know your identity. All data will be stored securely.
- **Data Use:** Data will be used in a thesis and anonymised. Small sample size means someone who knows you might recognise your comments.
- **Exceptions:** Confidentiality may be broken if there is a risk of harm to you or others.
- **Privacy Policy:** The trust's privacy policy can be accessed here: https://tavistockandportman.nhs.uk/your-information-and-privacy/privacy-policy/

Data Retention: Data will be kept according to the Trust's policies.

Participation

- **Voluntary:** You can withdraw at any time without any consequences and without giving any reason. You can do so by email, or by saying that you don't want to continue at any point during the interview.

- **Withdrawal:** You can withdraw your information up to 4 weeks after the interview. After this, your data will be anonymized and cannot be removed.

Support organisations

- Autistic girls network https://autisticgirlsnetwork.org/
- Samaritans https://www.samaritans.org
- Shout https://giveusashout.org/get-help/
- National Autistic Society https://www.autism.org.uk/contact-us/urgent-help and https://www.autism.org.uk/

Concerns and Complaints

Contact: Head of Academic Registry at academicquality@tavi-port.nhs.uk

---

Questions? Contact Louise Brackpool at LBrackpool@tavi-port.nhs.uk

Interested in Participating? Please read and complete the attached consent form and return to Louise at lbrackpool@tavi-port.nhs.uk

Thank you,

Louise Brackpool
Trainee Educational Psychologist
Tavistock and Portman NHS Trust

Appendix 16- Consent to participate standard

The Tavistock and Portman NHS
NHS Foundation Trust

Consent form for 18-25 Year olds

A retrospective grounded theory study exploring factors influencing school attendance for adolescent girls prior to their autism diagnosis.

Researcher: Louise Brackpool
Principal Researcher: Kate Farmer

Please tick ✓	Statement
	I understand that this research is part of the Child, Community and Educational Psychology Doctorate at the Tavistock and Portman NHS Trust.
	I have received and read the participant information leaflet, which contains a link to the Tavistock and Portman Privacy Policy.
	The research has been explained to me, and I have had the opportunity to discuss the details and ask questions about this information.
	I understand what I will be asked to do and this has been explained to me.
	I understand that my involvement in this study, and particular data from this research, will remain strictly confidential as far as possible, subject to legal limitations. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the research has been completed.
	I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without needing to give any reason.
	In the event of withdrawing my consent to participate, I understand that I can also request for any data to be withdrawn that has not been anonymised. I understand that once the data is processed (4 weeks after interview), my data becomes anonymised and cannot be withdrawn.
	I understand that the interview will be held via Teams, that this will be recorded, and the platform will be used to create text of the discussion (transcription).
	I understand that anonymised quotes from my interview may be used in the write up of the research.
	Whilst the quotes used will be anonymous and a range of quotes will be used, I understand that due to the small number of participants involved in the study, people who know me well may be able to identify my quotes if they read the research.
	I understand that these research findings will initially be published as a research thesis, and may at a later date, be published as a journal article. I also understand that a summary of findings will be sent to me if I wish to receive this and that a summary of main findings may be distributed on online forums.
	I understand that if the researcher has significant concerns for my own safety or that of anyone else, this will be discussed with me and actions to be taken will be agreed. In this instance, the researcher may also discuss this with her supervisor for support and guidance.
	I hereby fully consent to participate in the study which has been fully explained to me.

Please not that a more accessible version of this consent form is available if required.
Please tick the above and information below and return:

Participant information

Participant's Name (BLOCK CAPITALS) ……

Participant's Signature ……

Participant's phone number in the event of the distress protocol being initiated: ……

Date:……

Emergency contact in the event of safety and wellbeing concerns:

Name (BLOCK CAPITALS):……

Telephone number:……

This will be discussed with you during your interview if it is felt a necessary step to take.

Researcher's information

Researcher's Name (BLOCK CAPITALS) ……

Investigator's Signature ……

Date: ……

Appendix 17- Participant information sheet accessible

NHS
The Tavistock and Portman
NHS Foundation Trust

Tavistock and Portman Trust Research Ethics Committee
Accessible Participant Information Sheet

Research Study Information for Young People

Who We Are

- **Research Sponsor:** Tavistock and Portman NHS Trust

Project Title: Exploring School Attendance Experiences for Teenage Girls Prior to Autism Diagnosis

Researchers:



- Louise Brackpool (Trainee Educational Psychologist)
  - Email: LBrackpool@tavi-port.nhs.uk
- **Research Supervisor:**

Kate Farmer (Principal Investigator)
Affiliated with Tavistock and Portman NHS Trust

Research Ethics Approval

- This study has received formal approval from the Tavistock and Portman Trust Research Ethics Committee (TREC).

Study Details

- **What Will Involvement Require?**



- Short pre-interview questionnaire;
- Online interview lasting approximately 1 hour;
- The online interview will be recorded for later processing;
- Optional introductory call;
- Estimated total time commitment: 1.5 hours.

Potential Risks



- Discussing past school experiences might trigger emotional discomfort;
- Support resources will be provided;
- You can pause or stop the interview at any time.

Important Considerations



- **Small Sample Size Warning**
  - Only 6-10 participants will be involved;
  - Due to the small sample size, there's a slightly increased risk that someone who knows you well might recognize your experiences in the research thesis.

Voluntary Participation



- Your participation is completely voluntary.
- You can:
  - Withdraw at any time;
  - Stop the interview;
  - Withdraw your data up to 4 weeks after the interview.
- Withdrawal will not require explanation. You can withdraw by email or saying at any point in the interview that you do not wish to continue.

Confidentiality and Data Protection

Data Handling



- All data will be:
  - Stored on a password-protected computer;
  - Anonymized using initials or pseudonyms;
  - Retained according to Tavistock and Portman NHS Trust's Data Protection Policies;
  - Identifiable data (e.g. interview video) will be deleted once it is transcribed and anonymised (approx. 4 weeks);
  - The trust's privacy policy can be accessed here: https://tavistockandportman.nhs.uk/your-information-and-privacy/privacy-policy/

Limitations of Confidentiality

Important Exceptions:



- If there is evidence of imminent harm to yourself or others, we may need to:
  - Discuss support options with you;
  - Consult with research supervisor;
  - Ask you to seek appropriate support services;
- Confidentiality is subject to legal requirements.

After the Research



- Data will be erased after thesis publication.
- You can:
  - Choose to discuss your individual themes if you wish;
  - Choose to receive a summary of overall findings if you wish.

Questions and Concerns

If You Have Questions



- Research Team: LBrackpool@tavi-port.nhs.uk
- Academic Registry: academicquality@tavi-port.nhs.uk

If You Have Concerns

If you have any concerns about the research or researchers, please contact:



- Head of Academic Registry
- Email: academicquality@tavi-port.nhs.uk

Appendix 18- Participant consent form accessible

The Tavistock and Portman NHS
NHS Foundation Trust

Accessible participant consent form for 16-18 Year Olds

Project Title: Exploring School Attendance Experiences for Teenage Girls Prior to Autism Diagnosis

	Statement	Tick ✓
	I have read and understood the participant information sheet and have had the chance to ask questions.	
	I understand what will be involved if I take part in this research.	
	I understand that my participation in this research is voluntary and that I do not have to take part.	
	I understand that I can stop taking part at any time up until 4 weeks after the interview, and that I do not need to give a reason.	
	I understand that my involvement will be confidential, and that my name or other personal information will not be used or linked to the answers I give.	
	I understand and agree to my interview being recorded, and that any visuals I complete may be included in the write up of the thesis.	
	It has been explained to me how long my information will be saved for and what will happen to it after this time.	
	I understand that findings will be written up as part of a thesis, and that in the future, it could be published as a journal article.	
	I understand that as the research only includes 6-10 people, people which know me may be able to tell which answers are mine.	
	I understand information will be kept and stored safely.	

	I understand that if I tell the researcher something that concerns them about my own safety or anyone else's, they may have to let someone know. This will be discussed with me first.	

Participant information

Participant's Name (BLOCK CAPITALS) .....

Participant's Signature .....

Participant's phone number in the event of the distress protocol being initiated: .....

Date: .....

Emergency contact in the event of safety and wellbeing concerns:

Name (BLOCK CAPITALS): .....

Telephone number: .....

This will be discussed with you during your interview if it is felt a necessary step to take.

Researcher's information

Researcher's Name (BLOCK CAPITALS) .....

Investigator's Signature .....

Date: .....

Appendix 19- Microsoft form

School non-attendance experiences of teen-age girls with undiagnosed autism

25 Jul 2025

Please use this form to confirm you meet the criteria, select the dates you can be available to meet and confirm whether you would like to take advantage of the pre or post interview meetings/follow-ups.

* Required

1. What is your name? *

2. Please tick to confirm that you meet each of these criteria. Please contact researcher if you have any queries. *

- [ ] Female (assigned at birth) aged 16-25.
- [ ] School attendance less than 90% for one term or more, at some point during secondary school.
- [ ] Reduced attendance was not a result of COVID-19 restrictions (e.g. self-isolating), illness, medical needs or appointments.
- [ ] Diagnosis of autism received at any point after reduced school attendance.
- [ ] Reduced-attendance began prior to receiving a diagnosis of autism.
- [ ] Support not in place at school until attendance reduced.
- [ ] Can hold a conversation with others and answer questions.
- [ ] Able to participate online.
- [ ] I do not have any additional diagnoses such as learning difficulties, personality disorders, bipolar disorder, psychosis or clinical depression.
- [ ] I have an additional mental health condition not listed above

3. What area of the UK do you live in? *

- ◯ Scotland
- ◯ England (North)
- ◯ England (Midlands)
- ◯ England (South)
- ◯ Wales
- ◯ Northern Ireland

4. How did you hear about this study? *

- ◯ Social media (e.g. Facebook or X/Twitter)
- ◯ Support group
- ◯ School/college/university
- ◯ Other

5. How old were you when you began to experience difficulties attending school? This could mean still attending but struggling in the morning or evenings, or attending school but not attending lessons. *

6. How long did you experience reduced school attendance for (e.g. more than one day absent in any 2 week period, or 1.5 weeks in a term)? *

- ◯ 1 term
- ◯ 2-3 terms
- ◯ 1-2 years
- ◯ 2-3 years
- ◯ Other

7. How old were you when you received your diagnosis of autism? *

8. Did your parents or school suspect that you may be autistic at the time your school attendance difficulties began? *

- ◯ Yes
- ◯ No
- ◯ Don't know



9. Which of these dates and times are convenient for you to meet?

Please select more than one- I will then confirm which date/time. Nb. if no dates are convenient, please let me know as I may have other availability and can be flexible.

- [ ] Tuesday 5th August 10.30am
- [ ] Tuesday 5th August 1.30PM
- [ ] Tuesday 5th August 6pm
- [ ] Wednesday 6th August 10.30am
- [ ] Wednesday 6th August 1.30pm
- [ ] Thursday 7th August 10.30am
- [ ] Thursday 7th August 1.30pm

+ Add option Add "Other" option

Select total options: No limit

Multiple answers Required •••

10. Would you like any of the following?

- ◯ Pre interview meeting
- ◯ Post interview feedback to check my interpretation of your responses
- ◯ Findings summary sheet

11. Would you like a familiar person to join you when you have your interview? *

- ◯ Yes
- ◯ No
- ◯ Don't know yet

Appendix 20- Email confirmation

Hi XX,

Thank you for returning the consent form to me and completing the online form. I have completed the researcher part and am sending it back for your information.

I am really grateful to have the opportunity to speak with you and hope that by working together we can begin to make a difference for others who may find themselves in similar experiences.

I have scheduled you in **for XX at XX**. I'll send you a Teams invite shortly, but it will come from my University of Essex email account (copied in here) as the data generated from our meeting has to be stored on to that Onedrive account.

Just a reminder to make sure that you are in a confidential space for the meeting and also using a device with a screen big enough (laptop, PC or large tablet) as we will be using a Powerpoint to present the visual aspects of our discussion.

I'll drop you a couple of reminders in the lead up to it and look forward to meeting with you.

Kind regards,

Appendix 20- Reminder email

Dear XX,

Thank you for your previous email expressing interest in participating in this study.

I am emailing to ascertain if you are still interested in doing so. If you would like to participate, I would be grateful if you could return the consent form to me by XX.

I will not make contact with you again if I do not hear from you. I would like to thank you for your interest and wish you well for the future.

Kind regards,

Appendix 22- Appointment reminder email

Hi XX,

Just wanted to send a reminder for our meeting tomorrow at 3pm. The link is below.

Please make sure you are in a confidential space and that you are on a device with a reasonable sized screen (e.g. laptop/PC or large tablet) so that you can see a couple of the sorting activities that we will be doing.

I will start the meeting a bit earlier to get things set up and to sort out any potential issues. So if you get a notification to say I have started the meeting, please ignore this and just join at 3pm.

Please let me know if you have any issues joining. I'm looking forward to meeting with you.

Kind regards,

Appendix 23- Email responses to parents

Dear X,

I am so sorry to hear of your daughter's experiences and what must be incredibly tough for you and the rest of your family.

Unfortunately, the study is centred on gathering the views of the young people directly through interviews, and the age for involvement is 16-25. I'm sorry that your daughter wouldn't meet the inclusion criteria.

You may already be aware of them but, there are some organisations which can offer support either for your daughter or you, and also for guidance to navigate the education system.

Autism and mental health support organisations

- Autistic girls network https://autisticgirlsnetwork.org/
- Samaritans https://www.samaritans.org
- Shout https://giveusashout.org/get-help/
- National Autistic Society https://www.autism.org.uk/contact-us/urgent-help and https://www.autism.org.uk/

Education system/SEN support

- Your Local Authority SEND independent advice support service (SENDIASS- this is independent but every council has one)- search in google for: [your borough] SENDIASS
- SOSSEN is a national charity offering information, advice and support to parents and carers attempting to secure the right educational support for their children.

https://sossen.org.uk/about/

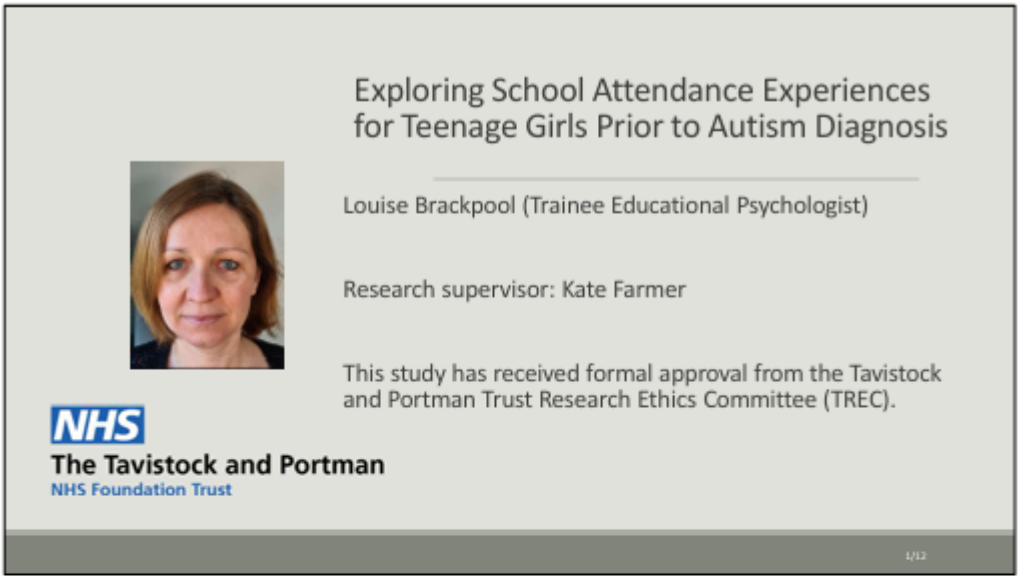
I hope these are of some help to you.

Kind regards,

Appendix 24- Additional procedures for Vulnerable Participants

- Written questions displayed on PowerPoint slides,
- Visual sorting activities,
- A familiar person could be present during the interview if needed; however, none chose to accept this offer.
- A pre-interview telephone conversation was offered to help prepare them for what to expect, with one participant requesting this,
- monitoring of participants' understanding throughout, for example, by noting requests for clarification, responses to slightly different questions, or signs of confusion,
- Visual reminders on each slide reminding participants that they could take a break or end the interview at any time,
- Periodic checking they were happy to continue or needed a break,
- One participant requested the interview take place across two sessions to reduce the duration of time in one go. This seemed to work well for them and did not appear to impact the flow of the interview,
- Consent and participant information sheets were presented visually, with accessible versions sent to those aged 16-18, or available as requested to take account of possible communication differences,
- Initial phone calls were offered to support informed consent,
- Participants were reminded of the consent information at the start of the interview and asked to repeat their understanding of the study and what would happen, ensuring the researcher was confident they were giving informed consent,
- Participants were given the opportunity to ask questions or clarification.
- During the interview, additional consent was obtained at various points; for example, when moving to the sorting activity, participants were asked if they were comfortable proceeding after a brief explanation of the activity.
- Participants were informed they could use the chat function to request breaks or end the interview if this was easier for them

Appendix 25- Interview PowerPoint and Script

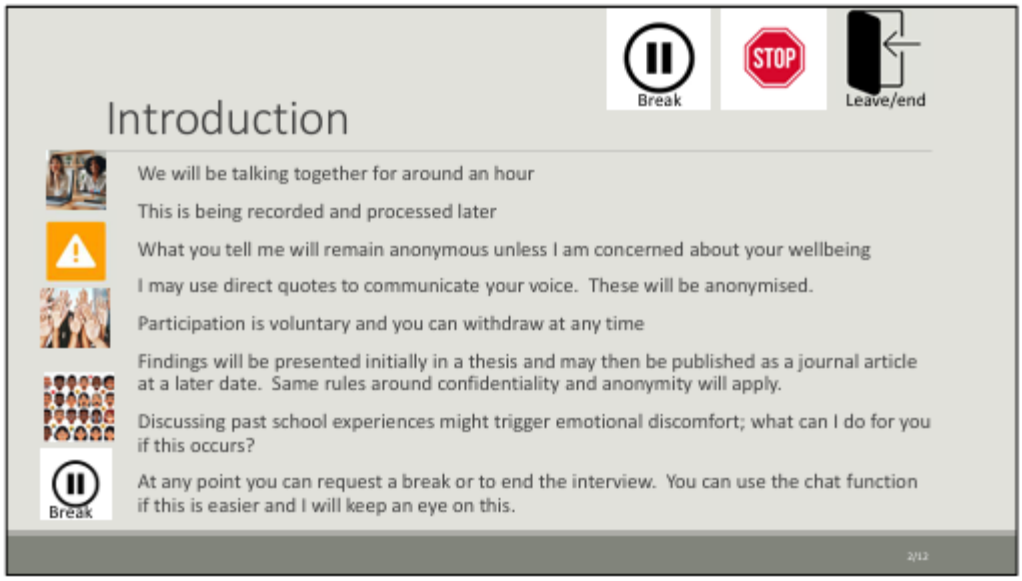


Hello, thank you for taking the time to speak with me about your experiences. To help us focus I have a Powerpoint with the questions and other visual to support the process so I'm going to share my screen if that's ok with you?

My name is Louise and I am a Trainee Educational Psychologist.

I am carrying out this research as part of this course which aims to understand the school experiences of teenage girls before they were diagnosed with autism. We want to find out whether not having autism recognised or supported early might have affected school attendance.

Before we get started, I have a few important things that I need to take you through first, most of which is information I've already sent you but this is just to check you've understood and are still happy to proceed. Is that ok?



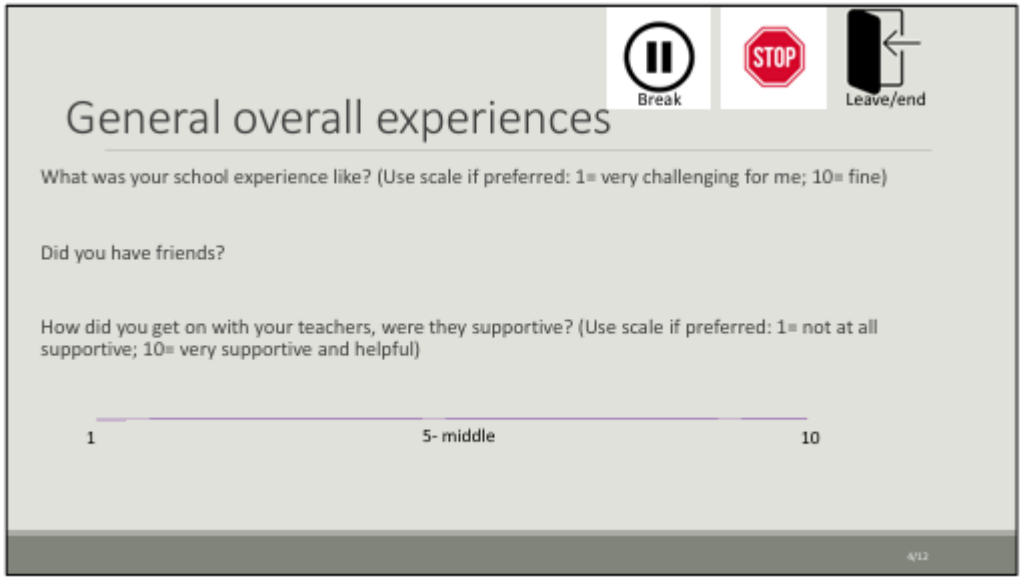
We'll be talking together for around an hour depending on how much information you share, but I won't let it go on for longer than an hour and quarter. The meeting will be recorded so that I can process the information later and not need to make notes. What you tell me will be anonymous and confidential unless I'm worried about your wellbeing. I will use pseudonyms in the write up, which will be a made up name as I feel this is more 2 'personal' and real than referring to you by a number or letter. Would you like to choose a made up name or would you prefer me to do that for you? I may use direct quotes to communicate your voice, but if I do these will be anonymised and your pseudonym will be used. Participation is voluntary and you can withdraw at any time. Some of the questions will be about experiences that you might have found difficult which could cause you some upset. So that I can support you in the best possible way, how would you like me to respond to you if this occurs (suggest a break, distract/talk about preferred activity), move on to the next question)? 2 And how I will know if you are upset- what will it look like to me? If you become very distressed, I will suggest that we end the interview and that you make contact with either your emergency contact or another familiar person for support. If I am very worried for your safety, I may discuss this with my supervisor for advice. You also have the organisations which I have already sent you and I'll send these to you again after the interview. At any point during the interview, you can take a break or change your mind and withdraw your consent. I will have reminders on each of the slides to remind you about this. You can either do this verbally, or use the chat function if that is easier. You could also answer questions in the chat if you prefer. Does that all sound ok and are you happy to continue? That's great, I'm now going to start recording.

RECORD RECORD RECORD

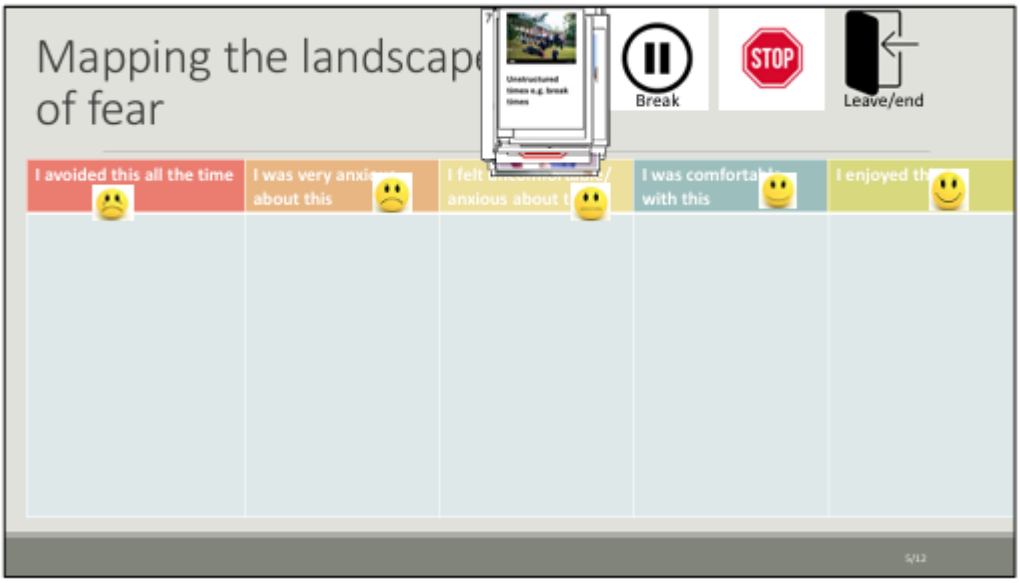


Before we get started, I'd like to just check that you've understood what will happen, could you explain to me what you understand will happen during the interview? Do you have any questions?

It might be that you don't know or can't remember the answers to some of these questions. It is fine for you to say you don't know or can't remember and you don't have to answer any question you don't feel comfortable with. You can give as much or as little information as you would like to, however if I feel that we are going off topic a little I might move us on so that we can capture as much as possible. Please also ask me to repeat or reword anything that you haven't understood. Are you happy to start?



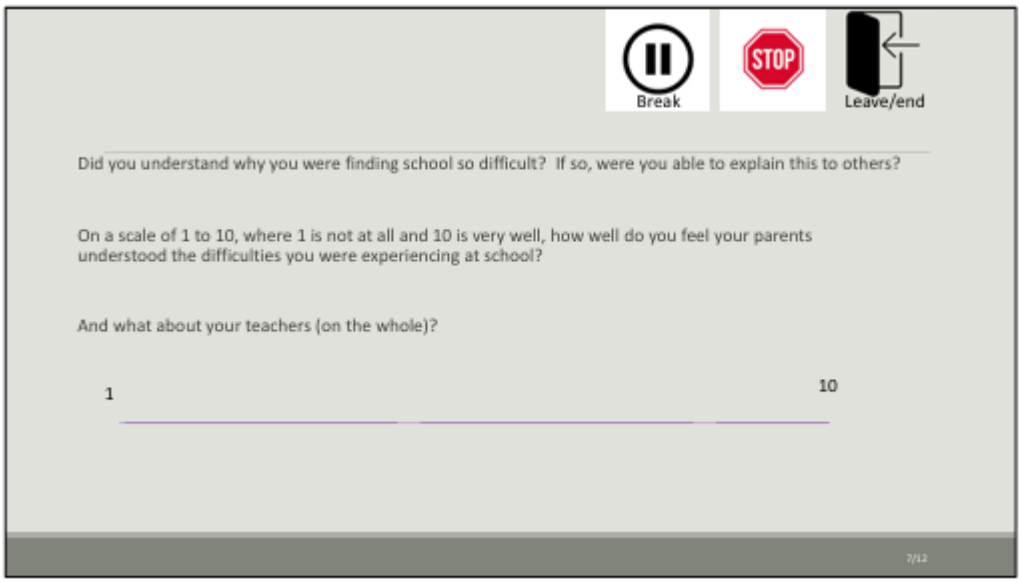
This is just a general overview, we will go into specifics later. Overall, 10 What was your school experience like? (use scale if preferred). Are there differences between different times at school e.g. primary versus secondary, or year 9 versus year 11? 4/12 What year group (roughly) would you say it changed in? Did you have friends at school? How did you get on with teachers generally? 4 Thank you for sharing those experiences with me. It sounds like… (reflect back understanding).



We're next going to do a sorting activity based on a couple of tools, one's called 'Mapping the Landscape of Fear' and the other is 'School wellbeing cards' to explore some of your school experiences in more detail to see what aspects may have contributed to you being overwhelmed and not attending. The cards are written in the present tense so you'll just need to think back to when you were at school. I'll read them out in the right tense to make it easier. Is that ok? The column you place them in is less important than any discussion we have around them, for example many of your answers might be 'it 5 depends' and then we talk about that a little. I need to switch my sharing screen for this as I can't do it on Powerpoint unfortunately. Hopefully it works smoothly!



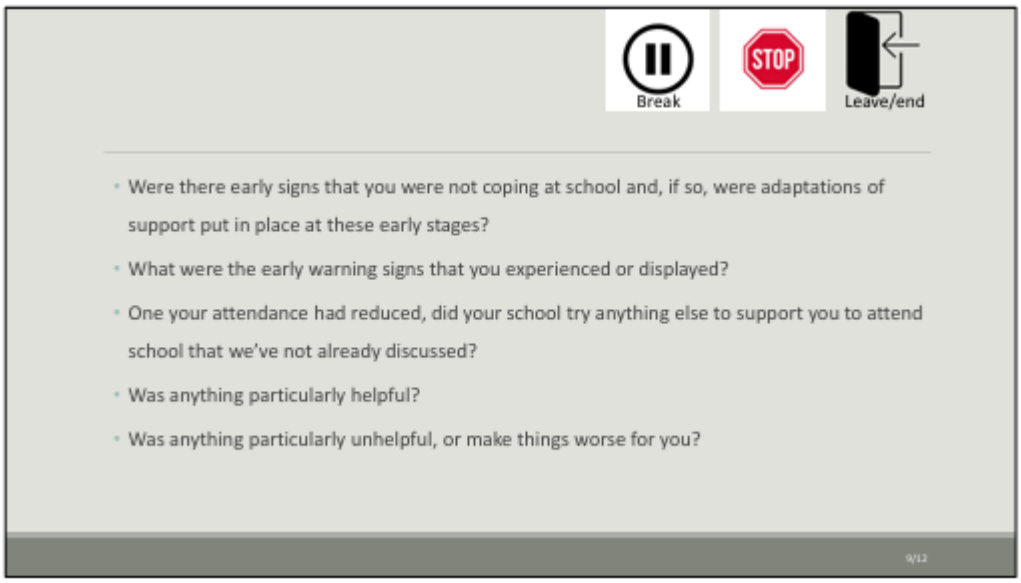
Thank you for sharing those with me. I really appreciate it and understand it might be tricky to think back. We'll have another sorting activity to do in a minute.



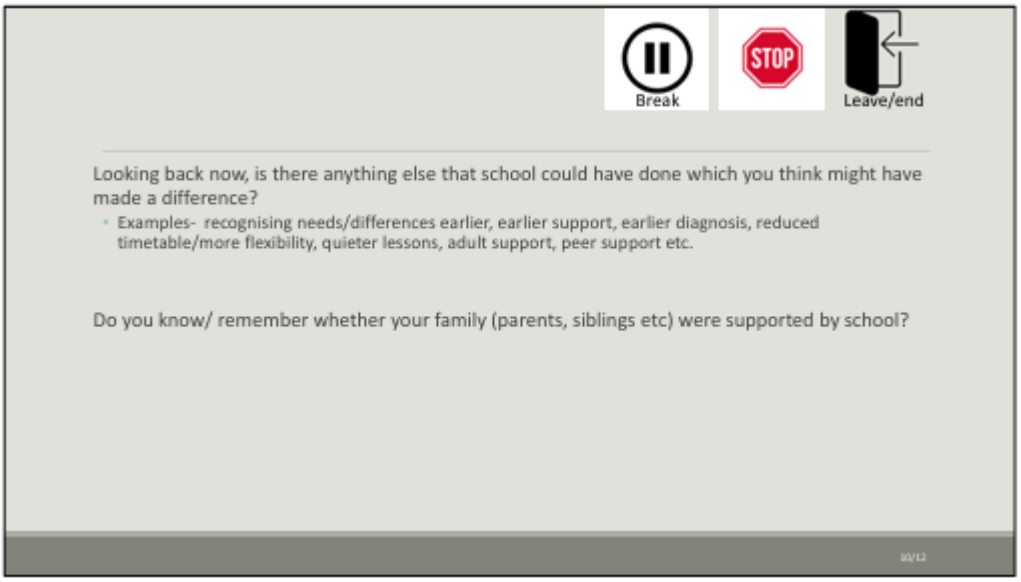
But for a moment I'd like us to think about whether you felt understood by others. On a scale of 1 to 10, where 1 is not at all and 10 is very well, how do you feel your parents understood the difficulties you were experiencing at school? And what about your teachers?



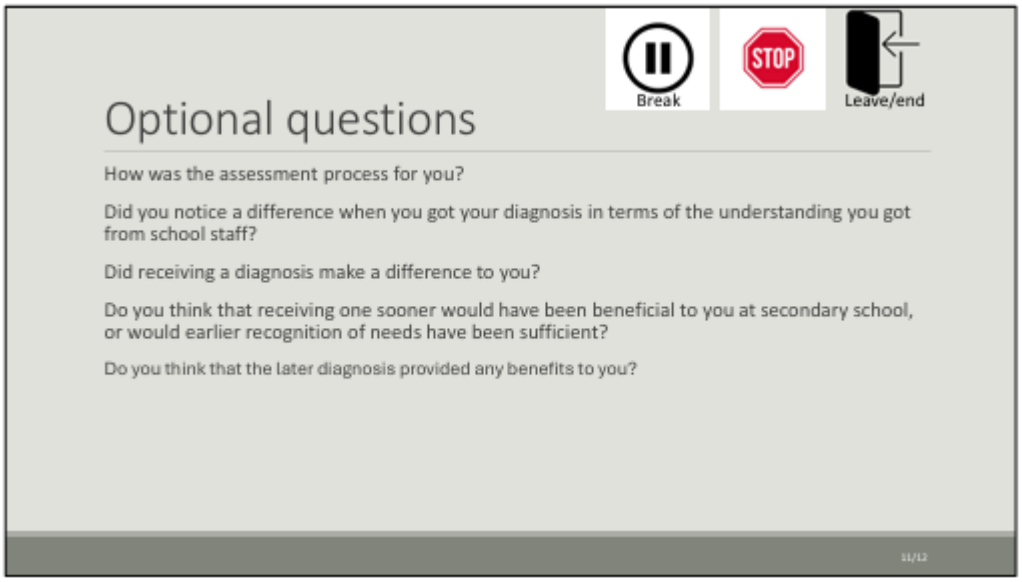
That's great thank you. We're going to have a look at another set of cards. Could you use them to let me know what you experienced that you felt supported you to attend school when you did (either before the reduction or if you were able to go back? I'll read them out again so that the tenses are correct.



Thank you for sharing those things with me. It's helpful to know what aspects supported you when you did attend. I'd like to just talk a little about your pattern of non attendance. When we think about EBSNA we think about it on a continuum with first signs happening long before attendance reduces, for example distress at home but fine once at school, does this relate to your experience? Can you recall roughly how long between you started 9 to find attending school challenging (e.g. exhausted or emotional at home) and your attendance reducing? Do you recall what year you were in when your attendance started to reduce?



Looking back now, is there anything else that school could have done which you think might have made a difference? If required- E.g. recognising needs/differences earlier, earlier support, earlier diagnosis, reduced timetable, quieter lessons, adult support, peer support etc. Do you know/ remember whether your family (parents, siblings etc) felt supported by school? If you are feeling ok about answering five more questions, I would like to ask you about your experience of your assessment and diagnosis. These are optional and if you have reached your limit on what you can manage it is fine for us to finish 10 there. Would you like to answer a few more questions or would you like to stop there?





We have reached the end of the interview. Thank you so much for answering all of the questions. Is there anything that you wanted to share that we haven't covered about school or the impact it had for you?

- How did you find it?
- Was there anything I could have done differently that would have made it better or easier for you? It's important to know this for future interviews.
- Next steps I will send you a follow up email tomorrow to say thank you and to remind you of the support organisations available. I'll then process your 'data' which will involve me identifying some key themes

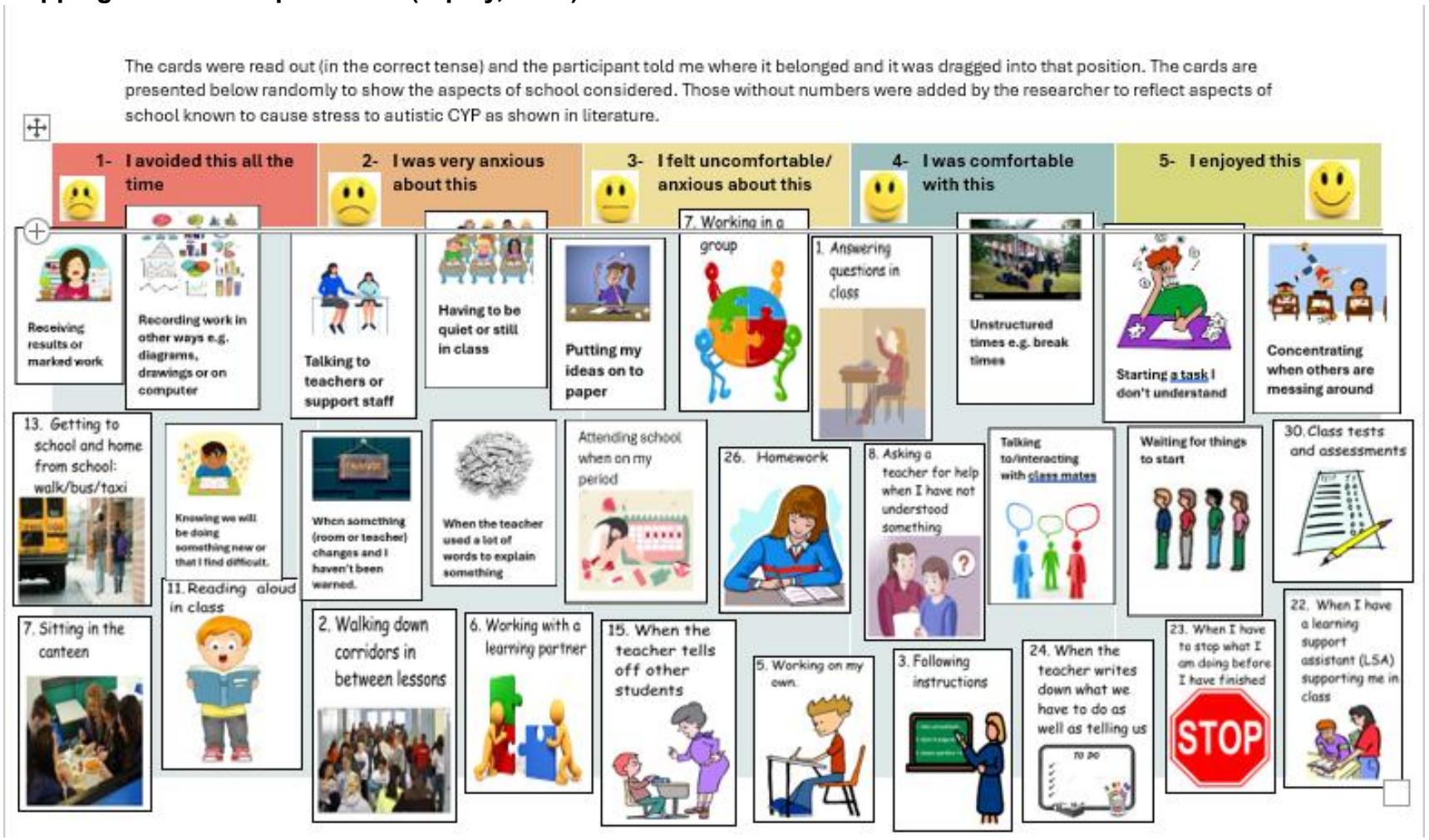
[If selected: I'll also email you with a summary of the findings when I complete the thesis- this will include the overall findings from all of the participants; is this still something you would like? I'm not sure when this will be yet but will likely be a few months]

[If selected: I see you selected that you'd like a follow up meeting. I'm not sure how long it will be, probably mid-end August. Is it ok if I drop you an email once I've analysed your information?]

or [I see you didn't select a feedback meeting which is fine. This was to feedback my interpretation of your views and experiences and check they were accurate. If you change your mind just let me know and we can schedule something in.]

Appendix 26- Card sorting tools

Mapping the Landscape of Fear (Ripley, 2015)



School Wellbeing Cards (Holder, 2025)- Risk Factors



Protective Factors

Protective factors- what did you experience or feel just before or during your school non-attendance? If/when you did re-integrate to a school, did you then experience/feel any of those you didn't before?

Just like me	A little like me	Not like me
		
		
		
		
		

Appendix 27- Card sort tool responses

Mapping Landscape of Fear work domain

	Answering questions in class	Following instructions.	Working on my own.	Working with a learning partner.	Asking a teacher for help when I have not understood something.	Reading aloud in class.	Recording work in other ways e.g. pictures, diagrams or on the computer.	When I have to stop what I am doing before I have finished	When the teacher writes down what we have to do as well as telling us	Homework.	Class tests and assessments	Concentrating when others are messing around	Starting a task I don't understand	Working in a group.	Putting my ideas on to paper	Receiving result or marked work	Knowing we will be doing something new or that I find difficult	When the teacher uses a lot of words to explain something	Attending school when on my period	Having to be quiet or still in class	When the teacher tells off other students	When something changes and I have not been warned	Total
Lina	2	5	4	3	3	3	4	3	5	2	1	3.5	1	3	4	3.5	3	3	3	4	3	4	70
Sam	3	4	5	4	5	4	3	4	5	4	4	1	4	1	5	4	4	3	5	4	5	4	85
Becca	3	5	5	3	3.5	2.5	5	3	5	4	4	4	3	2	5	4	1.5	4	4	5	2.5	3	81
Esmee	1.5	5	5	3	1	1	5	4	5	3	2	2	3	2	4	3	3	4	2	5	2	2	67.5
Emma	2	2	3	3	2	2	4	3	4	1	2	3	1.5	3	2	2	2	3	1.5	3	1.5	1	51.5
Total	11.5	21	22	16	14.5	12.5	21	17	24	14	13	13.5	12.5	11	20	16.5	13.5	17	15.5	21	14	14	355

Mapping Landscape of Fear social domain

	Unstructured time e.g. break	Talking to/interacting with classmates	Talking to teachers or support staff	Following instructions	Sitting in the canteen	Getting to and home from school	Walking down corridors between lessons	Waiting for things to start	Total
Lina	5	3	3	5	3	3	4	4	30
Sam	2	3	5	4	3	5	4	4	30
Becca	3	2.5	2.5		2	1.5	2.5	4	18
Esmee	1	2	3.5	5	1	1	2	4	19.5
Emma	2	2.5	2	2	1	2	3	3	17.5
Total	13	13	16	16	10	12.5	15.5	19	115

School Wellbeing cards risk factors (Nb. Emma was not presented this task due to time and anxiety the activities appeared to cause her.

	I often feel confused about what others mean	I often worry I won't understand the work or be good enough	I avoid or worry about specific lessons	I hide myself/my difficulties from others	I avoid or worry about specific teachers	I would rather be at home than at school	I find the school environment overwhelming (e.g. noise, crowds)	I worry about the school work	I am feeling pressure to attend school	I worry about coming in to school	They don't believe me	I feel worried at school	I worry that something bad will happen	I feel unwell when I think about school	I find it difficult to leave my house	Sometimes I feel like I don't belong	I feel worried at home	I worry about being away from my parent or carers	My parents or carers need me to be at home	The other kids are mean to me	I worry about break times	I don't have many friends	Total
Lina	3	3	3	3	3	3	3	3	3	3	3	3	3	3	2	2	2	1	1	1	1	1	53
Sam	2	3	3	3	1	2	3	3	2	3	3	3	2	3	1	3	3	1	1	3	2	1	51
Becca	2	2	3	3	3	2	3	1	3	3	2	3	3	3	1	3	3	1	1	2	2	2	51
Esmee	2	3	2	3	2	3	3	2	2	3	3	3	3	3	2	3	2	3	1	2	3	3	56
Emma																							0
Total	9	11	11	12	9	10	12	9	10	12	11	12	11	12	6	11	10	6	4	8	8	7	211

3 Just like me

2 A little like me

1 Not like me

Higher score= greater risk

School Wellbeing cards protective factors

	The teachers care about me	There is at least one adult I can talk to at school	There are people to help me	I felt a sense of belonging at school	My parents/carers are supportive of my education	I feel included at school	I can make a difference to my life	I feel safe in school	I have lots of friends	I enjoy learning and new topics	I want to attend school	I can show my true feelings at school	I have one special friend	I know what I want to do when I leave school	I have been able to do some home learning	Total
Lina	3	3	3	3	3	3	3	3	3	2	2	2	2	1	1	37
Sam	3	3	3	1	3	1	3	3	3	3	3	2	3	3	3	40
Becca	2.5	1	1	1	3	2	1	1	1	3	2	1	2	2	3	26.5
Esmee	2	2	1	1	3	1	2	1	1	3	2	1	1	2	3	26
Emma	2	3	2	1	3	1	2	2	1	2	1	2	2	1	1	26
Total	12.5	12	10	7	15	8	11	10	9	13	10	8	10	9	11	155.5

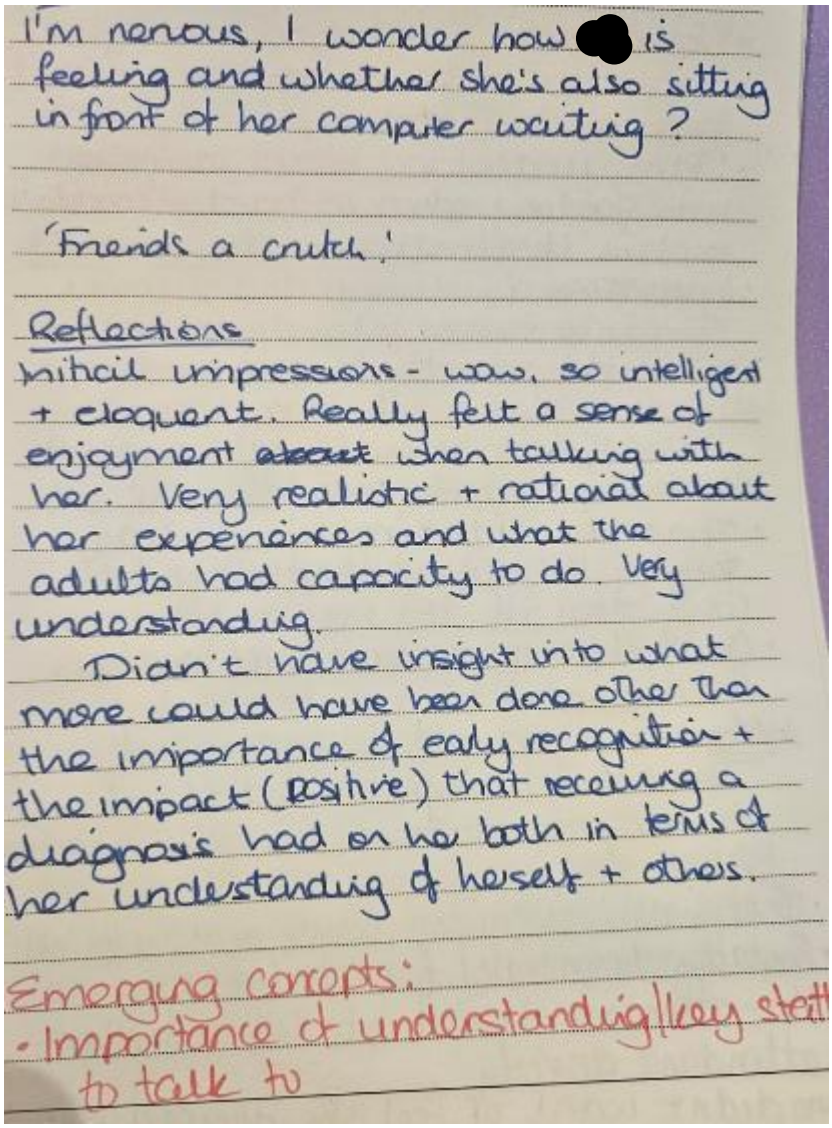
Higher score= greater protective factors involved when they were able to attend school/education

3 Just like me

2 A little like me

1 Not like me

Appendix 28- Reflective Diary Examples



I'm nervous, I wonder how [redacted] is feeling and whether she's also sitting in front of her computer waiting?

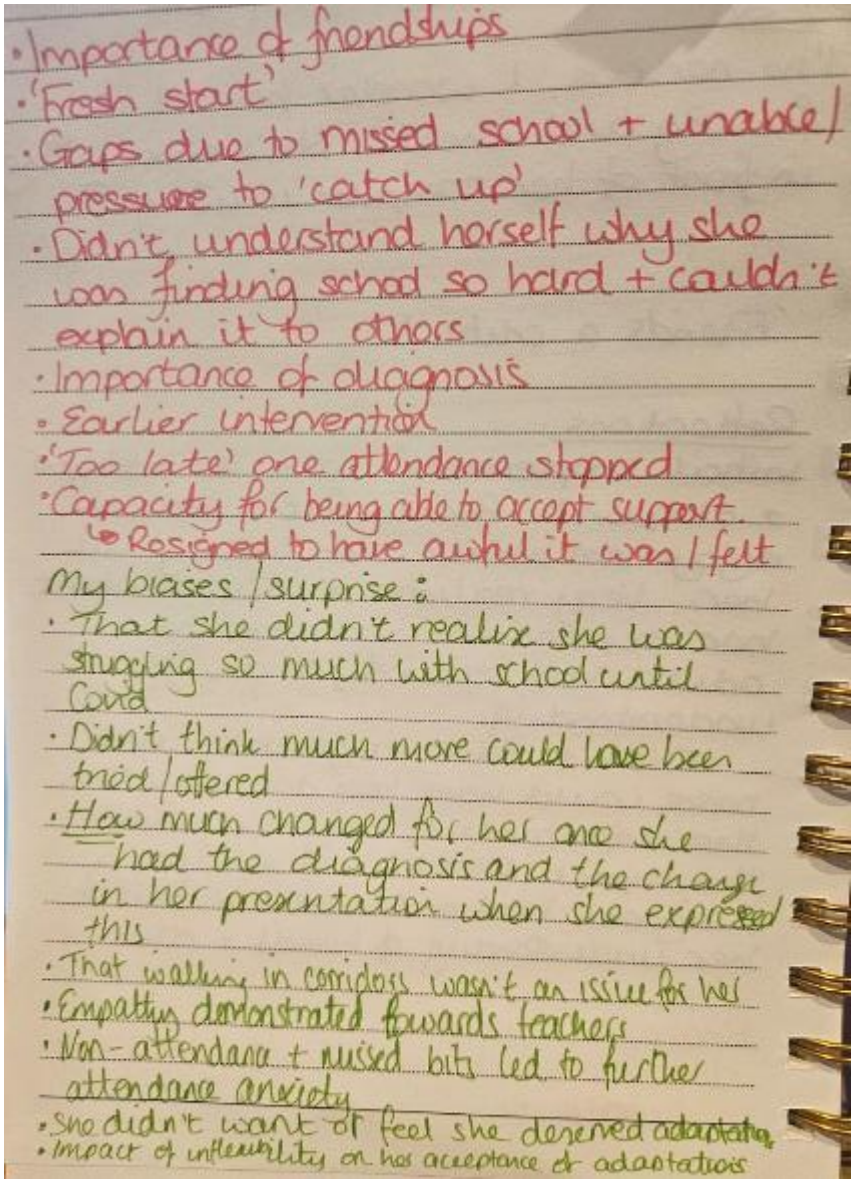
'Friends a crutch'

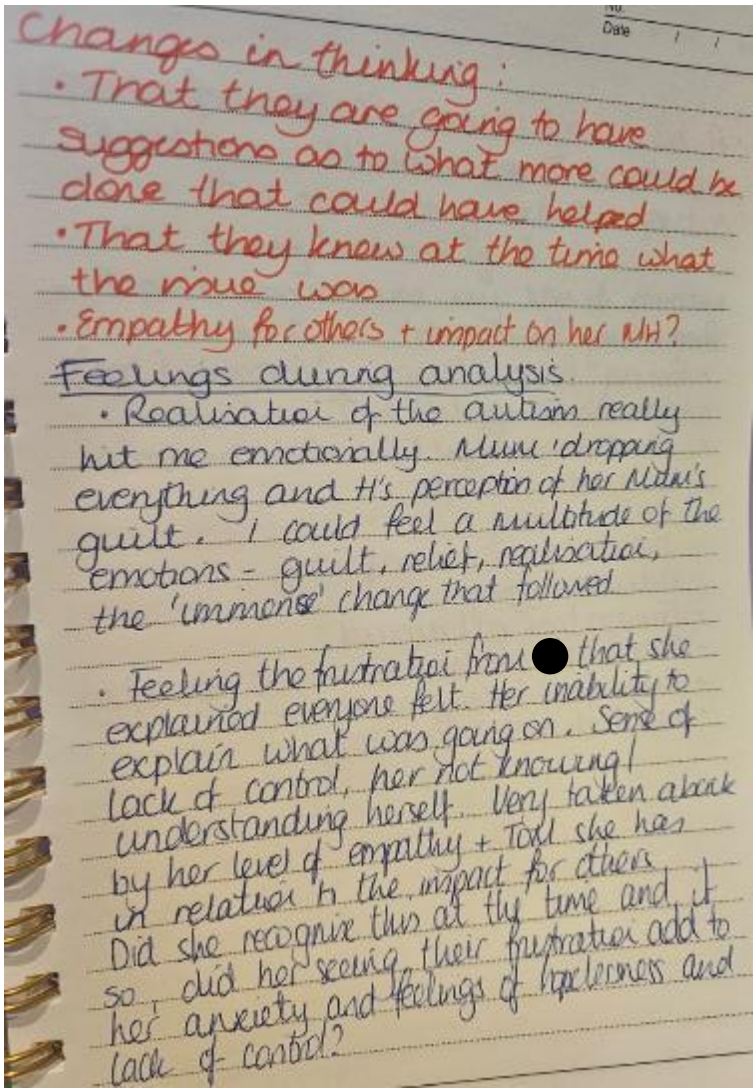
Reflections

Initial impressions - wow, so intelligent + eloquent. Really felt a sense of enjoyment ~~about~~ when talking with her. Very realistic + rational about her experiences and what the adults had capacity to do. Very understanding.

Didn't have insight into what more could have been done other than the importance of early recognition + the impact (positive) that receiving a diagnosis had on her both in terms of her understanding of herself + others.

Emerging concepts:
- Importance of understanding/key staff to talk to

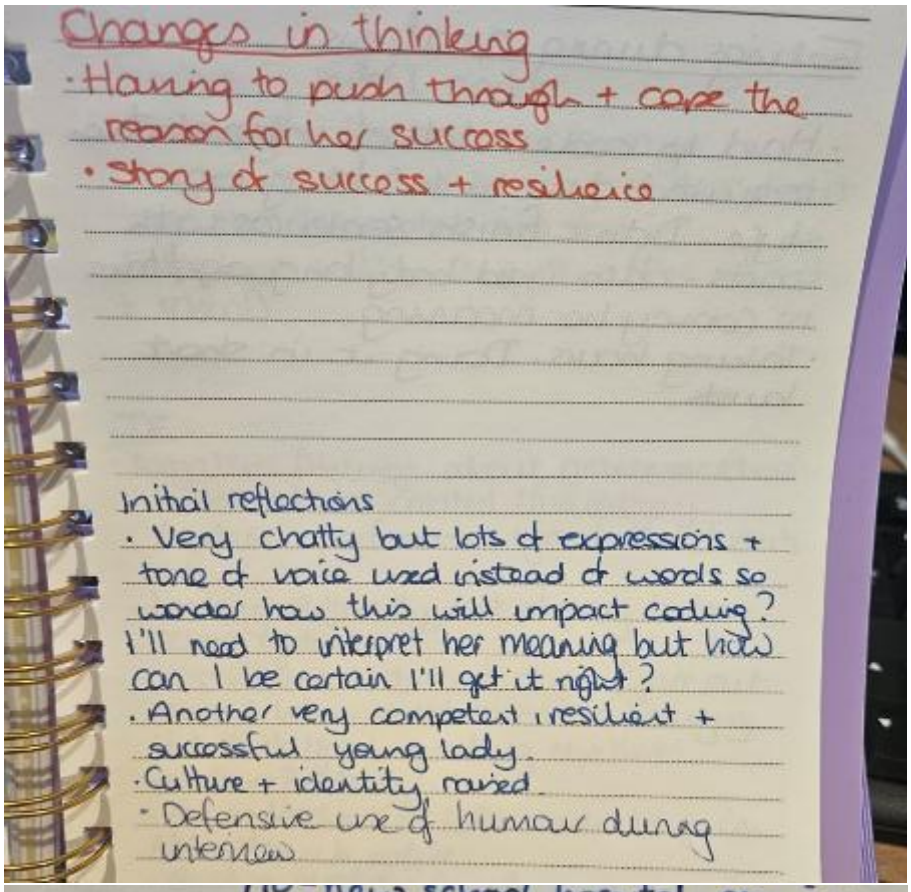

• Importance of friendships
• 'Fresh start'
• Gaps due to missed school + unable/ pressure to 'catch up'
• Didn't understand herself why she was finding school so hard + couldn't explain it to others
• Importance of diagnosis
• Earlier intervention
• 'Too late' once attendance stopped
• Capacity for being able to accept support.
↳ Resigned to have known it was / felt
My biases / surprise:
• That she didn't realise she was struggling so much with school until Covid
• Didn't think much more could have been tried / offered
• How much changed for her once she had the diagnosis and the change in her presentation when she expressed this
• That walking in corridors wasn't an issue for her
• Empathy demonstrated towards teachers
• Non-attendance + missed bits led to further attendance anxiety
• She didn't want or feel she deserved adaptations
• Impact of inflexibility on her acceptance of adaptations



Changes in thinking:
- That they are going to have suggestions as to what more could be done that could have helped
- That they knew at the time what the issue was
- Empathy for others + impact on her MH?

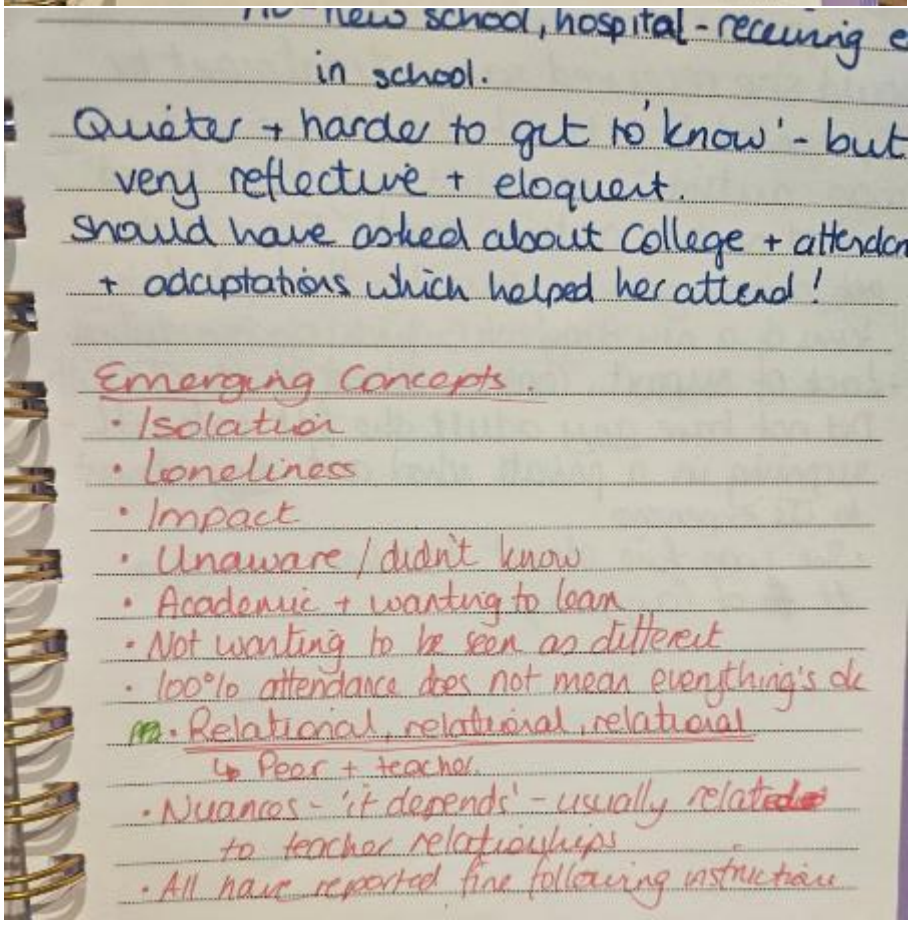
Feelings during analysis.
- Realisation of the autism really hit me emotionally. Mum 'dropping everything and H's perception of her Mum's guilt. I could feel a multitude of the emotions - guilt, relief, realisation, the 'immense' change that followed.

- Feeling the frustration from [redacted] that she explained everyone felt. Her inability to explain what was going on. Sense of lack of control, her not knowing/understanding herself. Very taken aback by her level of empathy + Told she has in relation to the impact for others. Did she recognise this at the time and if so, did her seeing their frustration add to her anxiety and feelings of hopelessness and lack of control?



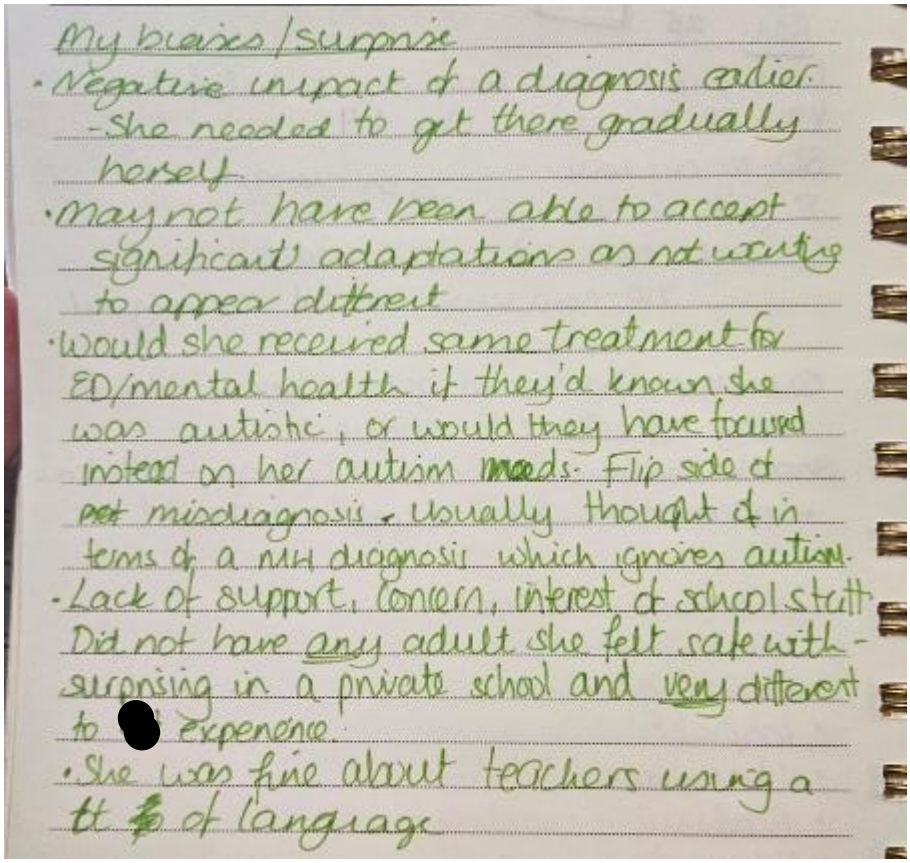
Changes in thinking
- Having to push through + cope the reason for her success
- Story of success + resilience

Initial reflections
- Very chatty but lots of expressions + tone of voice used instead of words so wonder how this will impact coding? I'll need to interpret her meaning but how can I be certain I'll get it right?
- Another very competent, resilient + successful young lady.
- Culture + identity raised.
- Defensive use of humour during interview



new school, hospital - receiving e
in school.
Quieter + harder to get to 'know' - but very reflective + eloquent.
Should have asked about College + attendan + adaptations which helped her attend!

Emerging Concepts.
- Isolation
- Loneliness
- Impact
- Unaware / didn't know
- Academic + wanting to learn
- Not wanting to be seen as different
- 100% attendance does not mean everything's ok
- Relational, relational, relational
  - Peer + teacher
- Nuances - 'it depends' - usually related to teacher relationships
- All have reported fine following instruction



My biases / surprise

- Negative impact of a diagnosis earlier. - She needed to get there gradually herself.
- May not have been able to accept significant adaptations as not wanting to appear different
- Would she received same treatment for ED/mental health if they'd known she was autistic, or would they have focused instead on her autism needs. Flip side of ~~not~~ misdiagnosis - usually thought of in terms of a MH diagnosis which ignores autism.
- Lack of support, concern, interest of school staff. Did not have any adult she felt safe with - surprising in a private school and very different to [redacted] experience.
- She was fine about teachers using a tt % of language

Appendix 29- Added interview questions

Combined (to keep number of additional/optional questions to a minimum):

Was your assessment process quite quick or did it take a long time?

How did the assessment process feel to you? We can scale it if this is easier.

To:

How was the assessment process for you?

Amended to capture diagnosis versus recognition of needs

Do you think that receiving one sooner would have been beneficial to you at secondary school?

To:

Do you think that receiving one sooner would have been beneficial to you at secondary school, or would earlier recognition of needs have been sufficient?

Added in response to 2nd interview

Do you think there were any benefits to you in terms of receiving your diagnosis later?

Added in response to all participants so far not understanding their own difficulties:

Did you understand why you were finding school so difficult? If so, were you able to explain this to others?

Amended in response to all three participants highlighting the importance of early intervention and recognising the first signs of anxiety.

Scale removed and question simplified.

Added:

Were there early signs that you were not coping at school and, if so, were adaptations of support put in place at these early stages?

What were the early warning signs that you experienced or displayed?

Appendix 30- Examples of initial codes and memos

Initial code	Line/quote	Memo
Mental health crisis, shut down and feelings of paralysis	My life was a lot less anxiety, like anxiety inducing when I wasn't in school and I sort of continued that mindset when I went back.	Non-attendance to reduce anxiety
Reliance on friends or catching up with friends	And I found them a lot more difficult and a lot less enjoyable when I didn't have the sort of support of someone I was close with sitting next to me	Reliance on friends
Missed knowledge	but then obviously even even starting in a year, you build upon knowledge from the last year	Realisation of false hope and that missed too much work. Primary barrier for attendance resuming
Concern about perception or judgement from others	I didn't really like drawing attention to myself.	Not drawing attention to herself
Lack of support, nurture and approachability	When I wasn't going at all, she came in pretty much ordered me to get up out of bed and come to school, and I was I completely shut down in that moment.	Push factor (away from school). Helpfulness of this when difficulties are so significant
Feeling forced, and the use of threats and consequences	Yeah, just generally.	Someone else said about the teachers shouting in general was an issue even if not directed towards them- check this- possibly N
Teacher's shouting/raising voice		
Avoidance of specific lessons or events	And...I know that often when I first started to not attend, it would be the days that I had lessons that I didn't like the thing that we were doing.	Early warning signs of anxiety and non-attendance
Key adult	[do you think that if you'd had like a key person or an adult at school that you were really you	

Initial code	Line/quote	Memo
Earlier recognition, diagnosis and support	were, you felt safe with that, that might have helped at all?] Yeah, maybe because I felt quite disconnected when when it was, you know, when I was going through the worst of it. [for you, the drastic change was the EOTAS package?] Yeah. Yeah. And even then, that wasn't perfect because I had also started from a point of being anxious and depressed. If it had been from the get go, with my perception being that it wasn't a strange thing to be doing. Like, if that was the norm…it probably would've been very different.	

Appendix 31- Examples of Line by Line Coding

Across participants

Time stamp	Initial code	Line	Memo
1:32	Good social life Good grades Nice teachers	"I had a good social life in school. Everything was going really well. I had nice grades, nice teachers"	School was good
3:18	Giving up on success	about 3 total days of year 11 prior to my GCSE and then I went to the 7 GCSEs that I sat.	GCSEs
4:50	Reliance on friends or catching up with friends	even if it wasn't like someone I was friends with outside of classes. It had to sort of be someone I was civil with and could actually talk to and ask questions without feeling stupid in the middle of a lesson.	Impact of support from peers
01:08:34	Stigma, stereotype and journey to accepting possibility of autism	Yeah, it's quite interesting to reflect on my diagnosis actually, because I hadn't really thought about like because I always say like, oh, you know, why didn't anyone notice sooner? But actually, when I actually think about it...the context is quite important because I wonder how that would have affected me if I had had that diagnosis when I didn't really understand autism .	Importance of educating students so that they understand and are accepting if it is suggested for them
01:04:03	Journey of acceptance Resentment Frustration, anxiety and distress	So I'm not sure how that really would have gone down if I had got the diagnosis then, but...I think....you know, it would have made things a hell of a lot easier if I had known	Acceptance at an earlier stage? That she didn't have needs recognised earlier

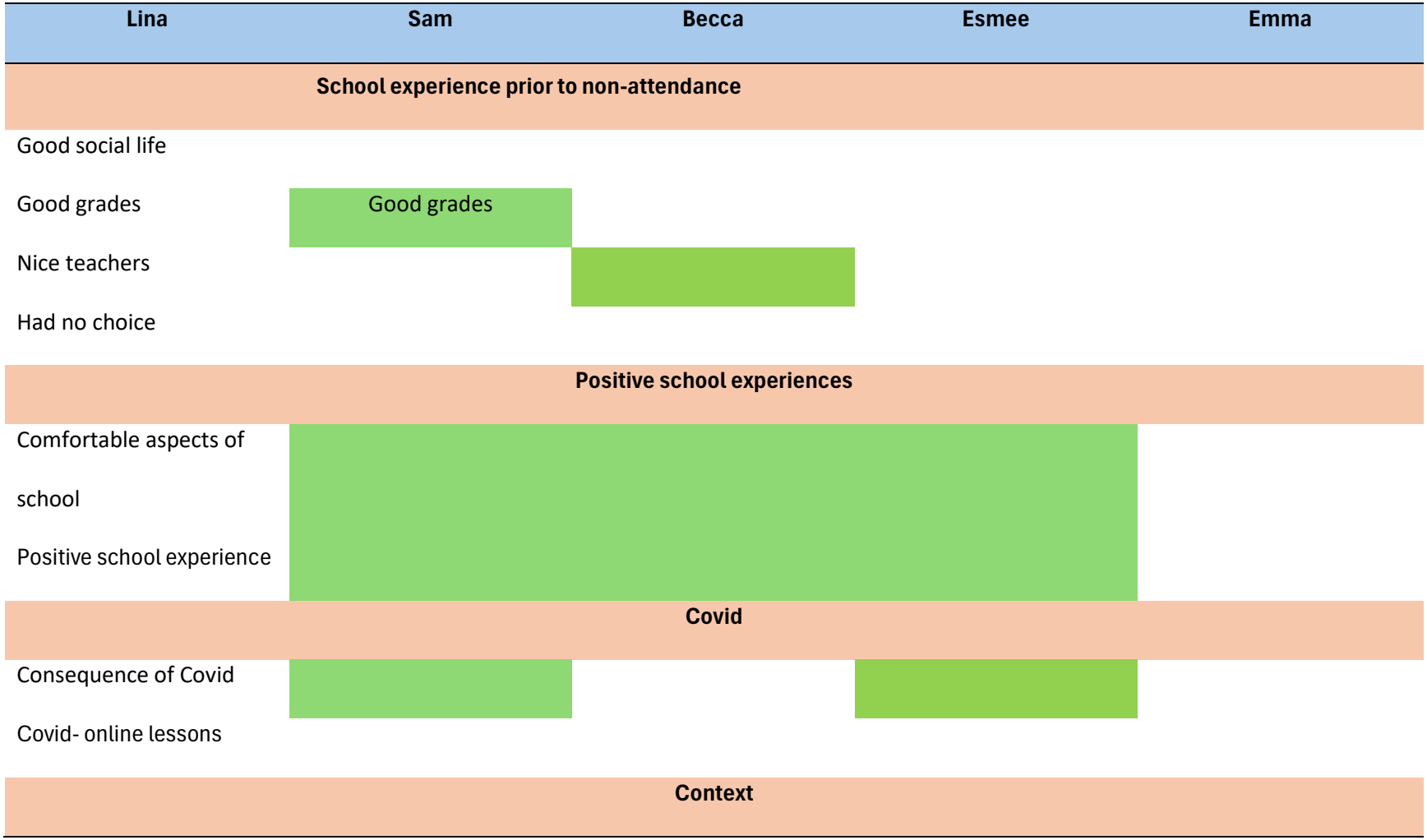
Time stamp	Initial code	Line	Memo
01:02:37	School experience causing trauma	But now that I've got the awareness, I am autistic, I think...that has also caused some trauma, I think, particularly in my school experience...Erm...I think...Yeah, I'd say that probably contributed.	
55:11:00	Frustration, anxiety and distress Resentment	Because now looking back knowing that I am autistic, it seems blaringly obvious, especially to like, you know, teachers who are supposed to kind of have a bit of awareness of these things, but again, times have changed, but...erm	It was obvious and it should had been noticed
53:30:00	Teachers should have recognised needs Lack of support, nurture and approachability from school adults	[was there anything they tried that made things worse?] Erm, no, I don't think they really did anything. I don't know, maybe they did, but I can't remember. But I don't can't remember anything.	
20:58	School experience causing trauma	And one day that I had because I went to a few because I wanted to see what they were like. I had to wear school, my old school uniform. And on that day I found it very, very difficult but I don't know if that's 'cause I associated the school uniform with those types of feelings, and those experiences perhaps.	
24:26:00	Exam arrangements	I...I think I've got arranged to do it at home a few times, so I still did the assessment but just didn't do it in school.	

Time stamp	Initial code	Line	Memo
25:51:00	Developing coping strategies, resilience and facing challenges	So I guess if I didn't have the option to do it at home then that would have caused me more anxiety, but I'd say I was comfortable with that.	Developed own coping strategies to manage with school based stress.
26:09:00	Things that helped in class	[teacher wrote down what they what you had to do as well as telling you] Oh, that would be really good. So that would be a 5.	Importance of strategies to support this
13:47	Autism traits making school confusing and stressful	[starting a task you hadn't understood] I I really struggled. I I open-ended tasks where I didn't know what was like wanted from me was a really really difficult.	
13:47	It depends Autism traits making school confusing and stressful	So definitely like it's it depends what year you go, but definitely on in between 1 and 2	Source of high anxiety and potential avoidance
16:53	Developing coping strategies, resilience and facing challenges	[you were putting in place your own structure] Yeah Exactly like, like, I knew that certain queues for certain bits of the cafeteria would get really bad. So if I didn't, if we were let out late by even a few minutes, I would think, actually, I'm not going to go eat lunch now. Either I wouldn't eat lunch or I would go really late when the like food options were less because then the really giant queues would be died down. Or I'd plan ahead of like, OK, I know I'm going to this class where they let where this teacher's really bad at letting us out on time. So I'll buy lunch at break.	Overwhelm of having to plan and think ahead to that detail

Time stamp	Initial code	Line	Memo
	Developing coping strategies, resilience and facing challenges	Or it got to the point where I was like I I hate the cafeteria so much. I'm going to bring a pack lunch, but I don't like having loads of extra bags, so I need to make sure the pack lunch is in a small enough container that I can fit it in my bag, but it isn't loads of mess, but it isn't doesn't have loads of wrappers in it because I don't like having then have extra wrappers I need to go and take to the bin because it's also just again, it's leaving the group and then and then and then if things like... Sort of even now I'm realising that I didn't realise I did the extent of planning.	Overwhelm of having to plan and think ahead to that detail
18:27	Own distress not realised or understood Lack of support, nurture and approachability from school adults Own distress not realised or understood	Like the main issues was the teachers so talking to them and stuff would be difficult, and especially when things got more and more difficult, I just gave up talking to teachers completely because it was like I I don't know how to do this I because you're not being constructive and I'm having to do all the heavy lifting on being mature when I'm not actually mature and I don't know how to be mature about this yet because I'm not even aware of all the issues I've got so.	X made a similar comment about being the one that had to do the work/make the effort
25:32:00	Own distress not realised or understood		

Appendix 32- Examples of initial codes split into early focused codes

Green fill means code also appeared for that participant



Lina	Sam	Becca	Esmee	Emma
Attendance pattern				
New school				
		School context- change to		
		education context		Education context
Adaptations offered- refused, unsuccessful or taken up				
Reduced number of			Reduced number of	
subjects in school	Well supported	Key adult	subjects in school	Exit card
				Sitting at the back or near
	Quiet space	phased return	Quiet space	the door
Part time timetable		home for lunchtime	Part time timetable	Part time timetable
			Exam arrangements	
			TA support	
			Parents taking her to	
			school	
			Flexi-schooling/EOTAS	

Lina	Sam	Becca	Esmee	Emma
			Extra 1:1 sessions with teacher she had good relationship with Support at break and lunch times Effective support from TA	

Appendix 33- Early focused codes, initial codes and data selection

Code	Memo	Lina	Sam	Becca	Esmee	Emma	Focus code Memo	N (/5)of P code appears for
							Didn't ask N or J specifically about early warning signs. N + A both describe gradual increase in these	5
			Early Signs of developing anxiety and school non-attendance					
Avoidance of specific lessons or events	Skips particular lessons (e.g. drama or PE), teachers, days of tests/assessments she felt unprepared for, canteen,	I was very anxious about it [tests and assessments in class], but I'd probably even put it in one because a lot of the time, even before I'd stopped, you know, before I'd sort of burn out and stop completely attending, I would skip days where I had tests I felt unprepared for'	I did. Yeah. That's just like me [avoiding specific lessons].	And...I know that often when I first started to not attend, it would be the days that I had lessons that I didn't like the thing that we were doing. So like if it was a day that had drama or PE, then I was probably more likely to not attend.' 'Yes, definitely. [avoid or worry about specific teachers]'	A little	when I didn't attend lessons because I couldn't predominantly, I think in my head at the time was linked to the the the lesson and the teacher.' '[if something changed, like a different room or a new teacher, but you haven't been warned] To begin with, it would just be really like would be uncomfortable and anxious. And then as things built up and built up and I got more aware that I wasn't OK, really anxious to the just a point where if something changed in the lesson and all like a suddenly a teacher changed something I'd leave, I I just. I'd walk out so progressively worse and worse, but definitely was a big source of anxiety that I didn't realise.'		4
Emotional consequences at home	Taking it out on parents, cry for hours after school, emotional meltdowns		and...I think I took a lot out of my parents to be honest, '		I'd often come home from school and just cry for hours. Yeah, at primary.' 'Erm, I think yeah, I just, I'd come home and be very upset or very distressed and a few times, literally I'd walk out the school gate holding it in and then just burst into tears'	But then it became that like the pressure and everything, and I I definitely would express to my Mum, I'm like, I don't want to go and I'd have really emotional like, like sort of meltdowns but not even realising there were meltdowns. I'm not going to school and my mum would just be like and my parents, I think sort of just thought, well, she's just started school like it's a big change from primary to		3
Increased absence	Attending but avoiding lessons, lower attendance compared to peers, missing days sporadically, reported as illness, refusing	my attendance was never, like, brilliant. It was usually in, like the 85 range. And then I stopped to get or maybe like 80 range. And then I stopped going, and it felt like 30 and then zero.'	then 10% I'd be forced by I forced myself to go in and I would like not attend.'	So year nine, actually, I think I got it wrong. It was, yeah, it was year nine when I started missing like a couple of days here and there.'	But in primary school, I would often have quite like I guess more days off than the average pupil but I didn't have long periods of not not attending, but often it would be if I had a day off it would be like I have a headache. ' 'Yeah. So I guess in primary school there was absence, but I think it was			4
Early physiological symptoms	Headaches, stomachaches, feeling sick, feeling of not being able to walk/get out of car, 'frozen in place', sleep difficulties, nightmares, irritability			I remember in, that's another one in primary school where I went through a phase where I felt sick at every lunchtime and I remember telling the teachers that and being like, oh, I can't go to lunch because I feel really sick and them just being like, 'oh, it seems to be that this only happens at lunchtime', like sort of accusing me of...I don't really. '	But looking back now, I don't really think it was a headache.' [what were the early warning signs that you weren't coping at school, do you think?] I mean, I've always. I always struggle with my sleep anyway, but sleep got much worse. I'd wake up a lot in the night with bad dreams or I don't really know what it was, but I think anxiety is like waking up with quite a lot of anxiety. 'I'd say physically the feeling of going to school like some days mum would drive me to school and my legs, I just literally, I	But I just was like, frozen in place by fear and anxiety of like, I don't want to go in.'		3
Leaving	Class, site, run off at drop off,		There were times, but before I had this card, I would just disappear. Like I would just, like, leave the classroom.'; And like there were maybe like two or three times they had to send out search parties for me.'		And there was times like Mum would drop me off at school and then I'd run off the school playground because I didn't want to go to school' 'and then kind of those days, they either tried to get me in the school or Mum would just take me home. '	in secondary school it got just that I just hated it so much, then felt so anxious about being there. It overruled the anxiety of, like leaving, and I was like, no, I'm leaving now because I I hate this so much'		3

	Disconnected from own emotional experience (awareness of own needs)						5
Own distress not realised or understood	Didn't realise, didn't know why, didn't understand, just built up and hit her	Because I couldn't. I didn't really know. '; ' I just didn't know I was struggling. '	I just didn't know why '; 'But like, because I didn't know, I just needed a quiet space. '	[breaktimes or other unstructured times] Erm, I don't know. It's hard to say because...obviously at the time I didn't know what anxiety was particularly'; 'I didn't really know what it was that I was feeling, so there wasn't really anything to not believe, if that makes sense, yeah.'	But I would say I don't think I really understood why I was finding school so difficult.' 'And they [school] say oh, but she didn't say that. Then it would be kind of because I didn't verbalise it, then things wouldn't get sorted out '	and there were definitely times before then that was like I'm not, I'm not realising it yet, but I'm not OK with going to school and I am struggling.'; 'In the sense that I it was incredibly like I sometimes when I think in year seven, I probably before I got diagnosed and stuff before I sort of thought about autism being a potentiality or anxiety and just didn't like it was probably more I was very anxious but didn't realise I was very anxious...But then built, built and built and built until don't do it anymore, yeah.'	5
Couldn't communicate difficulties	Because she didn't understand them herself or know why	I didn't even understand them myself, so when they would then ask me why I'm struggling, I wouldn't be able to give them an answer'; 'No one understood why I wasn't there. I couldn't tell them. They didn't know.'		No, not at all. I I mean they used to try and ask me like, what is it about school that you don't like and like what is it? Why are you feeling anxious like what is wrong? And I just like, oh, I don't know. Just can't go like it was'; 'But it was I think I used my eating disorder as a way to communicate that actually it wasn't OK. '	It was that I was finding things challenging and didn't really know how to communicate that.';	Yeah, because I I didn't. I couldn't explain it to myself, so it was more like I can explain, or at least even if I did try and explain it, I would always be worried, like, well, they don't like explaining in a way for other people to understand. Was also really difficult';	4
	Autism traits making school unpredictable, confusing and overwhelming (collapsed to 'barriers to attendance')						
Struggled with friendships and social situations **changed to friendship breakdowns and social pain**	Interacting + Friendships with classmates, anxiety working in groups or pairs + preference for working alone,						
Ambiguity and unpredictability	Understanding of language, the task, expectations, changing of rules between contexts, rules and norms, unexected changes						
Found it overwhelming	Environment a source of anxiety- distracted by others, noise, people, space, unstructured times						
Canteen was just noisy and busy	Source of high anxiety and avoidance- Noise, busyness, people staring/judging, social expectations/demands, crowds/lack of space, smells/food, cleanliness						
All or nothing, no grey area	Cognitive inflexibility- Stopping tasks before finished, sense of justice, piece of work not anticipated, rules, language used by teachers,						
I did a very good job of hiding it	copying others, hiding feelings at school, conforming- **changed to Achievement, diligence + presentation masking extreme struggles in barriers to attendance**						
Mum ended up driving me	Travel to and from school factor in not attending, made the day so much longer, one more thing she couldn't manage on top of school all day			Did do but due to location			

Appendix 34- Final focused codes, initial codes and quotes

Code	Lina	Sam	Becca	Esmee	Emma	Focus code Memo	N (/5)of P code appears for
	Cumulative stressors and overwhelm in the school environment and system						
Feeling forced, the use of threats, and consequences	They tried with therapy with the kind of threat that they'd fine my parents otherwise, because I can't just not be in school for no reason'; 'and then they tried to put me in therapy'; 'When I wasn't going at all, she [head of year] came and pretty much ordered me to get up out of bed and come to school, and I was I completely shut down in that moment.'	[Did you worry about the school work?] I think, yeah, I definitely did. I think yeah, because actually like, I wanted to do well for my parents.'; 'I definitely had pressure [to attend] from my parents. Yeah. '	Well, there was sort of never a doubt in my mind that I had to go to school, but I knew. Obviously it's the law'; 'Like, you know, kind of wanted to just not have that pressure on me again.'; 'So for me to not attend, it felt like a bit of a like...me being ungrateful or something, not that they said that, but that's how I felt.'	have felt more anxious about what people would think if I didn't respond.' ; I'd say it was all on me...I think I started to use quite a lot of emails because that was an easier way to like if I'd come out of class and I was upset about something, I'd e-mail about it rather than wait till the end of class and talk to someone at the end.'; 'I'd say probably from school, yes. So I guess a little bit [where pressure to attend com from].'	To begin with, no [did parents understand your difficulties?] to begin with like like my mum would sort of like yell at me to like you've got to. You've got to get up and.'; 'Like I don't think there was because how how do you fix just the innate pressure of schools. Like teachers are always going to have to be judged based on something. The easiest thing to judge is people's results.'		5
Occurrence in transcript	**10**	**2**	**7**	**5**	**3**		**27**
Just built up	I had a lot of school related anxiety that had just built up. And when COVID hit, I sort of realised that actually.'; 'Yes, but I only realised that once I, erm. Once COVID hit and I realised how much less stressed I was not being in school'; 'I think that experience just really tipped me over the edge because I realised I was so much happier'			but then I got very anxious and school got overwhelming again.'	In the sense that I it was incredibly like I sometimes when I think in year seven, I probably before I got diagnosed and stuff before I sort of thought about autism being a potentiality or anxiety and just didn't like it was probably more I was very anxious but didn't realise I was very anxious...But then built, built and built and built until don't do it anymore, yeah.' But then it became that like the pressure and everything, and I I definitely would express to my Mum, I'm like, I don't want to go and I'd have really emotional like, like sort of meltdowns but not even realising there were meltdowns. I'm not going to school and my mum would just be like and my parents, I think sort of just thought, well, she's just started school like it's a big change from primary to secondary school....So this is just normal, when it wasn't.		3
Occurrence in transcript	**4**			**2**	**3**		**9**
Autism traits making school confusing and stressful	I got really quite confused when it wasn't written. I'd always be turning to the person next to me and asking what they said, even if I was paying like full attention'; 'I would also put that in three on the same basis [working with a partner], so if it was someone I wasn't that close or comfortable with, I would struggle with it.'; 'It [canteen] was really packed really loud. the benches were extremely close together to the point where I'm like, wow, I really should not be that hard, like, I shouldn't have to climb over 16 people to get to the end of the bench There was no space to walk down the like the aisle was between benches. A lot of the time, the food would really distress me, tables weren't cleaned like after every person that ate in them, which is completely understandable, especially considering how many like people there. It wasn't reasonable to do that. It stressed me out.	and I would be like Guys, I don't think that's correct because obviously with with autism it's very like right and wrong...there's no grey area ; I think that's actually a main reason for why I didn't go [others messing around in class], especially during like year 10, year 11; 'it's just because it's over stimulating, isn't it? When there's lots, it depends' ; 'I hate that [working as part of a group]. I hate that I would put that like like, yeah, like, avoided all the time yeah, to be honest.'	I'd get quite upset if I didn't understand something, so probably 3 I'd say.'; 'Erm, I'd say I was anxious about that [unprepared for changes], but probably not. Well, I don't know...Yeah, probably 3.'; 'Well, I was quite uncomfortable with that [having to stop something before she'd finished it], maybe not anxious, but yeah, yeah.'; '[Clarified whehther it was due to not wanting to go to school, or not wanting to deal with the environment] Yeah, yeah. So maybe a little like me. And I think that was sort of a gut reaction because I was like, oh, no, I don't want to go to school, but I wanted to be at school if it was completely empty...and I just did my own thing.'; 'I know that I did find it really difficult being in that social space.' 'I didn't avoid it, but I was very anxious about it. [working as part of a group]';	The because it was art and it was quite ambiguous. Some of the tasks and I was struggling with the fact that there was a lack of structure and the teacher wasn't very good and the teacher would just sit at the front of the class and just let the class be talking really loud the entire time.'; 'Well, again, the situation's a bit different because I wasn't really set homework that much, but I think reflecting on my school experiences now, even if I have one piece of homework I'm worrying about it not necessarily to do with the content of the homework but say I've planned out to do something in a day and then I get told I've got homework to do. That would be quite anxiety producing.'; 'Or if it was like 3 pieces got set on one day, even if the pieces were set... like one was due in next week, another one due in two weeks in two weeks time. Just that amount would overwhelm me.' '[Sitting in the canteen for lunch] A one'; '[What about the journey to school, getting to school and home?] Erm one, mum ended up driving me.'	But at times it would at times it would get to a point where it was over stimulating and then difficult and make... And it was like and sometimes like that would then just lead me to, like, leave lessons. So sometimes it was too much.'; '[starting a task you hadn't understood] I I really struggled. I I open-ended tasks where I didn't know what was like wanted from me was a really really difficult. '; '[unstructured times/break times] I think without realising it, especially in year seven, I built a routine of like...once we'd finished our lunch, because we weren't allowed to eat inside. Like we'd then go to, like, specific classrooms, or we'd go to places that like. Sometimes I'd break off because it'd be like, oh, I need to do the thing for a lesson later. So I need to go to the library now. So I'll. But it was all very like planned.'; 'Like, I always struggled with like, just the idea of, oh, OK, so I now have to take the stressful work stuff from school into home, and so I can never really escape it. And also like, aren't I supposed to be taught in lessons?'		5
Occurrence in transcript	**25**	**13**	**10**	**11**	**24**		**83**

Anxiety in response to school environment and expectations	Three. Yeah, it did 'cause me anxiety [teacher telling off other students]. Erm unless, unless it felt warranted, in which case I would be like, well, you shouldn't have been doing so. And so you deserve that.'; 'In a in a lot of scenarios erm where people would say stuff, it would give me quite a lot of anxiety to not know what they meant or to feel like people interpreted it differently than I did. ; 'But then I'd stutter and suddenly I'd become extremely anxious that everyone suddenly thought I couldn't read.'	I'm like, yeah, these people are really, like these people are just a strange level of people. That's actually a normal. 'Well, that's so that exists so.' 'Yeah, yeah, yeah. Just like me. It's it's like with when you have a worry, I think with autism and you have ADHD as well, you're look, you're always looking for the next thing that can happen...So yeah'	[avoid specific teachers?] Yeah, I'd say any that shouted. I didn't like that.'; 'Probably a two or three. [teacher telling off other students] ....[depending on who it was and whether or not they're they were using that tone of voice, that or the shouting] Yeah'; "[answering questions in class] That would depend on the on the class and who was in it, but....erm probably 3, because that was another thing that used to come up in my school reports was I didn't participate enough in class and stuff.'; 'Two, I think [reading aloud in class], Err I know it was bad in primary school. I think it got a bit better in secondary, but probably yeah between 2 and 3."	[when the teacher told of other students?] Err two. I think because I wouldn't, I'd take it personally as well, especially because a lot of telling off was done to the class in general. So even if I knew that it wasn't necessarily me that did something or that they were telling off about it would still feel quite intimidating.'; "I think reflecting on my school experiences now, even if I have one piece of homework I'm worrying about it not necessarily to do with the content of the homework but say I've planned out to do something in a day and then I get told I've got homework to do. That would be quite anxiety producing."I would say one, I think this has changed since changing school environments, but if we're reflecting on secondary school and not sixth form, I would say one. [answering questions in class]'; I would answer it but be like pooing my pants. I'd really feel uncomfortable doing it. Yeah, I'd I could feel my face like going absolutely red and really hot and I'd get really flushed'	And then also the reaction to the wrong expectation is ridiculously like, you don't need to yell at a group of kids for sitting down on chairs. But you know.'; "Sometimes I didn't find that anxiety provoking because some teachers are like, yeah, go in, sit down, be prepared. Like other times teachers would get annoyed at you for not going in and doing that, whereas some teachers would be like, You can't enter my classroom like you have to wait outside. Like, what are you doing? So there was a bit of anxiety of like, especially with new teachers or at the beginning of terms or whatever when also or at the start of a term where, you know, they changed the seating plan. So you can't...and then being told off for something you didn't know, had no way of knowing and different teachers do it different ways. And the expectations are completely different. '; I think I still felt quite anxious talking to teachers because I didn't know how they were going to react. I didn't know if they were going to be kind and considerate, or if they were going to think...'What are you doing? like you know, I'm the teacher'; 'and it then just made me anxious about my own actions cos it's like you're being told off for something completely random so what if I do something completely random.'; 'And then as school became more and more stressful and everything, I completely avoided it and my mum would have to drive me.'		5
Occurrence in transcript	**3**	**1**	**15**	**18**	**13**		**50**
Friendship breakdowns and social pain	I think she viewed me as erm, kind of hopeless because she would beg me a lot, like, oh, Hannah, just come in today. It's not that bad. Like you'll be fine. And I'd be there like, no, I I can't do it. I just can't. And she would get extremely frustrated at my incapability and she didn't understand.'	It was my parents call it bullying, I call it just like life lessons '; so yeah, I would say like that's wrong. And then it kind of would their evils would be passed on to me.' ; Yeah, they were just like me. [other kids were mean to me]; 'It did make it [the bullying] worse because after that meeting there was a rumour being spread that I laughed at somebody having a panic attack. I was just like what? That even that didn't even happen. Crazy. You crazy, you crazy girl. '; 'because especially like as I went through school as well, people couldn't understand why I kept making friends, even though even though these like big reputation for like these big conflicts would happen';	So yeah, I'd say like I had friends up until probably year eight when things got a bit complicated'; 'And there was always, I think, because I don't know if it was because there was five or what it was, but there was always ruptures between us and two would go off and yeah.'; '[Did you have one close friend?] I did have one friend, who I would probably have described as my best friend, but she then took part in excluding me from the group so well, she was a bystander, so... And then she wasn't a good friend anymore.'; "I did have quite a few...Well, most, well all of the boys, actually, not all of them, but all of the ones who did it were boys... they would try and, like, goad me into talking and like, try and push my buttons as it were.'; 'Yeah. [The other kids are mean to me.]...Erm, not everyone was mean, but some of them were."	there was nastiness I think yes, and at secondary. I think some of it was perhaps due to what I'm interested in. Because I guess still being interested in Disney at secondary school is a little bit out of the ordinary. But I think, yeah, there was times that I went. I'd go to a party and then they'd start playing a song and take the mickey out of me.'; 'I could have a couple of friends come into a quiet space ... but they kind of abused it because I said to like couple of people, oh, you can come in and sit with me at lunch and then they'd bring along a load of people that I just didn't feel comfortable with sitting with.	At primary school, I was really academically doing great. I was like one of the top people in my class. Like I will. The teachers thought I was fun and confident and bubbly and sociable and like friends with loads of people and like, but in my head I felt like, Oh my, my friends don't like me, like they're... like there was even times where I got reinforced on that like they got reinforced that my friends have been talking behind me about my back and like and I would be stressed.		5
Occurrence in transcript	**3**	**19**	**11**	**24**	**7**		**64**

Not feeling aligned to learning system		But I never really felt aligned to the learning system at school. I just, I always had to work a lot harder than everybody else'; 'I look back at like maybe 20% was the was the fact that I just wasn't interested that much in it.'; 'Just cos like it's the it's the, it's the being aware of how different you think to everybody '; 'It just look that learning doesn't work for me. I don't. I can't. I cannot sit there, and you can't expect me to absorb what you're...'; 'waste of time [going to school]. '; ' just because I knew I was going to do better work at home than I was going to do	I think they knew it was a lot more than I just didn't like school because I'd always loved school. So and I had no problem sitting at home doing all the work that the school sent home.	[Did you want to attend but not the actual school or did you not want to do it at all?] Yeah, so I enjoy learning. I love learning, but I didn't like the environment.'	[did you enjoy learning new things] Yes, but...To a degree, it was like I just need to do. I need to learn something and it's good, but I don't. I still like. I'm still. I like to learn things on my own terms and not the way education is. So I think it's a little bit like. You know, it's all a bit like I hated learning still kind of afraid of it...Even though it can be good so.'; 'It just doesn't work, it's just the structures, it's....It's a problem. It doesn't work and and people just aren't willing to admit that school the complete system is flawed. Doesn't mean people aren't trying in it, doesn't mean people aren't wanting to.';		4
Occurrence in transcript		**14**	**2**	**1**	**5**		**22**
Lack of support, nurture and approachability from school adults	especially with um teachers, that sort of punish you for, for not listening, when you knew damn well that I was paying attention and that there was just one bit I missed in their list of five instructions [that I missed- inf].'; 'Three I didn't. Yeah, I I didn't cope well, especially when I stopped going and it felt more accusatory speaking to them. '; 'Oh, I'd probably go four because if it was completely on your own and I had a question, I would much rather turn to the person next to me, then talk to a teacher'; 'I would put it at a 2 [did you feel that teachers understood], only because I know they tried otherwise they would be a zero.'	[anything that they tried that made things worse for you?] They did do this thing once where they thought it'd be helpful to put me in a room with all my bullies and they were like, I think you should, like, tell them, like, how you've been feeling.	And any, I mean, there were some that had been at the school for quite a while. It tended to be them that were more sort of strict and not very approachable.'; 'Yes, I know my I know my form tutor was aware of what was happening, but she was, she was quite young in terms of like...not that long qualified, so she was quite pally with all the rest of the girls in my class and I kind of felt like she was one of them at the end like. I yeah. I felt it was almost, it almost felt like they were... they were all in cahoots, so I just didn't really get on that well with her.'; 'Erm, no, I don't think they really did anything. I don't know, maybe they did, but I can't remember. But I don't can't remember anything. [or perhaps it was happening behind the scenes?] Yeah, maybe, but then I didn't feel like anything had changed though. '	[were your teachers generally supportive?] I would say I would say no.' 'but I'd say I got very much underestimated. My ability was very much underestimated. Like I got told drop a GCSE. It'll be, you know, more relaxed, you'll cope better if you drop a GCSE. 'Well, I got six 3s, a 6, a 7 and an 8. So I don't really think I needed to drop a GCSE.'; 'So I did have a one to one, but then that relationship kind of broke down because I walked into the office one day and they were basically slagging me off and slagging all my family off. So that relationship kind of broke down because all that trust was lost.'; 'I would say it's probably hard to judge with secondary school anyway because you're not really... with that teacher maybe a couple of hours a week, so you don't really develop that kind of relationship with a teacher.'	'some teachers would think they were really helpful when they weren't... like a sort of, Oh well, I'm a great teacher. I must be really helpful. I'm really supportive when it's like, no, you're not. You're just assuming that you're doing the right thing'; 'Like the main issues was the teachers, so talking to them and stuff would be difficult, and especially when things got more and more difficult, I just gave up talking to teachers completely because it was like I I don't know how to do this I because you're not being constructive and I'm having to do all the heavy lifting on being mature ... and I don't know how to be mature about this yet because I'm not even aware of all the issues I've got so.'; 'Like this teacher I hated because she was so volatile. .... And was so happy at times. And ... like... And I was so stressed and I knew that, and I knew that she liked me. I knew that she thought I liked her, and I was like, OK, we're OK at the minute. She likes me. But like, I hate her because I I'm so stressed. I hate coming to into her lessons. I hate being here...But I'm doing well. She thinks I'm doing well.'; 'There were things like like they teachers were supposed to and had been emailed by like the pastoral team that I have to be sat either at the back or by the door with somebody, like with one of my friends. But some teachers would just disregard that some teachers would specifically would put me at the front '		5
Occurrence in transcript	**15**	**4**	**18**	**20**	**16**		**73**
Missed knowledge	but then obviously even even starting in a year, you build upon knowledge from the last year and after the first or second day of year 11, I realised that the lessons I've missed in year 10 made it so year 11 was not a fresh start' ; 'like there were a lot of tasks in year 10 and 11 that I didn't understand because of my missed knowledge and that did pretty much completely stop me from going to school'		Yeah. Yeah. And I didn't like missing the lessons and stuff. I found that really distressing because I didn't want to get behind.	but I would say afterwards I had to work really, really hard to catch up			3
Occurrence in transcript	**3**		**1**	**1**			**5**
						Total	**333**

Code	Lina	Sam	Becca	Esmee	Emma	Focus code Memo	N [root] P code appear: for
	Impact of prolonged exposure to stressors on their mental health and ability to attend school					Distress and maladaptive coping strategies, trauma rooted in schooling and compounding mental health needs	
Mental health crisis, shut down and feelings of paralysis	I was laying in bed, not really seeing my friends. I wasn't eating well. I wasn't well that emotionally.'; 'rather than sort of real incapability of attending it.'; '[Thinking about school caused me worry] Anytime in year 10 and 11 that it even crossed my mind about GCSE or about school, or about friendship problems because of not going to school, I would completely shut down'; 'And I was just sat there crying saying that I can't do it. I can't go in, stop trying to make me. I'm just so anxious. I can't do it.' ; 'None of it did anything to help, I wouldn't participate, I didn't even try. '; 'I think because I'd always had attendance that wasn't 100%. It was sort of. There wasn't really time to put accommodations in place before it dropped off completely'		And then Easter of year nine, it was actually CAMHS that said...Like, we're not going to, we don't think it's a good idea for her to go back.'; 'I'd sort of describe it as being like in a state of paralysis like I just... Either I wouldn't get out of bed or I wouldn't get out of the car when we got there; but I couldn't explain what it was that was the problem.'; 'Because I think my parents were so pleased that suddenly I'd gone to a new school and it was all fine. And then I don't know if, like, subconsciously going to hospital was a way of being like...escaping from it in a way. So 'Oh, I'm too ill to go to school, What a shame'.; 'Erm I suppose I was also struggling with quite a few mental health issues, so I mean at certain points I didn't see a future, so probably not	I think it was just that I was absolutely exhausted and burnt out and overstimulated.'; 'I'd say physically the feeling of going to school like some days mum would drive me to school and my legs, I just literally, I couldn't walk.'; 'But I think the mental health was because I wasn't coping and that the mental health condition that I had was kind of a way of me controlling things.'; 'off and then I think the end of year eight maybe start of year nine. I had time off, I got signed off for the doctors, but that was to do with mental health'	Yeah. And. And I was exhausting myself from completely. I I'm like, I mean, I'm definitely completely burnt out. I definitely burnt myself out. And that was definitely what was happening.'; 'at that point, like my mental health had taken such hit my anxiety was so bad I was getting really depressed.'		4
Occurrence in	**17**		**11**	**14**	**3**		**45**
Physiological signs and unhelpful or dangerous coping strategies	quite consistently I would get stomach aches all the time. I would get headaches, I'd feel nauseous. It would feel like an ache in my chest.'; 'I'd come back [from the toilet] and look at the person's work next to me because it was too much.'; and just use any distraction method I could get my hands on... to sort of not have to think about it, because that every time I did, I would feel ill and distressed.	Oh, for sure. Yeah, for sure [felt unwell when thinking about school]. Just like me. Oh, my God.'; 'There were times, but before I had this card, I would just disappear. Like I would just, like, leave the classroom.' 'So that I would, I would just, I'd piss off basically'	Yeah, I suppose I felt like quite sick and stuff like that. [when thought about school]'; 'But at that point I think I was using my eating disorder to kind of as a crutch to cope with the massive challenge of changing schools after 12 years so'; 'And that was already around at my last school [ED], but it got much worse.'	Yeah, because I think I might have got diagnosed may, June ish with an eating disorder. And then I had a couple of I was signed off and I think I can't remember exactly. "which was yeah, which was a dangerous coping mechanism, which I know now. But at the time it helped me.'; '[I felt unwell when I thought about school.] Oh, just like me'; 'I'd wake up a lot in the night with bad dreams or I don't really know what it was, but I think anxiety is like waking up with quite a lot of anxiety. '			4
Occurrence in	**5**	**6**	**5**	**5**			**21**
Impact on identity		It's actually some had some major effects like because I went to an all girls school, I also, and my mother was autistic, she wasn't incredibly feminine either. So then it also even had an effect on my identity as like a woman I was like, am I?'; '... I wasn't like the other girls and I wasn't liked by them either. '; 'So now I was just looking at myself being like... What the, what the heck?'					1
Occurrence in		**3**					**3**
Additional mental health needs			[asked if her MH needs were a result of her unmet autism or separate from it] I mean, I went through quite a bit of trauma when I was younger and unrelated to my autism, so I know that was a part of it. '	Which was yeah, which was a dangerous coping mechanism, which I know now. But at the time it helped me.'; '[did the eating disorder come after the autism diagnosis or before?] No before, which I think that is what I got to crisis point because I wasn't coping in school and that was a coping mechanism to make			2
Occurrence in			**1**	**2**			**3**

	Consequences of prolonged invisibility and unmet needs- crisis and trauma					Distress and maladaptive coping strategies, trauma rooted in schooling and compounding mental health needs	
Mental health crisis, shut down and feelings of paralysis	I was laying in bed, not really seeing my friends. I wasn't eating well. I wasn't well that emotionally.'; 'rather than sort of real incapability of attending it.'; '[Thinking about school caused me worry] Anytime in year 10 and 11 that it even crossed my mind about GCSE or about school, or about friendship problems because of not going to school, I would completely shut down'; 'And I was just sat there crying saying that I can't do it. I can't go in, stop trying to make me. I'm just so anxious. I can't do it.' ; 'None of it did anything to help, I wouldn't participate, I didn't even try. '; 'I think because I'd always had attendance that wasn't 100%. It was sort of. There wasn't really time to put accommodations in place before it dropped off completely'		And then Easter of year nine, it was actually CAMHS that said...Like, we're not going to, we don't think it's a good idea for her to go back.'; 'I'd sort of describe it as being like in a state of paralysis like I just... Either I wouldn't get out of bed or I wouldn't get out of the car when we got there; but I couldn't explain what it was that was the problem.'; 'Because I think my parents were so pleased that suddenly I'd gone to a new school and it was all fine. And then I don't know if, like, subconsciously going to hospital was a way of being like...escaping from it in a way. So 'Oh, I'm too ill to go to school, What a shame'.; 'Erm I suppose I was also struggling with quite a few mental health issues, so I mean at certain points I didn't see a future, so probably not	I think it was just that I was absolutely exhausted and burnt out and overstimulated.'; 'I'd say physically the feeling of going to school like some days mum would drive me to school and my legs, I just literally, I couldn't walk.'; 'But I think the mental health was because I wasn't coping and that the mental health condition that I had was kind of a way of me controlling things.'; 'off and then I think the end of year eight maybe start of year nine. I had time off, I got signed off for the doctors, but that was to do with mental health'	Yeah. And. And I was exhausting myself from completely. I I'm like, I mean, I'm definitely completely burnt out. I definitely burnt myself out. And that was definitely what was happening.'; 'at that point, like my mental health had taken such hit my anxiety was so bad I was getting really depressed.'		4
Occurrence in	**17**		**11**	**14**	**3**		**45**
Physiological signs and unhelpful or dangerous coping strategies	quite consistently I would get stomach aches all the time. I would get headaches, I'd feel nauseous. It would feel like an ache in my chest.'; 'I'd come back [from the toilet] and look at the person's work next to me because it was too much.'; and just use any distraction method I could get my hands on... to sort of not have to think about it, because that every time I did, I would feel ill and distressed.	Oh, for sure. Yeah, for sure [felt unwell when thinking about school]. Just like me. Oh, my God.'; 'There were times, but before I had this card, I would just disappear. Like I would just, like, leave the classroom.' 'So that I would, I would just, I'd piss off basically'	Yeah, I suppose I felt like quite sick and stuff like that. [when thought about school]'; 'But at that point I think I was using my eating disorder to kind of as a crutch to cope with the massive challenge of changing schools after 12 years so'; 'And that was already around at my last school [ED], but it got much worse.'	Yeah, because I think I might have got diagnosed may, June ish with an eating disorder. And then I had a couple of I was signed off and I think I can't remember exactly. "Which was yeah, which was a dangerous coping mechanism, which I know now. But at the time it helped me.'; '[I felt unwell when I thought about school.] Oh, just like me'; 'I'd wake up a lot in the night with bad dreams or I don't really know what it was, but I think anxiety is like waking up with quite a lot of anxiety. '			4
Occurrence in	**5**	**6**	**5**	**5**			**21**
Impact on identity		It's actually some had some major effects like because I went to an all girls school, I also, and my mother was autistic, she wasn't incredibly feminine either. So then it also even had an effect on my identity as like a woman I was like, am I?'; '... I wasn't like the other girls and I wasn't liked by them either. '; 'So now I was just looking at myself being like...What the, what the heck?'					1
Occurrence in		**3**					**3**
Additional mental health needs			[asked if her MH needs were a result of her unmet autism or separate from it] I mean, I went through quite a bit of trauma when I was younger and unrelated to my autism, so I know that was a part of it. '	Which was yeah, which was a dangerous coping mechanism, which I know now. But at the time it helped me.'; [did the eating disorder come after the autism diagnosis or before?] No before, which I think that is what I got to crisis point because I wasn't coping in school and that was a coping mechanism to make			2
Occurrence in			**1**	**2**			**3**

School experience causing trauma			But now that I've got the awareness, I am autistic, I think...that has also caused some trauma, I think, particularly in my school experience...Erm...I think...Yeah, I'd say that probably contributed.'	No..well...In primary school, there was a friendship group, but it was very rocky, very toxic friendship group, which I think I do have a bit of, perhaps trauma there.' 'Like I often have, like flashbacks or dreams about that, and I think after that I never really had a stable group of friends.'; Yeah. And I would say there's quite a lot of perhaps trauma there from primary school that is still there and will need to eventually be explored. ; But I would say at my old school, yes, and I felt quite traumatised going in, like even stepping foot in the school in the school grounds would...produce a sense of	So I'd say more on the not like me in the sense that if if somebody were to go, oh, do you want to go to school again? I'd be like absolutely not never again. But more from a fear place than I. I don't know. It's a weird one.'; 'So it would give me a little bit of like, but then sometimes that would almost I'd almost not trust that confidence that it gave me because I'm like, have they done that on purpose, or that and because then they'd also do things that then wouldn't help. And then I'd be like, oh, no, I let myself think I could trust this teacher to be a bit more caring and then they're not. And then... I'd just be like it just I just lost. Slowly lost all trust in the system completely.'		3
Occurrence in			**1**	**5**	**2**		**8**
						Total	**80**

Final theoretical codes, focused codes + initial codes

Theoretical code	Focused code	Initial code	Initial code	Initial code	Initial code	Initial code	Initial code	Initial code	Initial code		Initial code		
	Barriers to earlier recognition and effective response	Achievement, diligence + presentation masking extreme struggles		Unhelpful adaptation or provision	Too little too late Same as not enough could have been done?	Not wanting to appear different	All or nothing, no grey area	Teacher's ignoring agreed adaptations	Not enough could have been done Same as too little too late?	Early parental concerns dismissed	It depends'	Not realising or understanding own distress	Couldn't communicate difficulties
Balance of systemic barriers and protective factors	Moments of visibility and recognition	Knowing that teacher's tried and expression of empathy for the adults	Difference made by positive teacher relationship	Relying on and catching up with friends	Things that helped in class								
	Invisible path of distress to absence	Avoiding of specific lessons or events	Emotional consequences at home	Increasing absence	Early physiological symptoms	Leaving	Preferring to be at home and difficulties separating from parents	Covid made me realise					
Emotional response to unnoticed distress and lack of autonomy.	Emotional landscape of distress and a lack of belonging and autonomy	Feelings of frustration, anxiety and distress	Experiencing fear and perceived threat	Feelings of isolation, invisibility and struggling in silence	Lacking of control, safety and hope	Experiencing Internal conflict	Resentment	Lacking a sense of belonging and fearing judgement					
	Cumulative stressors and overwhelm in the school environment and system	Feeling forced, the use of threats, and consequences	Just built up	Autism traits making school confusing and stressful	Anxiety in response to school environment and expectations	Friendship breakdowns and social pain	Not feeling aligned to learning system	Lacking of support, nurture and approachability from school adults	Missed knowledge				
Activated threat response and consequences of being unable to act	invisibility and unmet needs- crisis and trauma Impact of prolonged exposure to stressors on their mental health and ability to attend school	Shutting down, feelings of paralysis and mental health crisis	Physiological signs and unhelpful or dangerous coping strategies	Impact on identity	Additional mental health needs	School experience causing trauma	Complete or partial non-attendance						
	Conditions enabling re-engagement and fostered feelings of safety and belonging	Having autonomy and choice and taking control of their learning	Fresh start	Calmer environment + more structure	Feeling a sense of belonging or inclusion	Feeling of safety at college/alternative provision	Part time attendance in school/flexi schooling	Caring adults and receiving support	Parental support and fight				
Reengagement, autonomy and resilience	Resilience, achievement and hope	Happiness, pride and hope	Developing coping strategies, resilience and facing challenges	Experiencing success and achievement									

	Conditions enabling re-engagement and fostered feelings of safety and belonging	Having autonomy and choice and taking control of their learning	Fresh start	Calmer environment + more structure	Feeling a sense of belonging or inclusion	Feeling of safety at college/alternative provision	Part time attendance in school/flexi schooling	Caring adults and receiving support	Parental support and fight		
Reengagement, autonomy and resilience	Resilience, achievement and hope	Happiness, pride and hope	Developing coping strategies, resilience and facing challenges	Experiencing success and achievement							
	Participant hindsight on missed opportunities	Teachers should have recognised needs	Needing a Full reset	Drastic change needed	Earlier recognition, diagnosis and support	I got lucky					
Retrospective critical insight and reflection- ecological systems- chronosystem	Diagnostic journey and its impact on identity, acceptance, and support	Positive feelings about diagnosis	Positive qualities from late diagnosis	Support and understanding without need of diagnosis	Journey of acceptance	Stigma, stereotype and journey to accepting possibility of autism	Impact of the diagnosis				

Appendix 35- Early Conceptual Code Diagrams



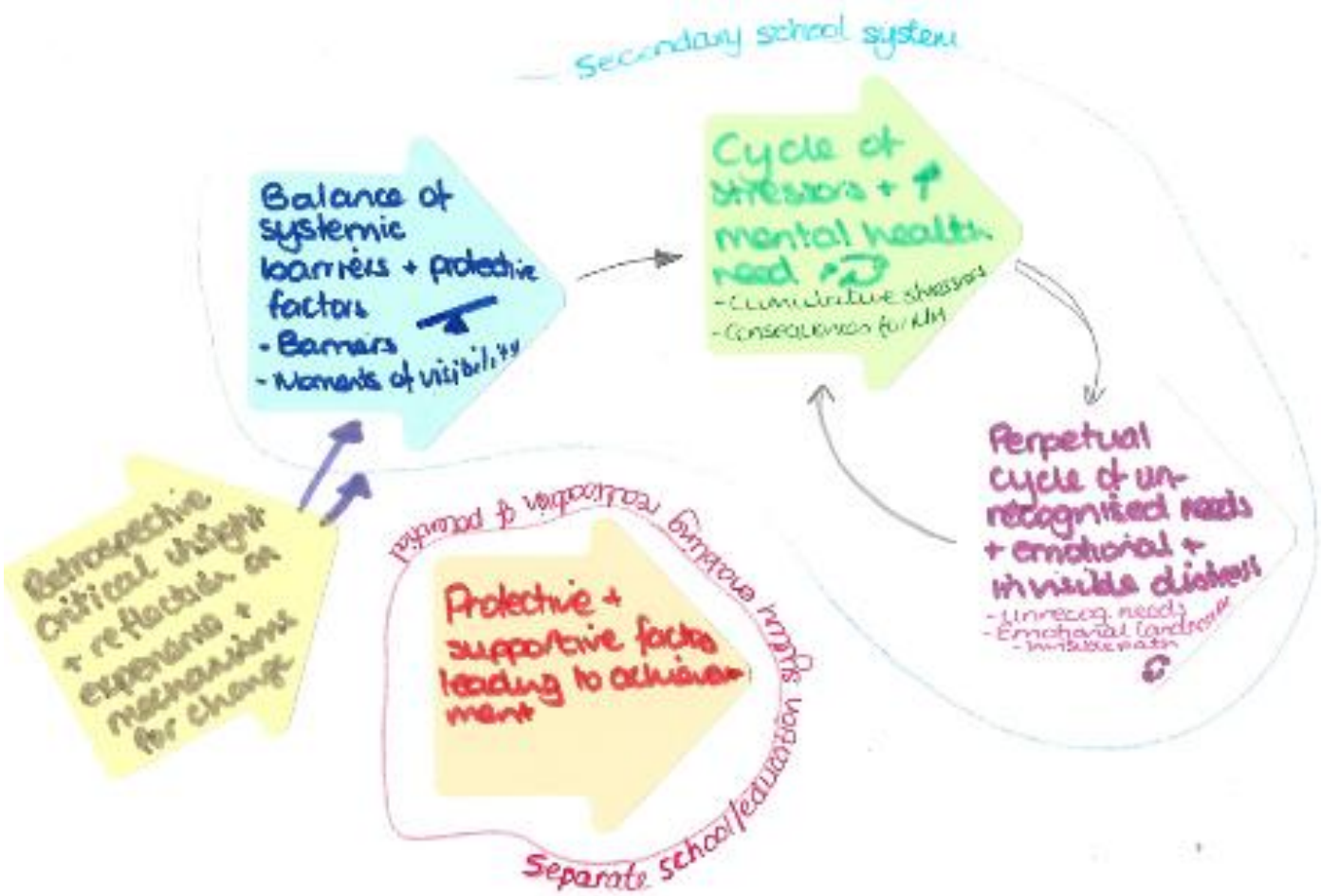
Version 1 of *'unnoticed distress, lack of autonomy and defence mechanisms'*



Version 2 of 'unnoticed distress, lack of autonomy and defence mechanisms'

The yellow notes are the initial codes and they surround the focused code they form.

Appendix 36- Early Theoretical Framework Diagrams



Version 1 of theoretical framework



Version 2 of theoretical framework

Appendix 37- Ethical approval

The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699

https://tavistockandportman.nhs.uk/

Louise Brackpool

By Email

17 April 2025

Dear Louise,

Re: Trust Research Ethics Application

Title: *'A grounded theory study exploring factors influencing emotionally based school non-attendance in adolescent girls prior to their autism diagnosis.'*

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

Please be advised that any changes to the project design including modifications to methodology/data collection etc, must be referred to TREC for review.

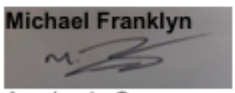
Failure to obtain prior approval for such changes may result in academic and/or research misconduct.

If you have any further questions or require any clarification, please do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,



Academic Governance and Quality Officer
T: 020 938 2699
E: academicquality@tavi-port.nhs.uk

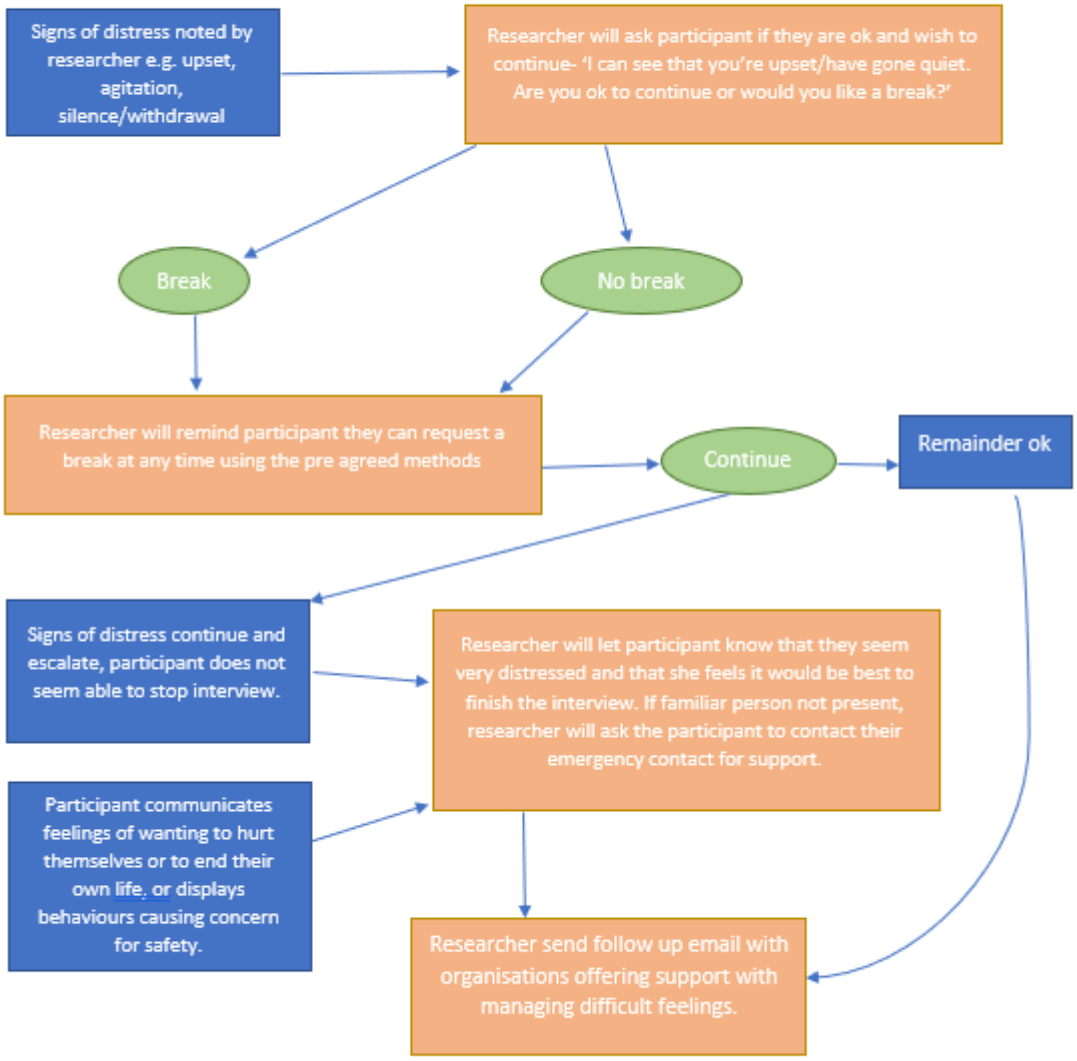
cc. Course Lead, Supervisor, Research Lead

Appendix 38- Distress Protocol

Distress protocol

Purpose

To highlight to participants the steps the researcher will take in the event of a participant showing signs of distress.



Appendix 39- Follow up thank you email

Email 7- follow up/thank you email

Dear X,

Thank you again for your time yesterday.

As promised, I have included below some organisations which could offer support with any difficult feelings our discussions may have given rise to. You will need you seek their support yourself if you feel that this would be beneficial.

Autistic girls network https://autisticgirlsnetwork.org/

Samaritans https://www.samaritans.org

Shout https://giveusashout.org/get-help/

National Autistic Society https://www.autism.org.uk/contact-us/urgent-help and https://www.autism.org.uk/

If you have opted in to receive a summary of the overall findings from the research then this will be emailed to you when this has been completed, likely sometime in late spring 2026.

Thank you again and I wish you all the best for the future.

Kind regards,

Louise

Appendix 40- Researcher Risk Assessment

The Tavistock and Portman NHS
NHS Foundation Trust

Fieldwork Risk Assessment Audit

Name: Louise Brackpool	School: Tavistock & Portman NHS Foundation Trust
Student number: 23002661	Supervisor / Director of Studies: Kate Farmer
Thesis Title: **A retrospective grounded theory study exploring factors influencing school attendance for adolescent girls prior to their autism diagnosis.**	
Fieldwork location: Researcher's home	Type of Fieldwork: Online Interviews
Proposed dates or periods of Fieldwork: June-July 2025	
Potential hazards or risks: *(rate high medium or low)*	
1. Emotional distress to participants as a result of recounting schools experiences which may have been difficult.	2. Emotional distress to researcher as a result of hearing difficult experiences and witnessing any distress/having to follow distress protocol.
3. Participants conducting the interview in a public space and being overheard by strangers/family member/friends etc.	4.
5.	6.
7.	8.
9.	10.
Potential Consequences for each hazard: *(please continue on a separate sheet if necessary)* 1. Mental health crisis causing high levels of distress and thoughts of self-harm or suicide. 2. Reduced emotional wellbeing and heightened anxiety 3. Others overhearing personal and/or private experiences that the participant would not ordinarily want them to know/hear. Leading to vulnerability and difficulties in relationships with family/friends.	
Controls in place for each hazard in order of likely risk: *(please continue on a separate sheet if necessary)* 3- Participant information sheet highlights importance of participants being in a private space. Interview will be rescheduled if it is apparent that the participant is not in a private space.	

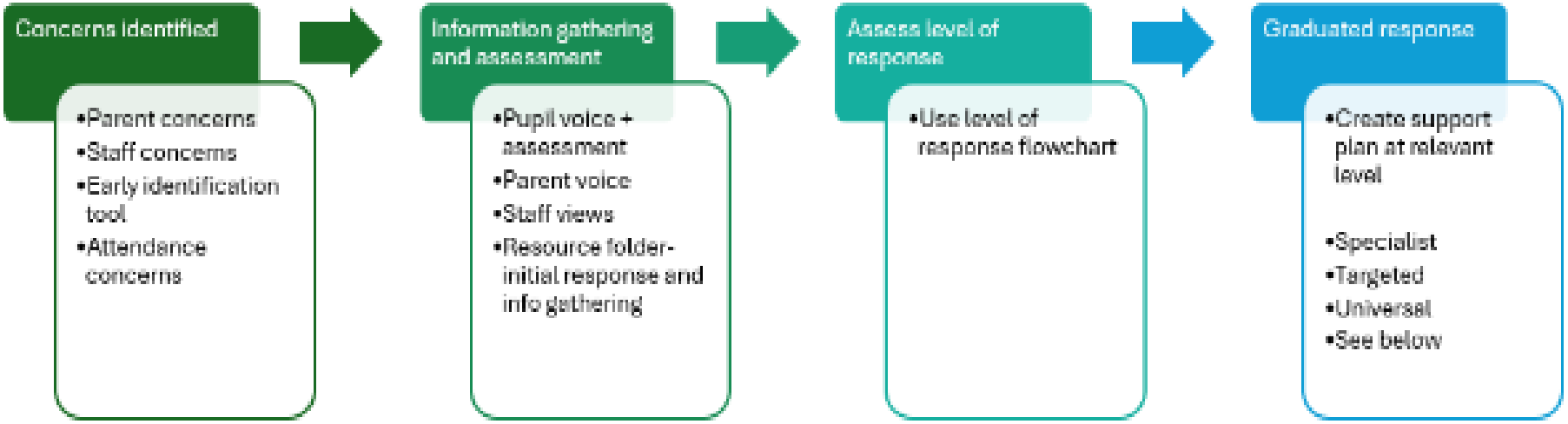
2- Support will be sought from research or personal supervisor via email or phone. Placement supervisors could also be utilized in any gap between contact with university supervisors. Support will also be sought from fellow TEPs. 1- Please see distress protocol for steps for participant to seek support from a familiar person. Option for participant to also have familiar person present at interview if they wish.

Appendix 41- Theoretical code order and related memos

Theoretical code	Focused code	Focused Code Memo
Balance of systemic barriers and early protective factors	Barriers to earlier recognition and effective response	Reasons behind needs not recognised earlier or when they were, why adaptations weren't successful- systemic and individual factors
	Moments of visibility and recognition	Moments when they did receive support once their needs were identified, which they recognised, but these were not enough to outweigh the barriers.
Emotional response to unnoticed distress and lack of autonomy.	Invisible path of distress to absence	Events/signs that were not noticed but were indicating increasing levels of distress, culminating in school absence- early signs that they were not coping.
	Emotional landscape of distress, and a lack of belonging and autonomy	The feelings associated with school attendance and not coping. Emotional response to the above.
	Cumulative stressors and overwhelm in the school environment and system	Reasons for the increasing distress and overwhelm- things about school and education that they found overwhelming.
Activated threat response and consequences of being unable to act	Impact of prolonged exposure to stressors on their mental health and ability to attend school	Impact of prolonged exposure to stressors on their mental health and ability to attend school
Long term outcomes- Re-engagement,	Conditions enabling re-engagement and	Factors enabling them to either attend a formal education provision or engage in alternative forms of education.

Theoretical code	Focused code	Focused Code Memo
autonomy and resilience	fostered feelings of safety and belonging	
	Resilience, achievement and hope	Outcomes for participants, including where they are now and what they have achieved.
	Participant hindsight on missed opportunities	Looking back, what else do they think they needed and could or should have been done.
Retrospective critical insight and reflection	Diagnostic journey and its impact on identity, acceptance, and support	Reflections on their diagnosis in terms of the timing of this and how they feel having received it.

Appendix 42- Example response pathway for schools [3]

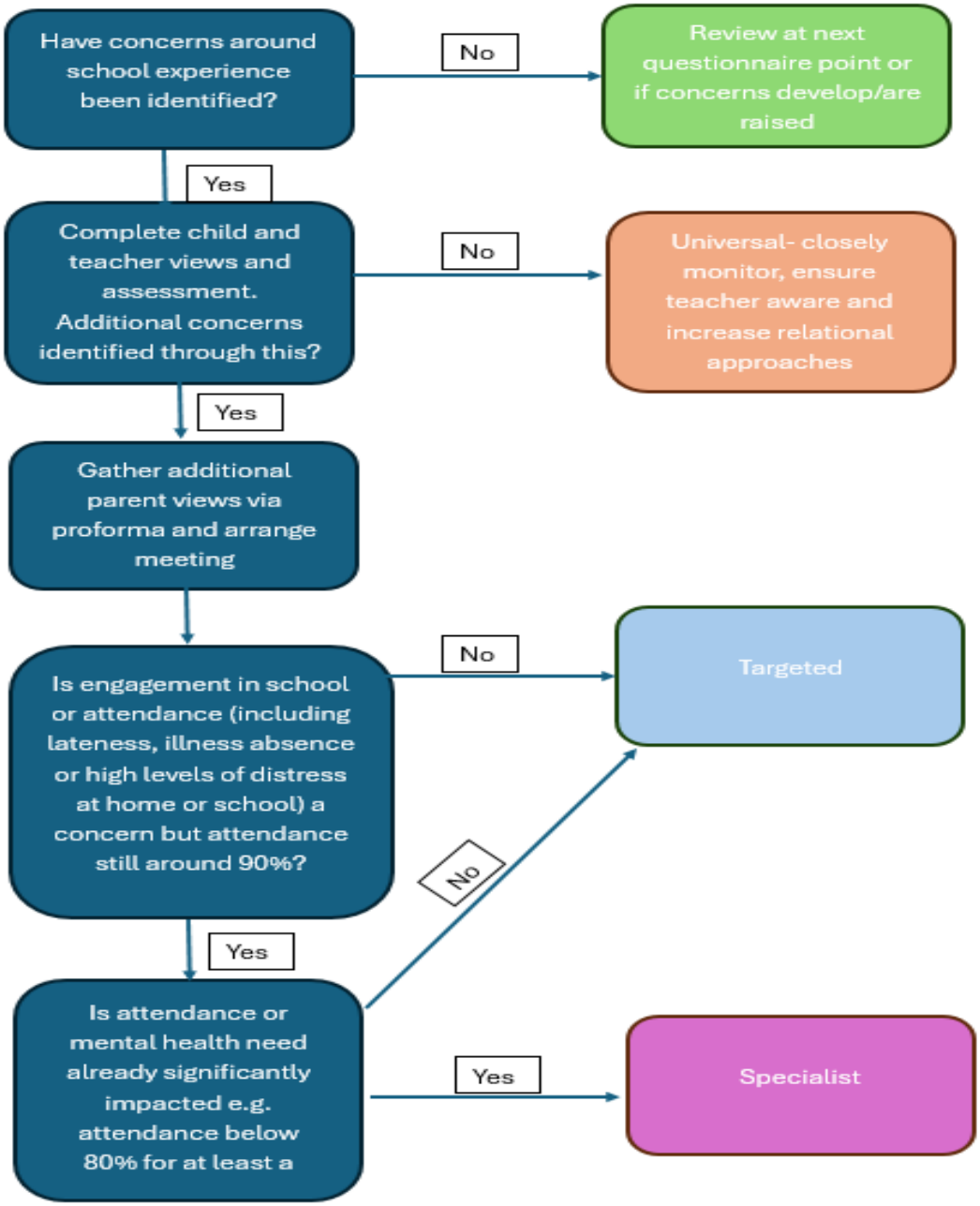


[3] These are currently working documents being co-constructed with the researcher's linked community of schools

Differentiated support for those experiencing school and overwhelming

To be read in conjunction with Mainstream Core Standards

Level of response flowchart



Appendix 43- Graduated response

To be read in conjunction with Mainstream Core Standards



Appendix 44- Early identification screening tool N.B. In development- working example

Section 2

	Often or always (60%+ of the time)	Sometimes (e.g. 40-60 % of the time)	Occasionally (e.g. 10-40% of the time)	Never (up to 10% of times)
Physiological symptoms				
Does your child report regular physical symptoms (e.g. headaches, tummy aches, nausea) without an obvious cause or on specific days (e.g. on days their least favourite lesson occurs)?				
Does your child report illness, which you suspect is not present, in order to remain home?				
Does your child experience exhaustion (i.e. requiring sleep) or emotional distress after a day at school or at the weekend?				
Does your child show any eating difficulties beyond what you consider typical for a child of their age? For example, controlling when, where or what they eat, severely restricted diet etc?				
Resilience				
Does your child show that they are resilient at a similar level to their peers, for example can manage set backs, making mistakes or when their expectations are not?				
Does your child express feelings of worry or anxiety about aspects of schooling (for example: friendships, school work, failing), at a level which you feel is not typical of most children their age?				
Has your child been described by teachers as a perfectionist, diligent, high achieving, compliant or overly quiet?				
Does your child struggle to leave the house even for activities you think or know they will enjoy?				

School attendance				
Is your child able to get ready for and go to school in the mornings, relatively happy to a level consistent with other children of their age?				
Has your child ever missed specific days of school, or been more upset before school because of particular lessons or teachers they dislike?				
Is your child happy to leave you in the morning at school drop off?				

School experience and resilience checklist

	Often or always (60%+ of the time)	Sometimes (e.g. 40-60 % of the time)	Occasionally (e.g. 10-40% of the time)	Never (up to 10% of times)
School experiences				
Has your child developed friendships and are they able to manage disagreements with their peers to a level you would consider typical for their age/common with their friends?				
Has your child refused to leave the house, get out of the car or attempted to run off at drop off?				
Does your child feel that teachers understand and listen to them?				
Has your child developed good				