A Photovoice Study Exploring Autistic Young People's Experiences of Mainstream School

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This thesis is not just research. It is a story of survival, of being let down and still showing up. I hope we keep listening and make the changes that are needed.

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Abstract

Autistic pupils experience high levels of psychological distress in UK mainstream secondary schools, yet their voices remain underrepresented in clinical research and policy. This thesis addresses that gap through a systematic literature review and an empirical study, both situated within a critical realist social constructionist (CRSC) epistemology.

The SLR synthesised 12 UK-based qualitative studies on autistic pupil voice in mainstream settings. Thematic synthesis identified three themes: conditions framing pupil participation, adult framing and the limits of participation, and recognising non-verbal and atypical voice. This review shows how methodological and epistemic practices determine whose perspectives are heard.

Building on these insights, the empirical study adopted participatory-action Photovoice. Eight autistic young people (aged 14-18) co-defined the focus, produced used self-selected photographs, and took part in individual and group workshops. Reflexive Thematic Analysis yielded five themes illustrating how inclusion and distress are shaped by sensory environments, relational safety and systemic misrecognition. Pupils described masking, conditional support and needing to reach visible crisis before help was offered.

Implications for education and mental health services include viewing school distress through a trauma-informed, relational lens; implementing early, pupil-led adaptations; and recognising symbolic or embodied communication as valid expressions of need. Dissemination was co-designed with participants and included school exhibitions, digital stories and practitioner briefings, to maximise impact on audiences that mattered to them.

(Keywords: *autistic pupils, school distress, Photovoice, pupil voice, critical realist-social constructionist, inclusive education, mental health, reflective thematic analysis*)

"People have opinions about autistic kids all the time…they just never ask us"

Photovoice Participant

Chapter One: Introduction

1.1 Chapter Overview

Autistic pupils[*] experience significantly poorer mental health and educational outcomes than their non-autistic peers [*], (Atkinson et al., 2024a). In a recent UK-wide survey, only 26% of autistic students reported feeling happy at school, and just 24% felt included (National Autistic Society, 2021); figures that reflect a crisis in psychological wellbeing among autistic pupils in mainstream education.

While many autistic pupils attend mainstream secondary schools in the UK, their lived experiences often revealed a disconnect between the rhetoric of inclusion and what pupils felt (Billington et al., 2023; El-Salahi et al., 2023). While frameworks such as the Children and Families Act (2014) and the SEND Code of Practice (DfE & DoHSC, 2015) promote inclusive education, autistic pupils report sensory overwhelm (Al Qutub et al., 2024; Billington et al., 2024a), peer misunderstanding (Cook et al., 2021; Crompton et al., 2020; Milton 2012) and institutional rigidity (El Salahi et al., 2023; Goodall 2018; 2020), all of which contribute not only to exclusion but also to

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[*] The term *pupils* are used throughout this thesis to reflect the UK educational context in which the research took place. While terms such as *young people* or *students* are also valid, *pupils* align with policy language and is used here for consistency and clarity.

[*] Identity first language (e.g. autistic pupils) is used throughout this thesis, reflecting the preferences of many within the autistic community and aligning with neurodiversity affirming practice. See appendix A for rationale.

sustained psychological distress, with a significant impact on pupils’ mental health and emotional wellbeing.

This chapter introduces the clinical, theoretical and conceptual foundations of the study. It draws on frameworks aligned with a critical realist social constructionist (CRSC) stance (Harper, 2011; Fletcher, 2017), including the neurodiversity paradigm (Kapp 2020; Walker, 2021), the double empathy problem (Milton 2021; Milton, 2022b) epistemic injustice (Fricker, 2007; Chapman & Carel, 2022b) and trauma informed approaches[*] (Fisher, 2022). These approaches reframe distress not as individual deficit but a consequence of social, relational and environmental dynamics, with significant implications for pupils’ mental health and wellbeing. These perspectives inform the study’s interpretation of pupils’ distress and inclusion, as well as its methodological and ethical commitments.

Key concepts are introduced and defined, with particular attention to language, identity and the interactional nature of distress in school contexts. This chapter also outlines the study’s epistemological stance, researcher positioning and approach to power and voice. Theoretical and policy tensions are mapped to provide the foundation for the research rationale, which is further developed in Chapter two.

1.2 Epistemology

This study is grounded in a CRSC epistemology (Harper, 2011) drawing on Critical Realism (Bhaskar, 1975, 2008; Vincent & O’Mahoney, 2018) and Social

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[*] trauma-informed practice as an applied lens not a framework

Constructionism (Burr, 2015). This stance recognises both the material realities that shape autistic pupils' experiences in school, and the interpretive processes through which those experiences are constructed, by pupils themselves and by the adults and systems around them.

CRSC supports an approach that attends to the structural conditions of school life, and to the ways in which autistic pupils interpret or resist those conditions (Billington et al., 2024; Botha & Cage, 2021; Goodall, 2020). Critical realism highlights how school-based distress may stem from material conditions such as sensory overwhelm or rigid routines, while social constructionism draws attention to how these experiences are named, interpreted, and responded to in clinical and educational contexts.

This was particularly important given the historical tendency of autism research and educational policy to treat distress as internal pupil level problem (Department for Education [DfE], 2022a, 2022b), rather than contextual and co constructed (Botha & Frost, 2020). The CRSC stance informed a methodology that resists pathologising difference, centres pupils’ meaning making, and treats distress as relational rather than a symptom to be managed. It reflects an ethical commitment to research that honours autistic experience and challenges dominant constructions of inclusion and mental health in mainstream schools.

1.3 Research Positionality and Reflexivity

1.3.1 Research Positionality

Reflexivity is central to qualitative research, requiring an awareness of how identity and context shape knowledge production (Berger, 2015; Finlay, 1998). My clinical training and professional values informed how I designed this project, related to participants, and interpreted their accounts.

My interest in this area developed through academic and clinical experiences, particularly on CAMHS placements, where I observed the emotional and psychological impact of autistic pupils being misread or marginalised in school settings. I frequently encountered systems focused on returning pupils to the classroom through behavioural strategies, rather than engaging with the meaning of their distress. In practice, this often meant that young people were expected to carry out significant emotional labour: the effort of managing internal discomfort while maintaining a calm or ‘coping’ appearance. For example, many young people I met described exhausting themselves by masking their needs during the school day, only to experience heightened distress once outside that environment. These observations shaped my understanding of masking and withdrawal not as absences of voice, but as protective strategies developed in response to relational and environmental demands.

This evolving understanding of emotional labour (see Section 1.4) also led me to question the systems surrounding autistic pupils. Masking and withdrawal were often misinterpreted as disengagement, rather than recognised as protective strategies. Through this reflection, I began to ask broader questions about how inclusion is defined in schools, and whether autistic pupils are genuinely supported to contribute to meaning making about their experiences or excluded from those conversations (Billington et al., 2024; Botha & Frost, 2020).

In response to these questions, I was drawn to participatory, pupil- led methods as a way of challenging these institutional dynamics. In both education and clinical settings, adults often decide what counts as acceptable behaviour or meaningful communication (Fletcher-Watson et al., 2019; Brown & McDonnel, 2024). Photovoice offered a way to co-construct space for alternative forms of expression, recognising that power does not just shape systems but research itself.

I do not identify as autistic. I bring an outsider perspective shaped by my identity, training, and the systems I have operated within. I hold a position of systemic power (Dwyer & Buckle, 2009) and with it, a responsibility to approach work with humility and a commitment to epistemic justice (Fricker, 2007). This meant paying close attention to who was heard, how expression was enabled and where my own interpretations might dominate, questions I reflected on throughout my research. I am mindful of how distress and communication are often misread through neurotypical and clinical frameworks. This awareness shaped how I framed the research, engaged with pupils and interpreted their accounts, continually asking what might be silenced, misread, or missing.

As a racially minoritised researcher, I brought an awareness of structural inequality and epistemic injustice to the way I approached this project. While all participants were White British and race was not analysed, this perspective heightened my sensitivity to whose voices are typically heard in research and education, and whose may be left out. I remained mindful of broader structural patterns, including racial disparities in autism diagnosis and access to support (Roman-Urrestarazu et al., 2021).

1.3.2 Reflexivity

Reflexivity was an ongoing stance. I kept a reflexive journal[*] and regularly discussed emerging decisions with supervisors to examine how my assumptions shaped the project. This is in line with best practice in reflexive qualitative research (Finlay, 1998; Berger, 2015).

I remained alert to how power operated across the research process, from recruitment and consent, to how images and stories were interpreted. As Foucault (1977) reminds us, research contexts are never neutral. Institutional logics shape what can be said, heard, or acknowledged. My aim was not to erase that power, but to recognise it and design for openness and safety wherever possible. This included offering participants visual methods, allowing pacing, and honouring moments of uncertainty or silence without rushing to fill them.

My choice of CRSC epistemology was informed not just by theory, but by these ethical and relational concerns. I wanted to hold space for the very real material conditions shaping autistic pupils' experiences of school, while also recognising that these experiences are shaped through the interpretations of adults, institutions, and

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[*] see appendix B for extract from reflexive journal

systems. Theoretical frameworks such as the neurodiversity paradigm, critical disability theory and epistemic injustice supported an approach that resists pathologising difference and attends to how pupils navigate, interpret and make meaning within exclusionary environments (Botha & Frost, 2020; Goodley et al., 2019; Walker, 2021).

As a clinician in training, I carry both proximity to institutional power and a responsibility to critique it. This study was one attempt to hold that tension; to use research not only to generate insight, but to centre perspectives that are too often medicalised, misunderstood or left out. For example, terms like Emotionally Based School Avoidance (EBSA)- common in education and CAMHS- highlight the ethical importance of how we frame autistic pupils' distress, and who gets to define it (Heyne et al., 2019; West Sussex Educational Psychology Service, 2018). I aimed to reflect carefully on what it means to describe, frame or speak about autistic pupils, especially within systems that routinely speak over them.

1.3.3 Epistemic Injustice and Social Model of Disability

The interpretive lens was shaped by critical theories that question how distress, communication, and behaviour are constructed within systems of power. Fricker's (2007) concept of Epistemic Injustice was particularly important in framing how pupil voice and distress are interpreted. Autistic pupils are often disbelieved or dismissed when their communication does not match neurotypical norms (Chapman & Carel, 2022a; Leedham et al., 2020). This includes testimonial injustice (being discredited as a knower), and hermeneutical injustice, (lacking the shared tools to make sense of one's experience).

These patterns reflect the wider institutional logics that determine whose perspectives are legitimised. This links to the Social Model of Disability (Oliver,1990) which locates disability in external barriers rather than individual impairment. Critical Disability Theory (Goodley et al., 2019) builds on this by highlighting how systems are shaped by power, cultural norms, and structural inequalities, including whose bodies, behaviours and ways of communicating are treated as ‘normal’ (Goodley, 2013; Goodley et al., 2019; Shakespeare, 2006). Schools often equate compliance with wellbeing and treat sensory or social difference as problems to be corrected, rather than experiences to be understood (Padilla, 2024).

Clinically, this has implications for how emotional wellbeing is interpreted and supported. Labels like “school refusal” or “EBSA” may be intended compassionately, but they often frame distress as internal or behavioural rather than contextual (Crompton et al.,2020; Heyne et al., 2019; O’Hagan & Hebron, 2017).

These frameworks also shape how I conceptualised voice. In this study, voice is not treated as synonymous with verbal expression. For many autistic pupils, communication is visual, embodied or silent (Lewis et al., 2023; Richard & Crane, 2020).

Drawing on neurodiversity-affirming and participatory approaches. Voice was treated as co-constructed, developing in context, not elicited on demand. This reflexive stance helped me remain attuned to what might be misread in participants communication, and in my own interpretations. It allowed me to hold the epistemological tension of recognising distress as real, without reinforcing deficit-based assumptions. In doing so, the study seeks not only to gather participant accounts, but to question the systems that shape what counts as knowledge.

1.3.4 Definition of Terms

The definitions below (table 1) reflect how key terms are used and understood in the context of education, policy and clinical practice. In line with a CRSC stance, these terms are treated as socially situated, shaping how autistic pupils' experiences are constructed and understood in practice.

Table 1

Key constructs used throughout the thesis, defined in CRSC terms[*].

Term	Definition
Autism	A form of neurodevelopmental difference characterised by distinct patterns of communication, sensory processing, and cognition. In this study, autism is not framed as a disorder but as a form of embodied difference.
Neurodiversity	The idea that neurological differences such as autism, ADHD, and dyslexia are natural forms of human variation. This framing resists deficit-based understanding and highlights the value of diverse ways of thinking and being.
Inclusion	Often defined in policy as the placement of pupils with SEND in mainstream classrooms. This study critiques inclusion when it is reduced to physical access, rather than ensuring emotional safety, meaningful participation, and recognition.
Belonging	A felt sense of being valued, safe and connected within the school environment. It goes beyond access, reflecting the emotional and relational conditions required for wellbeing.

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[*] Definitions compiled by the author drawing on APA (2013), Kapp (2020), Walker (2021), and relevant policy guidance (DfE & DoHSC, 2015).

School Distress	Emotional, psychological, or sensory overwhelm linked to the school environment. Used in this study as an alternative to terms like “school refusal” or “EBSA”, to emphasise systemic and contextual causes of pupil withdrawal.
Masking	The conscious or unconscious suppression of autistic traits to fit social expectations or avoid negative attention. Although it may help pupils avoid immediate harm, masking is linked to increased emotional distress and burnout over time (Pearson & Rose, 2021).
Reasonable Adjustments	Changes or accommodations that schools are legally required to make under the Equality Act (2010) to ensure pupils with disabilities can access education. In this study, the concept is critically examined in relation to how adjustments are interpreted, often narrowly, in ways that fail to address autistic pupils’ sensory and emotional needs.
Neurodivergent	A socially constructed term used to describe individuals whose cognitive and neurological functioning differs from dominant norms. In this study, it refers primarily to autistic pupils, though the term may also include other neurodevelopmental differences.
EBSA (Emotionally Based School Avoidance)	A term used in educational and mental health to describe reduced or non-attendance at school due to emotional distress, such as anxiety. EBSA is often framed around individual or family level factors. In this study the term is acknowledged but not adopted, as the focus shifts toward school distress, a more systemic framing (see definition above).

1.4 Setting the Scene and Language

1.4.1 Autism: From Diagnosis to Difference

1.4.1.1 Diagnosis and Framing

Autism has traditionally been defined through a medical lens, as a neurodevelopmental disorder characterised by difficulties in social interaction, restricted interests and sensory sensitivities (APA, 2013). Over successive iterations of the DSM and ICD, the definition has shifted from multiple subcategories (e.g. Asperger’s, PDD-NOS) to a single diagnosis based on a spectrum of traits (Rosen et al., 2021). There is also growing recognition of the co-occurrence of autism with other neurodevelopmental traits, particularly ADHD, contributing to increased diagnostic rates among previously under-identified groups, including girls, racialised pupils, and those with co-occurring presentations (Russell et al., 2022).

Despite these changes, the medical framing of autism remains dominant in clinical and educational contexts, where diagnosis often determines access to support. However, this framing has been critiqued for positioning autism as deficit and pathologising non-normative ways of being (Woods, 2020). Here, autism is understood not as a deficit but as a form of disability, arising not from inherent impairment, but from how systems and environments construct difference as dysfunction (see Section 1.3.4).

1.4.1.2 Neurodiversity Paradigm and Autism-Led Theory

This study adopts a neurodiversity-affirming stance (see table 1 for definition) and avoids deficit-based terms such as “impairment” or “disorder,” except when referencing clinical frameworks. However, it is also mindful of critiques that the neurodiversity paradigm may marginalise non-speaking autistic people and those with intellectual disabilities. Some scholars have noted that the discourse has been shaped disproportionately by those able to communicate verbally and may risk reproducing individualising narratives if not grounded in systemic critique (Johnstone & Cromby, 2024). This study uses neurodiversity not as a universal answer, but as a critical lens for interrogating power, context and recognition.

Autistic-led theories such as monotropism (Murray et al., 2005) and energy accounting (Bertilsdotter Rosqvist et al., 2023) offer additional insight. Monotropism conceptualises autistic attention as deep, focused, and less easily redirected, an attentional style that may conflict with the fast-paced demands of mainstream classrooms (Billington et al., 2024). Energy accounting reframes self-regulation not as behavioural failure, but as cognitive and emotional budgeting, where masking, sensory input and social effort drain internal resources (Cage & Troxell- Whitman, 2019).

1.4.1.3 Communication and The Double Empathy Problem

Communication differences are frequently cited as core features of autism, often framed as individual deficits in social understanding and reciprocity (Lord et al., 2020). However, this framing has been increasingly challenged by relational theories. Milton’s (2012, 2022) Double Empathy Problem reframes communication breakdowns as mutual misinterpretation between autistic and non-autistic individuals. Within this framework, the problem is not that autistic pupils fail to connect, but that their ways of expressing meaning are frequently misread by others, including both adults and peers, who operate within neurotypical norms. [*] This has important implications for how socialisation is understood in schools. Rather than

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[*] The term neurotypical is used here to describe individuals whose cognitive, communicative, and behavioural norms align with dominant expectations. However, what is considered “typical” is itself a socially constructed category shaped by historical, cultural, and institutional norms (Botha, 2021; Goodley, 2017).

placing the burden of adaptation solely on autistic pupils, the Double Empathy framework invites a focus on supporting neurodivergent-neurotypical understanding on both sides.

These dynamics are particularly visible in school settings. Educators often hold fixed assumptions about what communication should look like, and may interpret difference, such as silence, reduced eye contact or literal responses, as defiance or disinterest (Fletcher-Watson et al., 2019; Hodge, 2023; Thompson, 2022). These misinterpretations can result in exclusion, repercussions, or missed opportunities for support. This study approaches behaviour as a form of communication, not simply something to be managed, but as an expression of emotion, need, or distress, especially when other modes of communication are inaccessible or misrecognised.

Such framing also shapes what is counted as valid communication. When pupils' communication is treated as a fixed skill to be corrected, they are positioned as lacking, rather than as meaning-makers navigating environments not designed for them. Richards and Crane (2020) illustrate how visual or sensory methods, such as classroom “talking walls,” can enable expression among pupils who may struggle with standard language. Similarly, Lewis et al. (2023) show how drawings and objects allow emotional expression when words fall short. Together, the need to legitimise alternative modalities as valid forms of meaning making is clear.

This thesis adopts a relational understanding of communication: as co-constructed, context-dependent, and shaped by systems of power. When neurotypical norms are centred, autistic communication is more likely to be misread, marginalised, or pathologised, often contributing to emotional withdrawal and disconnection from school (Halsall et al., 2021). These interpretive failures are not neutral; they shape the level and timing of support and actively reproduce epistemic inequalities in whose voices are heard, legitimised or dismissed (Fricker, 2007; Chapman & Carel, 2022a).

1.4.2 Educational Inclusion and Belonging

1.4.2.1 Historical and Policy Context

Inclusion has long been positioned as a central goal of UK education policy (see Appendix C for timeline). Legislative frameworks such as the Children and Families Act (2014) and the SEND Code of Practice (DfE & DoHSC, 2015) define inclusion (see table 1) as a legal and ethical right aiming to ensure that all children, including those with special educational needs and disabilities (SEND), can be educated in mainstream schools.

Yet in both research and practice, inclusion is frequently reduced to classroom access or physical placement, rather than meaningful participation, emotional safety, or recognition (Cunningham, 2022; Hodges et al., 2022; Leonard & Smyth, 2022; Padilla, 2024; Thompson, 2022). Historically, integration efforts focused on placing autistic pupils in mainstream classrooms without addressing the structural barriers and normative assumptions that shape those settings (El-Salahi et al., 2023; Runswick-Cole, 2014; Slee, 2018).

These deficit-based framings often overlook how autistic pupils’ experiences are shaped by relational, sensory and institutional dynamics, positioning them not as learners to support, but as problems to manage (Billington et al., 2024; Botha & Frost, 2020; Li et al., 2023). While schools are legally required to make “reasonable adjustments”, what counts as reasonable is inconsistently interpreted, particularly around emotional safety, sensory regulation, and communication needs (Al Ghazali & Wright, 2025; EHRC, 2017). Many pupils are placed in environments without the resources, flexibility, or training needed to support their participation and belonging (National Audit Office 2023; Nachman, 2024; NAS, 2021).

From a critical disability perspective, this gap between policy rhetoric and lived experience reflects a deeper structural issue: schools tend to reward conformity to normative routines, behaviours, and learning styles, assumptions presented as neutral, yet often excluding pupils whose ways of being fall outside these expectations (Ainscow et al., 2019; Botha et al., 2022; Goodley, 2013; Lebenhagan, 2024; Shakespeare, 2006).

1.4.2.2 Current Context: Post- COVID Pressures

The COVID-19 pandemic further exposed the practical challenges and limitations of inclusion frameworks. During this period, many autistic pupils reported reduced anxiety and improved engagement during home learning, as lockdown conditions removed social and sensory demands (Asbury et al., 2021; NAS, 2023). Simultaneously, reports of school-based anxiety, persistent absence and masking increased (Ambitious about Autism, 2025; Nordin et al., 2023).

Rather than reflecting on these patterns, many schools attempted a return to “business as usual.” Post-pandemic policy has increasingly equated inclusion with attendance, introducing national attendance drives, fines, and “catch-up” targets (Department for Education, 2022; Tait & Knight, 2021). This framing positioned absence as family dysfunction or defiance, obscuring the systemic and emotional conditions that drive school distress (DfE, 2022).

At the same time, referrals for neurodevelopmental assessments rose sharply (NHS Digital, 2023) alongside increases in elective home education and penalties for non-attendance (Office for National Statistics, 2023). These trends reflect not just a service crisis but a widening mismatch between pupil needs and policy enforcement (Children’s Commissioner, 2023; DfE, 2022).

1.4.2.3 Performative Inclusion

Although inclusion remains a legal entitlement, it is often enacted as a surface-level placement strategy; what researchers have described as a performative model (Foster & Pearson, 2019). This model focuses on physical presence in mainstream classrooms while overlooking whether pupils feel recognised, safe, or emotionally supported (Leonard & Smyth, 2022).

There is growing concern about covert forms of exclusion that remain under-recognised in policy, including off-rolling,[*] persistent absenteeism, and school-based

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[*] Off-rolling refers to the practice of removing pupils from a school’s ‘roll’ without a formal permanent exclusion, often to improve performance statistics (Ofsted, 2019)

distress. These are often reframed through diagnostic or behavioural labels, such as “emotionally based school avoidance” (EBSA), that obscure the relational and systemic nature of the distress they name.

In recent years, persistent absence among autistic pupils has risen dramatically: from 30% in 2018 to 44% in 2023 (DfE, 2024). A 2025 analysis reported a 166% increase in persistent absence, with over a quarter of autistic pupils missing at least 10% of school time, most often due to unaddressed anxiety, sensory overload, or emotional unsafety (Ambitious about Autism, 2025; Corcoran & Kelly, 2022).

These challenges are exacerbated by delays in Education, Health and Care Plans (EHCPs), rising pressure on under-resourced schools, and accountability systems that prioritise attendance and attainment over wellbeing (Billington et al., 2023; Goodall, 2020; NAO, 2019; Tan et al., 2024). As a result, inclusion is often shaped by cost-efficiency and system performance, rather than by pupils lived experiences or emotional needs (Hill et al., 2023; DfE, 2024).

Yet inclusion is not a policy outcome or attendance figure; it is a relational and ethical process. Without attention to emotional safety, sensory regulation and psychological wellbeing, inclusion risks becoming a performative act that conceals the very harms it was intended to prevent.

While much of the literature rightly critiques the systemic barriers autistic pupils face in school, a smaller number of studies also highlight moments of genuine support. These are often attributed not to formal policy, but to individual staff who build trust, check in, and make small meaningful adjustments (Fox & Asbury, 2024; Goodall, 2020). Such moments do not negate the wider structural issues, but they suggest that everyday relational care can significantly shape how inclusion is experienced.

Historically, the move toward inclusion in England was driven by the Warnock Report (1978) and the 1981 Education Act, which encouraged a shift from segregated “special units” toward mainstream provision. However, recent studies argue that inclusion is still largely measured in terms of attendance and attainment, rather than belonging or emotional safety (Billington et al., 2024; Morris & Stevens, 2024). Where pupils do report positive experiences, these tend to emerge from isolated acts of care rather than consistent system wide practices.

The discrepancy between policy and lived experience reflects long-standing concerns in autistic led and critical disability research (Kapp 2022; den Houting, 2022). The COVID-19 pandemic further exposed the fragility of inclusion systems unsupported by sustained investment in accessibility and emotional wellbeing. While the SEND Code of Practice (DfE & DoHSC, 2025) affirms that neurodivergent pupils should participate fully and meaningfully in school life, implementation is frequently delayed, diagnosis dependent or under-resourced (Kelly et al., 2023; Billington et al., 2024).

In this thesis, the phrase “systems of power”, refers to the institutional processes, such as behaviour policies, attendance targets, funding thresholds, and diagnostic gatekeeping, that shape how need is recognised and responded to in schools. These systems are not neutral; they are shaped by professional assumptions and social values that tend to privilege verbal communication, behavioural compliance and neurotypical forms of coping (Foster & Stabel, 2023; Padilla, 2024). As such, even when pupils are technically “included”, their experience may still be one of invisibility or emotional unsafety. Without attention to these deeper systemic dynamics, inclusion risks becoming symbolic rather than substantive.

1.4.3. *School Distress*

1.4.3.1 Inclusion without Belonging

Building on this distinction, when inclusion is framed in terms of physical access or attendance, it often neglects the emotional and relational dimensions of school life. While often used interchangeably, inclusion and belonging are conceptually distinct. Belonging reflects a felt sense of safety, value, and connection, a particularly critical distinction for autistic pupils whose ways of expressing discomfort may diverge from neurotypical norms (Allen & Kern, 2017; Clarke & Crane, 2021; Goodenow, 1993). In the absence of belonging, many pupils mask distress, disengage, or withdraw emotionally, patterns often misread within attendance-driven frameworks (Halsall et al., 2021). Such misrecognition is shaped not only by how pupils behave, but by how their absence is named (Heyne et al., 2019).

1.4.3.2 Language, Labels and Framing of Absence

The language used to describe non-attendance is far from neutral. Earlier terms such as *school phobia*, *school refusal*, and *truancy* framed absence as a problem rooted in pupil defiance, dysfunction, or parenting failure (Broadwin, 1932; Kearney, 2008; Pellegrini, 2007). More recently, the term *EBSA* has become widespread in UK educational and CAMHS contexts, describing anxiety-related difficulty attending school (West Sussex EPS, 2018; Worcestershire CC, 2023). EBSA locates the issue primarily within the child through the lens of internalised anxiety, rather than interrogating the relational or environmental stressors that often underlie distress (Heyne et al., 2019; McDonald et al., 2022).

Despite its prevalence, EBSA remains poorly supported by national data. It is not routinely tracked in CAMHS referrals (NHS Digital, 2023) and support remains inaccessible for many families, highlighting a broader systemic gap (Children’s Commissioner, 2023). This disconnect between the language used to frame school-based distress and the responsiveness of services reflects a persistent tendency to individualise problems that are relational or systemic in nature.

Labels like EBSA or *refusal* may offer a shorthand for professionals, but they risk reducing the individual to symptoms rather than looking externally for explanation. They point to a shared reality: that many pupils are not avoiding school out of defiance, but are responding to environments that have become emotionally, socially, or sensorily overwhelming (Ambitious about Autism, 2024).

This tendency to pathologise distress leaves little space for pupils’ own meaning-making. They are rarely invited to define their experience or shape how their needs are understood. For this study, the term *school distress* is adopted to centre the emotional, relational, and environmental factors that make school inaccessible (see table 1). This framing aligns with autistic-led critiques that challenge behavioural assumptions and neurotypical norms (Crompton et al., 2020).

Language shapes how behaviour is interpreted and how support is offered. When distress is framed as non-compliance, it invites correction or reintegration. When understood as a systemic signal, it invites listening and change (Botha & Frost, 2020).

1.4.3.3 Masking, Emotional Labour, and Misrecognition

Masking refers to the conscious or unconscious effort to hide or suppress autistic traits to meet social expectations (Hull et al., 2017; Pearson & Rose, 2021). This may involve avoiding stimming, forcing eye contact, mimicking classroom behaviour, or concealing sensory discomfort. While widely reported among autistic pupils (Halsall et al., 2021), masking remains contested in terms of how it is defined and understood, particularly in relation to gender, developmental stage and culture. Although measures such as the CAT-Q have been developed (Hull et al., 2019), masking is still difficult to capture through standardised tools, and many experiences remain under-recognised in clinical and educational contexts (Cook & Hull, 2020). In schools, masking is less about how it is defined and more about how it is lived: for many pupils it becomes a survival strategy to get through the day.

In schools, pupils may over-conform to rules or minimise behaviours to avoid being seen as disruptive (Cook et al., 2018). These strategies can allow them to remain undetected, while internal distress intensifies. Sustained masking has been linked to anxiety, emotional exhaustion, identity confusion, and autistic burnout (Cage &

Troxell-Whitman, 2019; Mantzalas et al., 2022). Crucially, while these strategies may protect pupils from immediate judgement, they also create conditions for misrecognition, where the absence of visible struggle is taken as evidence of coping.

Pupils who mask effectively are often perceived as coping, even when struggling internally (Goswick & Cage, 2024; Tierney et al., 2021). The absence of visible distress may lead to silence being misread as disengagement, and shutdowns interpreted as rudeness or defiance (Roberts & Kington, 2020). These misinterpretations are not benign; they reflect deeper epistemic dynamics, where distress expressed through non-normative means is neither recognised nor believed (Chapman & Carel, 2022; Leedham et al., 2020), leaving little space for alternative expressions of distress (Fletcher-Watson et al., 2019; Padilla, 2024;).

From a clinical perspective, this dynamic has significant implications. Pupils may be praised for managing, even as their distress escalates, a paradox where the better one masks, the less likely they are to receive help. Pupil-centred support plans often rely on verbal disclosure, which may be absent when pupils are masking or shut down, creating a mismatch between need and visibility that leaves distress unsupported.

Research recent has linked masking and camouflaging to internalised mental health difficulties, including anxiety, suicidality, and self-injury (Chapman, 2020; Miller et al., 2024). Autistic people are at significantly higher risk of suicide and self-harm injury than neurotypical peers, with four major risk factors including: experiences of ableism and otherness, camouflaging, and autistic burnout (Forcey-Rodriguez, 2023;

Lewis, 2023). In some cases, distress may remain hidden in school but become visible at home, through meltdowns or what is increasingly recognised as “after school restraint collapse” (McDonnell, 2023). Together, these patterns point to the hidden emotional labour many pupils describe: the effort of holding themselves together outwardly while coping with significant internal strain (Hochschild, 1983; Gray, 2018).

Research has shown that autistic pupils often continue to endure overwhelming classroom environments while attempting to appear socially appropriate or unaffected. This ongoing effort to perform emotional regulation, particularly in settings that misread or minimise affective signals, can lead to significant psychological strain and unmet need (Botha & Frost, 2020; Kapp et al., 2021; Preece & Marsh, 2020). Because this labour is often invisible, behaviour policies tend to respond to disruption rather than depletion, meaning pupils who internalise distress may appear “fine” while experiencing exhaustion and disengagement (Cage & Troxell-Whitman, 2019).

This hidden work is rarely acknowledged in school assessments or behaviour frameworks, yet it deeply shapes how autistic pupils experience safety, inclusion and the legitimacy of their needs. Recognising emotional labour as a systemic, rather than individual, challenges dominant models of “support”, and calls for a shift in how distress is recognised and understood, particularly when expressed through withdrawal or effortful self-regulation.

1.4.3.4 Sensory Distress and School Environment

For many autistic pupils, the physical and sensory features of school are not just uncomfortable, but overwhelming, with crowded corridors and fluorescent lighting (Billington et al., 2024; Groom & Craggs, 2021; Zazzi & Faragher, 2018). These environmental conditions contribute to anxiety, shutdowns, and dysregulation, particularly when pupils are expected to remain in overstimulating spaces without means to regulate (Josefsson & Taneja-Johansson, 2024; Richards & Crane, 2020). Based on input from over 4000 stakeholders, The National Autistic Society (2023) reported that sensory overload and transitions were among the most frequently cited barriers to school participation. Quantitative research has also linked lighting and sound sensitivity to stress behaviours in autistic pupils (Al Qutub et al., 2024).

Despite this, school environments are rarely designed with sensory accessibility in mind. Behaviour policies often assume fixed standards for participation and attention, offering little flexibility for movement or quiet regulation (Padilla, 2024). As Fisher (2022) notes, sensory responses are often misread as behavioural problems, leading to correction or punishment. A pupil covering their ears may be seen as disengaged or non-compliant, rather than attempting to cope with environmental overload (Thompson, 2022). Similarly, the use of fidget tools may be viewed as distracting rather than as a self-regulation strategy, and request for quiet spaces can be interpreted as fussy or avoidant rather than a legitimate need for sensory recovery. (Lewis et al., 2023). These reflect normative expectations about behaviour and attention, which can inadvertently punish pupils for coping in ways that fall outside neurotypical norms.

As discussed in section 1.3.4 from a critical disability perspective, these sensory responses are not incidental. The school environment itself actively contributes to exclusion by enforcing normative expectations about how pupils should process, behave, and attend (Chapman & Carel, 2022; Padilla, 2024). When distress is treated as individual dysfunction rather than a valid response to inaccessible conditions, it is more likely to be pathologised than supported.

Recognising the sensory environment as central to inclusion shifts the burden from the pupil to the system. As Groom and Craggs (2021) and Padilla (2024) argue, inclusive schools must be designed to anticipate, not just react to, sensory needs. Rather than asking autistic pupils to cope better, this perspective requires schools to rethink what it means to create spaces that are emotionally and sensorily safe. This requires not only physical adaptations but a cultural shift in how sensory experience is legitimised and supported (Howard & Roche, 2023; Lewis et al., 2023)

1.4.3.5 Social Relational Aspects of School

Social development is often cited as a key reason for promoting school attendance among autistic young people, based on the assumption that school offers opportunities to build friendships and develop social skills (DfE, 2022). Yet this framing rarely considers how those relationships are experienced, or what social inclusion looks like for autistic pupils. Research consistently shows that autistic pupils are at heightened risk of social isolation, peer rejection, and relational mismatch in mainstream settings (Botha & Frost, 2020; Cook et al., 2021; Crompton et al., 2020; Goodall, 2020; Halsall et al., 2021).

Rather than lacking social motivation, many autistic pupils report a strong desire for connection, but experience misrecognition when their relational styles do not align with neurotypical expectations (Hodge, 2023). Crompton et al. (2020) found that autistic pupils often communicate more fluently with other autistic peers than with non-autistic ones, suggesting that shared experience, not “social skill”, underpins connection. These findings align with the Double Empathy Problem (Milton, 2022), highlighting how relational misalignment, rather than autistic deficit, drives social misunderstanding. Many also report masking their natural communication styles to conform, which can conceal distress while contributing to emotional fatigue and loss of authenticity (Cook et al., 2021; Pearson & Rose, 2021).

Misinterpretation in peer and teacher interactions can lead to emotional withdrawal and reduced engagement, especially when cues such as silence, literal communication, or reduced eye contact are misread as disinterest or defiance (Halsall et al., 2021; Leedham et al., 2020). These patterns can erode trust in relationships and intensify feelings of isolation and school-related anxiety.

Although social development is frequently used to justify inclusive placement, recent empirical and third-sector research points to a striking disconnect between policy rhetoric and autistic pupils’ day-to-day experiences. One consistently reported experience is that of being “present but peripheral”: physically in the classroom, but socially and emotionally excluded (Goodall, 2020). A 33-study systematic review identified “demands of mainstream placement,” “social participation,” and “impacts on the student” as recurrent themes across secondary settings, with social pressures, not academic ones, most often cited as sources of distress (Horgan et al., 2023; Mercado-Garrido et al., 2024).

1.4.3.6 Psychological and Mental Health Impact of School on Autistic Young People

This study reframes school distress not as an individual clinical problem but as a relational and systemic phenomenon. Autistic pupils are at significantly increased risk of developing mental health difficulties, including anxiety, depression and emotional dysregulation (Crane et al., 2019; NHS Digital, 2022). While these outcomes are often framed as intrinsic to autism, a growing body of research challenges this view, highlighting how distress often emerges in response to environmental and relational stressors, particularly within school settings (Botha & Frost, 2020; Fisher, 2022; Goodall, 2018).

Mainstream school environments frequently expose autistic pupils to persistent sensory overload, peer rejection, inconsistent adult responses, and pressures to mask or perform compliance (Billington et al., 2024; Lewis, 2023; Padilla, 2024). These demands can accumulate over time, contributing to what has been described as autistic burnout: a state of chronic physical and emotional exhaustion from sustained efforts to navigate non-affirming environments (Cage & Troxell-Whitman, 2019; Maclochlainn et al., 2022).

When distress is masked or misinterpreted, it often goes unsupported or is met with repercussions. Pupils may be praised for “coping” while struggling internally, and criticised when distress becomes visible. Over time, this reinforces patterns of shutdown and internalised anxiety (Maclochlainn et al., 2022; Tierney et al., 2021). This study takes the position that school avoidance and disengagement should be understood as relational signals, not pupil deficits. Such framing supports a shift away from individualised, behavioural models toward a contextual, systemic understanding of school distress.

Trauma informed practice is used here as an applied lens that extends the study’s CRSC and Critical Disability commitments. It offers a way of understanding pupil distress as shaped by systemic factors, including how school environments respond to difference. From a trauma-informed perspective, this is deeply concerning. Fisher (2022) argues that when schools reward masking and penalise distress, they undermine emotional safety and increase cumulative stress. Support that does not align with a pupils need, risk deepening disconnection (Howard & Roche, 2024). Overtime, these experiences can contribute to negative self-perception, internalised shame, and identity confusion, particularly when pupils feel that their authentic ways of expressing emotion or coping are consistently rejected or pathologised (Botha & Frost, 2020; Cage & Troxell-Whitman, 2019; Pearson & Rose, 2021). These patterns of misrecognition in schools are mirrored in the research literature, where autistic pupils’ perspectives are also marginalised or mediated through adult accounts. These parallels highlight how similar patterns of misrecognition operate in both schools and research, reinforcing the importance of methods that listen differently and give autistic young people greater influence in how their experiences are represented.

While research into autism and education has expanded, there remains a lack of qualitative studies that centre autistic pupils’ own meaning-making. Much of the literature continues to rely on parent or teacher reports, meaning autistic pupils’ perspectives are often absent or mediated through adult interpretations (Goodall, 2020; Leedham et al., 2020). Even within qualitative research, autistic pupils are often positioned as data sources rather than co-constructors of knowledge (Fletcher-Watson et al., 2019; Horgan et al., 2023). Few studies explore symbolic forms of expression such as images (Goodall, 2020) and even fewer embed participatory approaches that give pupils meaningful influence over research design or interpretation (Brown & McDonnell, 2022; den Houting, 2022). These gaps suggest a need to explore how autistic pupil voice is positioned and represented in qualitative research, and to consider the implications of privileging certain forms of expression. This highlights the importance of frameworks that not only document autistic pupils’ perspectives but also rethink how their voices shape research itself. One such framework is Participatory Action Research (PAR).

PAR is an approach that seeks to redistribute power in the research process by positioning participants as collaborators rather than subjects (McIntyre, 2008). It has its roots in critical pedagogy (Freire, 1970), and community psychology. PAR focuses on working alongside those directly affected by a topic, aiming to generate knowledge that is useful, relevant, and action oriented (Cornwall & Jewkes, 1995; Kindon et al., 2007). It has been widely used in educational, health, and social research, especially with marginalised groups, where traditional methods can reinforce hierarchies or overlook lived experience (Baum et al., 2006; McIntyre, 2008).

Rather than researchers defining the problem and participants supplying data, PAR promotes shared ownership: participants help shape the questions, co-interpret the findings, and influence how the results are shared (McIntyre, 2008). This collaborative approach aligns with rights-based and emancipatory approaches that aim to centre participant voice and agency in the research process (Freire, 1970; Reason & Bradbury, 2001). Approaches such as Photovoice, developed within this PAR tradition, demonstrate how visual and verbal meaning making can be combined with collaborative principles (Wang & Burris, 1997; Latz, 2017). However, full PAR can be difficult to achieve within doctoral constraints, and participatory depth varies depending on context, for instance, around ethical approval, recruitment and time needed for analysis (Baum et al., 2006; Fletcher-Watson et al., 2019). These considerations are discussed further in Chapter 3 (see Section 3.2).

While partial PAR can still support meaningful involvement, it can also risk reinforcing existing hierarchies, particularly when researchers retain control over interpretation or dissemination (Cook, 2012). In such situations, participations can appear collaborative while underlying power dynamics remain unchanged. Researchers have therefore emphasised the need to examine how power is shared, how accessible processes are, and how tokenism can be avoided in practice (Fox, 2024; den Houting, 2022). Despite these challenges, PAR remains a valuable framework for centring lived experience and building more inclusive, responsive research.

1.5 Conclusion

Although inclusion is a legal right in England (DfE & DoHSC, 2015), autistic pupils continue to report sensory, social, and emotional distress in mainstream schools, along with unmet mental health needs (Nordin et al., 2023; Billington et al., 2024). These challenges stem not from autism itself, but from how schools frame and respond to difference (Padilla, 2024).

There is a growing need for research that listens differently, work that examines not only what autistic pupils say, but the conditions under which their perspectives are interpreted. Behaviour, emotion and communication cannot be separated from the context in which they are read and responded to. While autistic pupils' voices are increasingly included in qualitative studies, less attention has been paid to how they participate in shaping research aims, interpretations, or outcomes (Horgan et al., 2023).

Chapter Two: Systematic Literature Review

2.1 Chapter Overview

This chapter presents the systematic literature review (SLR) that informed the current research. It outlines the review aims, search strategy, methodological approach and quality appraisal process. Synthesised findings were developed using thematic synthesis (Thomas & Harden, 2008) and inform the rationale and positioning of the empirical study.

2.2 Scope and Aims

SLR’s offer a structured, transparent, and replicable approach to reviewing and synthesising existing evidence (Gough & Richardson, 2018; Siddaway et al., 2019). They allow researchers to assess the state of knowledge, evaluate methodological quality, and identify conceptual gaps to inform future research (Fink, 2019).

This review examines how autistic pupils’ voices are represented in qualitative research on mainstream schooling and how these representations reflect different levels of participation. Drawing on Shier’s (2001) Pathways to Participation, it critically evaluates how autistic pupils are positioned in relation to study design, data collection, and interpretation.

The aim is to inform more inclusive and participatory approaches to educational research and clinical practice with autistic young people.

2.2.1 Review Question

How are autistic pupils' voices represented in qualitative research on mainstream schooling, and what does this reveal about their level of participation in the research process?

2.2.2 Defining Voice in the Context of Participation

In this review, autistic pupil voice is understood not as simple verbal expression, but as a form of participation. This includes involvement in shaping research questions, generating data, influencing analysis or contributing to dissemination. Voice is treated not as something researchers "give" but as something enabled or constrained by the level of participation afforded within each study.

2.3 Methodology

2.3.1 Preliminary Scoping

A preliminary scoping search confirmed no SLRs had addressed this topic in the past decade. Searches were conducted across Google Scholar, PyschINFO and Prospero to identify existing reviews and map how terms such as voice, participation and autistic pupils are used in the literature.

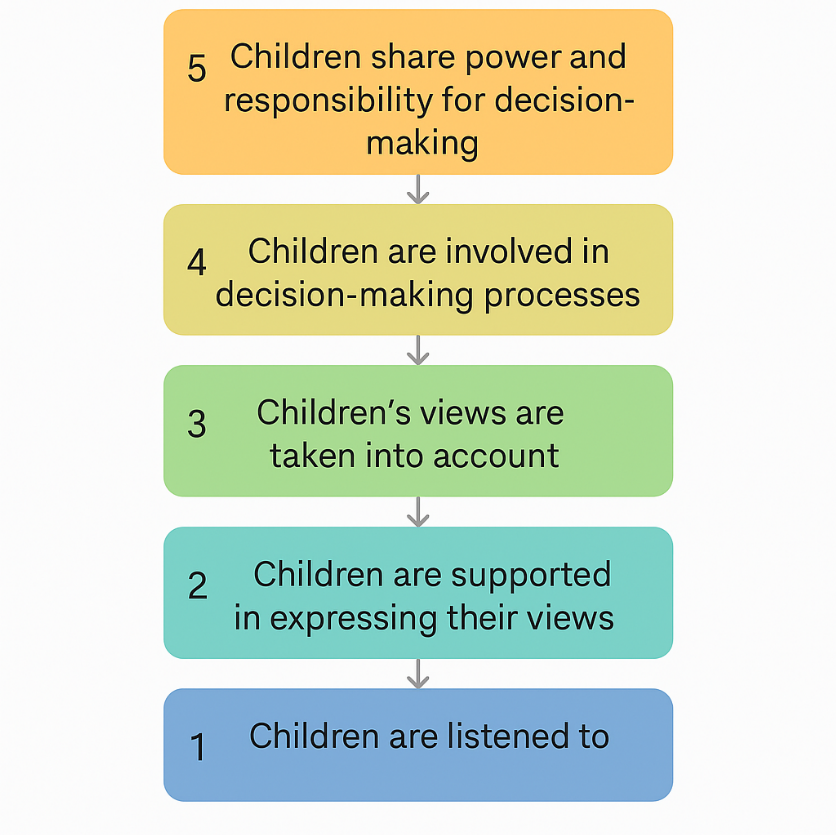
The SPIDER tool (Cooke et al., 2012) structured the review question and guided search term development (Table 2). Given the varied terminology for pupil involvement (e.g. consultation, engagement, participation), a broad range of synonyms was used. Language choices were approached reflexively, recognising that how researchers describe autistic pupils, and their contributions reflects broader assumptions about capacity, participation and power (Crane et al., 2021; Milton, 2022).

Scoping identified a growing body of qualitative studies focused on inclusion, wellbeing, and sensory experiences in mainstream school. While reviews such as Horgan et al. (2023) synthesise autistic pupils educational experiences, they do not assess how pupils are positioned in the research process or evaluate the level of participation they are afforded. Most studies report what pupils say, without interrogating the frameworks through which voice is recognised or shaped.

Some recent primary studies (e.g. Price and Romualdez, 2025), have adopted participatory methods such as photovoice, but these have not been systematically reviewed in terms of voice representation or participatory positioning. This review addresses that gap, applying Shier’s (2001) framework to assess how pupils were involved in study design, data collection, and interpretation, and whether their roles reflected tokenism or collaboration (Figure 1).

Figure 1

Shier's (2001) Pathways to Participation Framework



2.3.2 Search Strategy

A systematic search was conducted on 20/04/2025 across APA PsychArticles, ERIC, Scopus, and CINAHL which were selected for their interdisciplinary relevance to psychology, education and social care. Boolean operators (AND/OR), truncations (e.g. participant to capture "participate", "participation" etc) and phrase searching (e.g. “pupil voice”) were tailored to each database’s syntax (appendix D). [*] Email alerts were set up to capture any newly published studies.

Search terms were structured using the SPIDER tool (Cooke et al., 2012), focusing on Sample, Phenomenon of interest, Design, Evaluation and Research Type (Table 2). Language choice was approached reflexively: it was necessary to include medicalised terms such as “autism spectrum disorder” to reflect how studies are indexed in mainstream databases. This reflects a methodological tension between inclusive epistemology and the practical need to retrieve relevant literature using dominant classificatory language (Crane et al., 2021; Milton, 2022).

Searches were conducted independently, in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA 2020; Page et al., 2021) and best practice guidance for qualitive review reviews (Siddaway et al., 2019).

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[*] After the main search was completed, I ran an extra search adding identity first terms (e.g. autist*); this retrieved no additional UK studies, so the original search strings were retained.

Table 2

SPIDER Framework for Review Design and Search Strategy

SPIDER Element	Definition in Review Context	Example Search Terms
Sample	Autistic pupils aged 5-19 in UK mainstream schools	autism, autistic, “autism spectrum disorder”, ASD, neurodivergent
Phenomenon of Interest	Representation of pupil voice and participation in the research process	“Student voice”, “pupil voice”, experience, perspective, opinion, narrative, insight, agency, participat*
Design	Qualitative methodologies used to document or engage with pupil perspective	qualitative, interview, “focus group”, Photovoice
Evaluation	How pupil participation and voice are represented, framed or interpreted by researchers	perceptions, views, insights, experiences, interpretation, representation, positioning, framing, contribution
Research Type	Peer-reviewed qualitative (or mixed-method with extractable qualitative data) studies on school-based experiences	qualitative, interpretive, participatory

2.3.3 Inclusion and Exclusion Criteria

The inclusion criteria aimed to ensure conceptual relevance, methodological transparency, and analytic coherence with the review aims. A summary is provided in Table 3.

Table 3

Inclusion and Exclusion Criteria

Criterion	**Inclusion**	**Exclusion**
Study type	Peer reviewed journal articles (ensures quality and consistency)	Grey literature, opinion pieces, non-empirical articles, literature reviews (excluded for rigour and transparency)
Date range	2014-2025 (aligned with *Future in Mind* policy shift towards pupil voice and mental health provision in schools)	Pre-2015
Language	English	Non-English
Location	UK- based studies (aligned with UK educational and clinical context of thesis)	International studies
Participants	Autistic pupils aged 18 or under	Studies involving only parents, teachers, clinicians or non-autistic participants

Setting	Mainstream schools or specialist settings where pupils are reflecting or enrolled in mainstream schooling	Only focused on special schools/ alternative provision settings that do not explore pupils mainstream school experiences
Methodology	Qualitative or mixed methods (where qualitative data is extractable)	Quantitative-only studies; case studies; qualitative studies with fewer than 5 participants (excluded for limited comparability)
Data Source	Direct contributions from autistic pupils (e.g., interviews, focus groups, creative methods).	Studies relying solely on adult interpretations of pupil experience

A 2015 cut-off was chosen to align with the *Future in Mind* policy (Department of Health & NHS England, 2015), which marked a national shift toward valuing pupil voice and participatory approaches in school based mental health provision. and Only UK-based studies were included to ensure contextual relevance to the educational and clinical systems underpinning the empirical strand of this thesis.

Only peer-reviewed articles were included to promote quality and transparency. While this may exclude participatory work in grey literature, the compromise was considered necessary for analytic rigour. Case studies and qualitative studies with fewer than five participants were excluded due to concerns around comparability in thematic synthesis (Thomas & Harden, 2008). Studies were only included if they had direct contributions from autistic pupils; however, studies were retained if adult interpretations were presented alongside pupil voice.

All included studies were appraised using the Critical Appraisal Skills Programme [CASP] tool (2018), with appraisal results presented after the study overview table, allowing readers to engage with the material before considering its quality (table 6).

2.4 Results

2.4.1 Study Screening and Inclusion

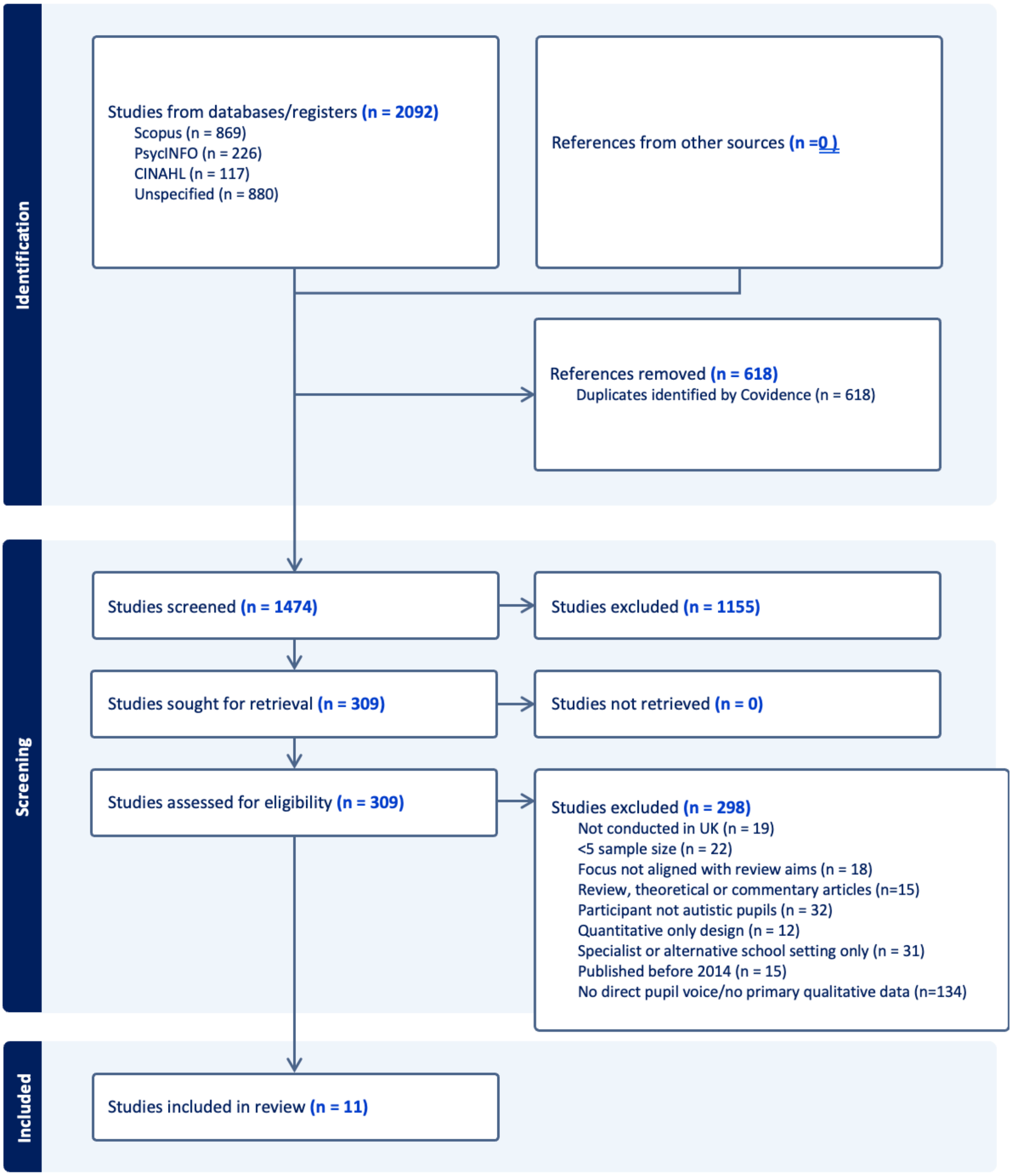
All identified records were managed using Covidence, an online systematic review platform, which supported screening, duplicate removal, and data extraction. Database searches yielded 2092 records. After removing 618 duplicates, 1474 titles and abstracts were screened against the predefined criteria. Of these, 309 full text articles were reviewed.

297 studies were excluded at full text stage, most commonly due to: absence of direct pupil voice, use of quantitative only methods, focus on non-mainstream settings, or ineligibility by data or location. A total of 11 studies met all criteria and were included in the final synthesis.

The full process is summarised in the PRISMA diagram (Figure 2).

Figure 2

PRISMA Flow Diagram of Study Screening and Inclusion



2.4.2 Data Extraction and Synthesis Approach

Twelve UK-based qualitative studies published between 2014 and 2025 met the inclusion criteria. Key data were extracted into a structured table (see table 5), capturing methodological and participatory features relevant to the review aims. This contextualised how autistic pupil voice was represented and positioned across studies.

To assess the depth of participation, each study was rated using Shier's (2001) Pathways to Participation, based on author description of pupil involvement in all stages of the research. Each study received a final Shier rating reflecting the highest level of influence observed.

2.4.3 Participation Appraisal

Shier's (2001) five-level Pathway to Participation builds on Article 12 of the United Nations Convention on the Rights of the Child (UNCRC), which affirms children's right to express their views and have them given due weight. The framework offers a structured model for assessing children's influence, from Level 1 (being listened to) to Level 5 (shared power and responsibility). While the full model includes parallel stages of adult commitment (openings, opportunities, obligation), this review focused on the five participation levels, as structural commitment was rarely reported in published articles.

Ladder frameworks have previously been used to assess participation in education and health contexts. For example, Larsson et al., (2018) applied Shier’s model in a scoping review of child-led health interventions, findings most studies stalled at Level 3, with very few reaching co-researcher status. Macer (2014), reviewing UK primary school research, also found limited progress beyond consultative participation. A recent autism specific scoping review by Newson et al., (2024) similarly found that participatory claims often masked tokenism and emphasised the need for clearer power-sharing criteria. These studies demonstrate both the utility of Shier’s model to evaluate how autistic pupil voice is enabled in research, and the gap between participatory rhetoric and practice.

Reflective questions from Shier’s framework informed the decision rules applied in this review (table 4). Each study was assigned a final rating based on the highest level of described participatory evidence described by the researchers. Table 4 presents the included studies, participation ratings, and key methodological notes on how pupils voice was represented and positioned.

Table 4

Operational Criteria Used to Assign Shier Participation Levels (Adapted from Shier, 2001)

Shier Level	Decision Rule Applied in This Review	Typical Indicators in Articles
1 Listening	Pupils invited to share views but had no influence over the research process	Researcher-led interviews; no member checking; no participatory design
2 Support	Pupils were supported to express views using visual or adaptive tools, but researchers retained full analytic control	Visual prompts, sensory tools, AAC; no participatory design, no co-analysis or advisory role
3 Taken into Account	Pupil input shaped some part of the study (e.g. methods, codes, interpretation)	Member checking; changes to themes or tools based on pupil input
4 Involved in Decision-Making	Pupils influenced two or more decisions in the research process	Advisory roles, co-analysis workshops, input into dissemination
5 Shared Power and Responsibility	Pupils named as co-researchers or co-authors; involved throughout design, analysis, and reporting	Co-authorship; reflexive commentary by pupils; shared ethics application

Table 5

Data extraction summary and participation ratings for included studies

Author(s), Year	Study Aim	Participants	Setting	Voice representation method	Analysis Approach	Pupil Involvement in Research Process	Strengths and Limitations	Shier Rating Level
Costley et al., 2021	Explore autistic adolescents' experiences of anxiety	n=18, aged 12-17; 11 boys, 7 girls	Secondary school	Co-designed semi-structured interviews; visual aids; sensory supports	Thematic Analysis	Interview schedule co-designed by adult autistic researchers, not pupils; no co-analysis.	+ Co-designed tools – Adult led interpretation	2- support
Dillon et al., 2014	Compare school experiences of autistic vs non-autistic adolescents	n=14 autistic pupils; mean age 13.6	Secondary school	Interviews + questionnaires	Content Analysis	No pupil involvement beyond data collection	+ Self-report data– No co-construction or reflexivity	1- Listening
Goodall, 2019	Understand autistic boys' educational	n=7 boys; aged 13-16	Alternative provision: study framed as reflection	Visual tools (drawings, rankings); CRAG input	Reflexive TA	Children used multiple creative tools, and an advisory group contributed to designing those	+ Advisory input– Reflexivity limited	4- Involved in decision-making

Author(s), Year	**Study Aim**	**Participants**	**Setting**	**Voice representation method**	**Analysis Approach**	**Pupil Involvement in Research Process**	**Strengths and Limitations**	**Shier Rating Level**
	experiences		on mainstream schooling			tools, no analysis report.		
Fox & Asbury, 2024	Explore friendship experiences of autistic children	n=19; aged 7-11	Mainstream & special schools	Parent-supported interviews; scrapbooks, emojis	Reflexive TA	Scrapbooks/emojis enabled expression; visual artefacts were not analysed; adults framed interpretation	+ Child-led tools– Creative artefacts not analysed– No co-analysis	2-support
Goodall, 2020	Explore autistic youth definitions of inclusion	n=12; aged 11-17	Alternative provision & study group; included pupils reflecting on mainstream schooling	Draw/write, rankings; advisory group input	Reflexive TA	Participants helped shape data collection tolls (drawings, ranking); advisory group input; no pupil co analysis	+ Multimodal access– Reflexive engagement lacking	4- involved in decision making
Goodall, 2018	Explore how autistic pupils	n=12; aged 11-17	Alternative provision; pupils	Creative participatory tools: CRAG	Reflexive TA	participatory approach (CRAG, visual tools) shaping	+ Symbolic expression enabled– Visual data	4- involved in decision making

Author(s), Year	**Study Aim**	**Participants**	**Setting**	**Voice representation method**	**Analysis Approach**	**Pupil Involvement in Research Process**	**Strengths and Limitations**	**Shier Rating Level**
	would improve education		accounts positioned as reflections on mainstream school	advised methods		study design; analysis remained adult led	under-analysed	
Cook et al., 2016	Explore autistic boys' learning, friendships, bullying	n=11 boys; aged 11-17	Mainstream & special schools; authors reported distinct findings for mainstream pupils	Verbal interviews	Inductive TA	Researcher led verbal interviews; no reported adaptations or feedback	+ Direct pupil data– No adaptation or reflexivity	1-Listening
Cook et al., 2018	Explore masking, friendships, and bullying in autistic girls	n=11 girls; aged 11-17	Mainstream & special school; data from mainstream participants included	Verbal interviews + parent input	Inductive TA	Verbal interviews and parental context; no alternative methods or child involvement beyond data provision	+ Gender-specific data– Adult-led interpretation	1-listening

Author(s), Year	**Study Aim**	**Participants**	**Setting**	**Voice representation method**	**Analysis Approach**	**Pupil Involvement in Research Process**	**Strengths and Limitations**	**Shier Rating Level**
			in synthesis					
Neal & Fredrickson, 2016	Explore successful school transition	n=6; aged 11-12	Secondary school	Adapted visual prompts in interviews	Reflexive TA	Emotion cards/rating scales used to help expression; no evidence of pupil influence on study design or findings	+ ASD-informed scaffolds– Limited reflexive insight	2-support
Hummerstone & Parsons, 2021	Understand what makes a good teacher	n=12; aged 11-15	Secondary school	Photo elicitation to prompt discussion; photos themselves not analysis; no member checking	Inductive TA	Students selected visual content but didn't co-analyse	+ Visual scaffolds– No shared interpretation or reflexivity	2-support
Cunningham, 2022	Explore what makes an autism-friendly school	n=11; Y3-Y7	Primary (with SRP)	Three Houses visual tool; member checking	Inductive TA	Pupil involvement: member checking of preliminary themes; pupil suggested renaming “quiet” of “safe” corners	+ Accessible tools and member checking –power dynamics	4- involved in decision making

Author(s), Year	Study Aim	Participants	Setting	Voice representation method	Analysis Approach	Pupil Involvement in Research Process	Strengths and Limitations	Shier Rating Level
							under examined	

2.4.4 Quality Appraisal

The methodological quality of included studies was assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP, 2018) (see table 6). CASP is a widely used tool in qualitative health and social research (Feder et al., 2006) offering a structured 10-domain framework to evaluate study design, ethics, analysis and the value of findings. It is recommended for doctoral research and aligns with PRISMA guidance for transparent and rigorous synthesis (Long et al., 2020).

Table 6

CASP Quality Appraisal Summary of Included Studies

Study	Clear Aims	Qualitative Method	Design	Recruitment	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value
Costley et al. (2021)	Yes	Yes	Yes	Yes	Yes	Can’t Tell: some reflexivity but limited depth	Yes	Yes	Yes	Yes: valuable contribution to pupil voice and co-production
Dillon et al. (2014)	Yes	Yes	Yes	Can’t tell: Limited detail on how autistic participants were approache	Yes	Can’t tell: No discussion of researcher positionality	Can’t tell: Lacks depth on assent/safeguarding	Yes	Yes	Yes: valuable contribution by comparing self-reported experienc

Study	Clear Aims	Qualitative Method	Design	Recruitment	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value
				d or if sampling bias was addressed						es of autistic vs non-autistic peers
Goodall (2019)	Yes	Yes	Yes	Yes	Yes	Brief reflexives note in limitations; limited depth	Yes	Yes	Yes	Yes: valuable participatory study highlighting emotional, sensory, and relational experiences
Fox & Asbury (2024)	Yes	Yes	Yes	Yes	Yes	Can’t tell: Lacks explicit discussion of power dynamics	Yes	Yes	Yes	Yes: valuable for creative, child-led tools challenging adult-centric assumptions

Study	Clear Aims	Qualitative Method	Design	Recruitment	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value
Goodall (2020)	Yes	Yes	Yes	Yes	Yes	Can't tell: Limited commentary on positionality	Yes	Yes	Yes	Yes: valuable in reframing inclusion using autistic pupils' own definitions
Goodall (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell: No explicit reflexive statement	Yes	Yes	Yes	Yes: explores emotional, sensory, and relational experiences grounded in pupil definitions
Cook et al. (2016)	Yes	Yes	Yes	Can't tell: Participant selection not explained	Yes	Can't tell: No reflexivity; no discussion of co-construction	Can't tell: Limited discussion of assent/safeguarding	Yes	Yes	Yes: valuable comparison of autistic boys' experienc

Study	Clear Aims	Qualitative Method	Design	Recruitment	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value
										es across settings
Cook et al. (2018)	Yes	Yes	Can't tell: Limited detail on recruitment and parental involvement	Yes	Yes	Can't tell: No reflection on parental influence on interpretation	Can't tell: Limited discussion on consent/safeguarding during sensitive interviews	Yes	Yes	Yes: highlights masking and relational burden in autistic girls' school experiences
Neal & Fredrickson (2016)	Yes	Yes	Yes	Yes	Yes	Can't tell: No reflection on researcher assumptions or influence	Can't tell: Minimal detail on consent/safeguarding	Yes	Yes	Yes: strengths-based insights into transitions and pupil agency
Hummerstone & Parsons (2021)	Yes	Yes	Yes	Yes	Yes	Can't tell: Limited reflexivity, particularly re: neurotypical	Yes	Yes	Yes	Yes: valuable use of photo elicitation to contrast pupil/staff

Study	Clear Aims	Qualitative Method	Design	Recruitment	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value
						interpretation				perspectives
Cunningham (2022)	Yes	Yes	Yes	Yes	Yes	Yes: reflexive positionality and pupil co-analysis described	Yes	Yes	Yes	Yes: participatory design using accessible visual tools to inform real school change

Across the dataset, most studies met CASP criteria demonstrating clear aims, appropriate qualitative designs, and ethically sound practices. Methodological quality was generally moderate to high.

However, reflexivity was a consistent weakness: only three studies explicitly addressed researcher positionality, neurotypical assumptions, or the interpretive lens applied to pupil voice. Given the important of reflexivity in participatory and inclusive research, this omission raises concerns about how authentically autistic perspectives were represented, and how adult interpretation shaped and constrained meaning.

Several studies implied ethical approval but offered limited detail on how assent, emotional safeguarding or vulnerability were addressed. This lack of transparency makes it difficult to evaluate how pupil wellbeing was protected or whether ethical procedures facilitated genuinely informed participation.

Participatory or creative approaches e.g. visual methods were often associated with richer accounts of pupil experience. However, few studies critically examined how these methods shaped power dynamics or influenced meaning-making processes.

To support rigour and minimise individual bias, three studies (30%) were double rated by an additional reviewer with qualitative research knowledge. Of 30 items, there was 93% agreement; two minor discrepancies were resolved through reflexive discussion. This process addressed common critiques of CASP’s subjectivity and strengthened the reliability of appraisal (Long et al., 2020).

Consistent with Thomas and Harden (2008), no studies were excluded based on CASP scores. Instead, appraisal findings informed interpretation during synthesis, particularly in relation to reflexivity, ethical transparency, and credibility of participatory claims.

2.4.4.1 Reflexivity

I approached the appraisal and synthesis process reflexively, recognising that pupil voice may appear participatory on the surface while offering limited genuine influence. This informed a critical stance toward studies that lacked transparency around pupil involvement or framed participation predominantly through adult assumptions. This was shaped by the review’s broader concern with how power, interpretation and participation are negotiated in research with autistic pupils.

2.5 Synthesis

2.5.1 Method of Synthesis

Thematic synthesis (Thomas & Harden, 2008) was selected due to its widespread use in qualitative reviews and its capacity to preserve the nuance of participant accounts while enabling cross-study comparison (Noyes et al., 2022). Its inductive structure aligned with the aim of this review: to explore how autistic pupil voice is represented in qualitative research on mainstream schooling, and how this reflects pupils' level of participation.

The method was practically appropriate: most included studies used thematic and inductive designs, providing a consistent foundation for synthesis. The review followed a three-phase process:

1. Line by line coding of findings sections, including both participant quotes and author interpretations relating to voice and participation
2. Groupings of descriptive codes into preliminary categories reflecting shared patterns.
3. Development of analytic themes exploring how autistic pupils were positioned within the research process.

Analysis was informed by a CRSC stance, with attention to the ways voice can be either represented or marginalised through methodological choices and adult framing. To enhance transparency, decisions around coding and theme development were documented in a reflexive journal throughout (see Appendix E). Shier’s (2001)

Pathway to Participation was used as an interpretive framework helping to evaluate participatory depth as themes moved from descriptive to analytic level.

The eleven studies included (2014-2025) primarily used interviews with autistic adolescents, (n=9), while several employed creative methods such as drawing, photo elicitation or visual ranking. The extent to which these methods supported meaningful pupil influence varied and was critically assessed using Shier's framework.

2.5.2 Thematic Synthesis of Findings

The synthesis examines how autistic pupil voice was represented and positioned, not only what was said, but how, by whom, and with what influence over interpretation. From a CRSC perspectives, pupils' accounts were treated not as neutral 'data', but as socially and methodologically constructed expressions of experience.

Three analytic themes were developed:

1. Conditions that enable or silence pupil participation
2. Adult framing and the limits of participation
3. Recognising atypical and embodied expression as voice

These are summarised in Table 8, with a breakdown of subthemes and contributing studies. A full mapping of studies onto Shier's (2001) framework and theme contributions is available below (table 7). Overall, studies with higher participation ratings (levels 3-4) typically contributed to multiple themes and offered more nuanced, affect rich representations of autistic pupil's experience. By contrast, studies at Levels 1-2 more often framed voice through adult defined structures, with limited co-construction or recognition of non-verbal expression. Appendix F details which studies contributed to each theme and subtheme.

Table 7

Mapping of Themes to Shier Participation Levels

Shier Level	Contributing Studies	Main Themes Supported
1 - Listening	Cook ,2016; Cook, 2018; Dillon ,2014	*Adult framing and the limits of participation*
2 - Support	Costley 2021; Fox & Ashbury, 2024; Neal &Frederickson, 2016; Hummerstone & Parsons, 2021	*Conditions framing pupil participation* *Recognising non-verbal and a typical voice*
3 - Taken into Account	n/a	*Conditions framing pupil participation* *Recognising non-verbal and a typical voice*
4 -Involved in Decision-Making	Goodall 2018; Goodall 2019; Goodall 2020; Cunningham, 2022	*All Three Themes* (richest data)
5 - Shared Power	n/a	n/a

Overall, the themes indicate that autistic pupils' contributions were contingent on methodological design, adult framing, and the level of participatory involvement.

Voice tended to flourish when emotional safety and co-construction were prioritised but becomes masked when pupils are limited to token consultation.

Table 8

Overview of Main Themes and Subthemes

Main Theme	Subtheme	Description
Conditions framing pupil participation	Trust as a precondition for voice	Pupils were more likely to share when they felt safe, supported and emotionally understood by trusted adults.
	Suppressing Voice in Unsafe Settings	Pupils described bottling up emotions or masking distress in response to unsupportive environments
	Inclusion as a feeling, not a place	Inclusion was described as belonging and being understood, not just physical presence in mainstream schools
Adult framing and the limits of participation	Adult framing and lack of reflexivity	Researchers often interpreted pupil views through adult or neurotypical assumptions, with limited reflexive engagement with their own positionality
	Participation Framed without pupil power	Participation was often framed by adults rather than co-constructed with pupils; decisions were made about, rather than with, autistic participants
Recognising (and missing) non-verbal and atypical voice	Symbolic Expression minimised or ignored	Pupils used metaphor, drawing, or silence to express themselves, but these were rarely analysed as valid data or included in theme development
	Misinterpreting behaviour as non-voice	Affective or embodied expression, such as shutdowns or withdrawal were often misread as non-participation rather than recognised as valid expressions of voice shaped by sensory overwhelm. This limited how autistic communication was represented.

2.5.2.1 Theme 1- Conditions Framing Pupil Participation

Across 11 studies, autistic pupils were more likely to express themselves meaningfully when research contexts fostered emotional safety, relational predictability, and accessible communication scaffolds. These mirrored what pupils described as supportive in school, suggesting voice was shaped not only by research design but by how broader school experiences were accessed and interpreted.

This pattern was most evident in studies rated Level 2-4 on Shier's (2001) Pathway to Participation, where researchers adapted tools or involved pupils in shaping aspects of the research. In contrast, Level 1 studies relied on adult-led interviews, with emotional safety discussed as a topic rather than embedded methodologically. See Table 7 for a mapping of studies against Shier's framework and their thematic contributions.

These patterns appeared in eight studies, including Goodall (2018, 2020) and Fox & Asbury (2024). While no causal link is claimed, the findings suggest that emotional and relational conditions influence how autistic pupils' perspectives are shaped and recognised. However, Dillon (2014) captured vivid peer exclusion in a Level 1 design, showing that relational rapport can sometimes compensate for methodological limitations. This theme includes three subthemes (Table 8), each illustrating how participation and emotional safety shaped whether, how, and in what form autistic pupils' voices were expressed in research and school contexts.

Subtheme 1.1 - Trust as a Precondition for Voice

In six studies (Cunningham, 2022; Fox & Asbury, 2024; Goodall, 2018, 2020; Hummerstone & Parsons, 2021; Neal & Frederickson, 2016), pupils expressed themselves more freely when they felt understood, respected, and emotionally safe with trusted adults. In Neal & Frederickson (Level 2), participants spoke more openly when staff were “gentle” and routines predictable. In Cunningham (Level 4), quiet spaces and flexible pacing enabled pupils to “think before talking.” In Goodall (Level 4), pupils co-designed drawing-based tasks to depict trusted relationships, suggesting that participatory design itself supported emotional safety. When relational safety is present, pupils use less effort on self-monitoring and can express themselves more fully.

Subtheme 1.2 Suppressing Voice in Unsafe Settings

In four studies (Cook et al., 2016; Dillon et al., 2014; Fox & Asbury, 2024; Goodall, 2018), pupils described masking, withdrawing, or bottling up emotions in response to relational or sensory threats. Goodall (2018) and Fox & Asbury (2024) interpreted these as protective strategies, while Cook (2016) and Dillon (2014) described them without analytic commentary. When participation is low, suppression is recorded but not interpreted; where depth is higher, the same behaviour is reframed as adaptive communication. This contrast shows how low participation levels can obscure silence as a situated form of voice.

Subtheme 1.3 Inclusion as a Feeling, not a Place

Two Level 4 studies and one Level 2 (Cunningham, 2022; Goodall, 2020; Hummerstone & Parsons, 2021) showed that pupils reframed inclusion as felt recognition. In Cunningham, member checking led to renaming a theme from “Quiet corners” to “Safe corners,” illustrating how pupil language reshaped analysis. In Goodall, pupils’ drawings depicted inclusion as “being respected as a person,” decentring physical placement. These affect-rich accounts emerged primarily in studies with greater participant influence and echoed subtheme 1.2, where feeling accepted reduced the need to mask and eased sensory distress.

Summary

Theme 1 shows that emotional safety is not just an ethical concern but a methodological condition shaping how autistic pupil voice emerges. In Shier Level 4 studies, voice was more emotionally grounded and supported by pupil-led methods like drawing or member checking. In contrast, Level 1–2 studies discussed emotional safety but did not embed it in design. Autistic voice became more recognisable only when participatory safety was in place, highlighting that representation depends on the depth of pupil involvement.

2.5.2.2 Theme 2 Adults Framing and the Limits of Participation

This theme explores how autistic pupils’ perspectives were shaped, filtered, or constrained by adult-led processes across the included studies. While many sought to engage pupils, participation was often framed by researchers rather than co-

constructed. Design and analysis remained adult-controlled, with limited critical reflection on positionality or the assumptions underpinning interpretation.

These patterns were most evident in studies rated Level 1–3 on Shier’s (2001) Pathways to Participation, where pupils were invited to share their views but rarely influenced how those views were framed or represented. Even when creative tools were used, they were often positioned as elicitation aids rather than valid expressions of voice. Non-verbal communication was frequently overlooked, and in some studies, parental accounts were used to interpret or reshape pupil meaning without reflecting on how adult norms shaped knowledge construction.

Together, these dynamics point to a broader issue: the representation of autistic pupil voice was shaped not just by methods, but by adult-led framing and the absence of shared interpretive space. Few studies engaged critically with positionality or acknowledged how neurotypical frameworks shaped what was recognised as meaningful. A full mapping of participation levels and thematic contributions is shown in Table 7.This theme includes two subthemes (Table 8), illustrating how limited participatory influence and adult framing constrained the authenticity of pupil voice in the research process.

Subtheme 2.1: Adult Framing and Lack of Reflexivity

In five studies (Cook et al., 2016; Costley, 2021; Fox & Asbury, 2024; Goodall, 2018; Goodall, 2019), researchers presented detailed pupil narratives but rarely reflected on their own roles in shaping meaning. Interpretive lenses were often unexamined, with data analysed through researcher-defined categories and little discussion of potential neurotypical assumptions or positional bias.

For example, in Goodall (2018), pupils described exclusion, but the analysis focused primarily on support needs without questioning how those categories were defined. In Fox & Asbury (2024), pupils used scrapbooks and emoji-based tools to share complex social experiences, yet findings were interpreted through developmental frames (e.g. age/maturity) rather than pupils’ own meaning-making. Similarly, Costley et al. (2021) grouped pupil reflections into predefined categories (academic, social, emotional) with limited attention to the impact of those analytic boundaries.

Across these studies, symbolic or creative modes were used to elicit speech but not treated as valid data. This suggests adult framing shaped not only what counted as voice, but how it was constructed in analysis.In contrast, Cunningham (2022) demonstrated greater reflexivity by incorporating member checking and engaging more critically with pupil-led interpretations, offering a partial example of shared framing.

Subtheme 2.2: Participation Framed, Not Shared

In three studies (Cook et al., 2018; Costley, 2021; Fox & Asbury, 2024), adults, including parents, facilitators, and researchers, played a dominant role in shaping how pupil perspectives were represented. Parent interviews were sometimes used to interpret pupil accounts, without reflexive attention to how this dual framing may have displaced the original voice.

For instance, in Cook et al. (2018), parental narratives were used to explain pupils' masking and distress, but the potential for adult interpretations to override pupil meaning was not explored. In Fox & Asbury (2024), parent-facilitated interviews may have supported access, but the blurred boundary between pupil and adult voices went unacknowledged. In Costley (2021), staff commentary was used to interpret pupil responses, but without critical reflection, pupil voice was filtered through adult perspectives.

These studies did not ignore pupil voice but often treated it as data to be interpreted about pupils rather than with them. Participatory tools were included but functioned more as scaffolds for expression than mechanisms for shared authorship. This reflects a broader pattern: participation was defined by adults and used to support pre-existing research aims, rather than to open space for pupils to shape meaning on their own terms.

Summary

This theme illustrates that autistic pupil voice was often shaped, and at times constrained, by adult decisions about what counted as meaningful data and how it was interpreted. Few studies reflected on how their own assumptions influenced coding or theme development. Even when creative or symbolic tools were used, they were rarely analysed on their own terms, limiting opportunities for co-construction. Rather than treating voice as neutral, this theme highlights how representation is constructed through methodological choices, epistemic positioning, and pupil influence. In studies rated Shier Levels 1-2, pupils were “heard,” but their accounts were reframed through adult lenses, showing how limited participation constrains how voice is ultimately constructed and understood.

2.5.2.3 Theme 3 Recognising A Typical and Embodied Expression as Voice

This theme explores how autistic pupils expressed themselves through non-verbal, embodied, or symbolic means, including metaphors, drawings, silence, masking, and emotional shutdown. These alternative forms of communication were particularly visible in eight studies (e.g. Costley 2021 (Level 2); Cunningham, 2022 (Level 4), Goodall, 2018, 2019, 2020; Fox & Asbury, 2024; Hummerstone & Parsons, 2021), especially in those rated at Shier Levels 2 to 4, where pupils were scaffolded to express their views or participated in co-designed activities.

Despite the presence of rich affective data, these expressions were often marginalised in analysis, treated as background or translated into adult frameworks. In contrast, studies with greater pupil input were more likely to recognise non-verbal cues as meaningful forms of communication. These findings suggest that autistic voice is not always verbal, and when researchers overlooked symbolic or embodied expression, important dimensions of pupil experience are lost. Such patterns were most visible in studies rated at level 2-4 on the pathways or participation. See table 7.

Subtheme 3.1: Symbolic Expression Visual and Metaphor-Based Communication

In seven studies (Cook et al., 2016, 2018; Cunningham, 2022; Fox & Asbury, 2024; Goodall, 2018, 2020; Hummerstone & Parsons, 2021), autistic pupils conveyed distress, identity, and relational insight through metaphor, visual tools, or silence. For instance, a participant in Goodall (2018) described school as “closed in… like I couldn’t breathe,”. This metaphor reveals internal emotional overwhelm and illustrated how pupils made sense of inaccessible or hostile environments.

However, symbolic expressions were treated as illustrative rather than analytic. Both Cook et al. (2016) and Cook et al., (2018) studies (level 1) described pupil withdrawal and discomfort narratively but did not examine them as forms of communication. Hummerstone & Parsons (2021) used visual photo-elicitation, but interpretive attention remained focused on verbal responses. Only a few studies such as Goodall (2018), Cunningham (2022) and Fox & Asbury (2024) actively analysed these non-verbal signals as part of pupil voice, treating visual and metaphor-based expression as meaning making in its own right.

Subtheme 3.2: Embodied Voice- Misrecognition Through Normative Assumptions

This subtheme explores how behaviours such as masking, shutdown, and emotional withdrawal were interpreted through adult behavioural frameworks, limiting how voice was urecognised (Cook et al., 2018; Costley, 2021; Fox & Asbury, 2024;

Goodall, 2019) In Cook et al. (2018), masking was discussed largely through post-school exhaustion described by parents, rather than analysed as an in-situ survival strategy. Goodall (2019) reframed anxiety and sensory overload as barriers to learning, rather than affective forms of voice or agency. In Costley (2021), pupil shutdowns were categorised as “behaviour incidents”, without deeper exploration of communicative intent.

These examples reflect a broader pattern: when pupils’ communication falls outside neurotypical or verbal norms, it is often misinterpreted or dismissed. Autistic voice can therefore be hidden in plain sight- present, but unrecognised. Unless researchers adopt more inclusive analytic frameworks, embodied or affective expression risks being erased or reframed as deficit. Openness occurred more with participation depth, most evidence in Level 4 studies, and sometimes at levels 2-3.

Summary

Theme 3 highlights the need for qualitative research to move beyond speech-centred assumptions about voice. Across the reviewed studies, autistic pupils communicated through silence, metaphor, drawing, and embodied affect, but these forms were often under-analysed. While some studies rated Shier Levels 2-3 showed openness to multimodal expression, few treated non-verbal communication as valid data in its own right. The few that did, mostly those rated at Level 4, demonstrated that what counts as voice, and whether it is recognised at all, depends on the degree of pupil influence over analytic decisions. This theme points to the importance of epistemological flexibility and reflexivity when interpreting autistic voice, especially when that voice is symbolic, sensory, or affective rather than conventionally verbal.

2.6 Discussion

2.6.1 Interpreting Findings in Context

This review explored how autistic pupil voice is represented in qualitative research on mainstream schooling, with specific attention to how participation levels shaped voice construction and representation. Most studies were rated at Levels 1–3 on Shier’s (2001) Pathways to Participation, indicating that while pupils were listened to or supported in expressing views, they were rarely involved in co-defining questions, analysis, or meaning. No study reached Level 5 (shared power and responsibility). Accordingly, any interpretation of what full co-researcher status might enable, whether in terms of pupil agency, data quality, or influence on outcomes, remains speculative and should be framed as a prompt for future empirical investigation rather than a conclusion supported by this review’s evidence base.

The three analytic themes developed in this review, (1) Conditions Framing Pupil Participation, (2) Adult Framing and the Limits of Participation, and (3) Recognising (and Missing) Non-Verbal and Atypical Voice, each reflect how autistic voice was shaped through interactional, methodological, and epistemic processes. These themes are not isolated: they intersect through the participatory depth afforded to pupils.

Across the dataset, voice was typically constructed through adult-led, verbally focused methods (Larsson et al., 2018; Macer, 2014). Where visual or symbolic tools were used, they were often treated as elicitation aids rather than valid forms of communication. In contrast, studies rated at Level 4, where pupils influenced research tools or analytic direction, yielded richer, more emotionally grounded accounts of inclusion, distress, and agency (e.g., Goodall, 2018; Cunningham, 2022). This suggests that voice is not simply captured through method but co-constructed through participatory and relational contexts, a finding echoed in other reviews using Shier's framework (Larsson et al., 2018; Macer, 2014).

From a CRSC perspective, pupil voice is not a fixed attribute, but a situated expression shaped by institutional norms, researcher positioning, and interactional dynamics. Theme 1 (Conditions Framing Pupil Participation) illustrates that pupils communicated more openly when relational safety and flexible, co-constructed methods were present. Theme 2 (Adult Framing and the Limits of Participation) shows how interpretive control remained largely with adults, who often analysed pupil perspectives through predefined, neurotypical categories. Theme 3 (Recognising Atypical and Non-Verbal Voice) highlights how metaphor, drawing, silence or withdrawal were visible in data yet rarely recognised as epistemically valid expressions.

This aligns with Milton's (2012) double empathy problem, which theorises that breakdowns in communication are mutual and socially mediated, not autistic deficits. In this review, gap widened in studies where autistic perspectives were framed through adult led categories (e.g. Cook et al., 2018) and narrowed when pupils co-constructed meaning or reframed inclusion on their own terms (e.g. Goodall, 2020).

These findings suggest that methodological choices, including who defines what counts as voice, actively shape whether autistic perspectives are recognised or misinterpreted.

Fricker's (2007) theory of epistemic injustice further illuminates this issue. In many studies, autistic pupils' non-verbal or symbolic expressions were included but not analysed (e.g. Cook et al., 2016; Fox & Asbury, 2024). This points to testimonial injustice: a failure to treat pupils as credible knowers due to normative expectations around communication. Voice was often considered legitimate only when verbal and adult validated.

While several studies claimed a participatory approach, this was not always reflected in the actual research process. Studies rated at Shier Levels 1-2 often maintained adult control over research decisions, with pupils consulted but not actively involved in shaping research aims, interpreting findings, or informing dissemination. In these cases, autistic perspectives were sometimes reinterpreted through problem-focused or diagnostic frameworks, without critical reflection on the researcher's role or underlying power dynamics (e.g., Cook et al., 2016). This echoes wider critiques from critical disability theory around tokenism, where pupils appear included, but adults retain control over key decisions, leaving power imbalances unaddressed (Wang et al., 2022).

2.6.2 Strengths and Limitations

2.6.2.1 Strengths

This review extends existing literature by offering a systematic analysis of how autistic pupil voice is represented in relation to participatory depth. While earlier reviews (Newson et al., 2024; Zanuttini, 2023) noted the scarcity of participatory methods, they did not appraise voice in connection with pupils' influence over research processes. This review advances the field by:

1. Clarifying the participation gap- using Shier's (2001) Pathway to Participation to show that no studies exceeded Level 4, with most remaining at Level 2 or below.

2. Demonstrating the representational consequences- showing how higher participation levels were linked to more emotionally grounded, co-constructed accounts.

3. Contributing methodological clarity- offering a transferable appraisal framework for assessing voice and inclusion across qualitative studies.

To support this, the review combined thematic synthesis with a participatory appraisal lens, analysing not only what pupils shared but how research design shaped whose voices were included, how they were interpreted, and which forms of expression were recognised. These contributions highlight the relational and methodological conditions that shape autistic pupil voice in research.

The review followed PRISMA guidance and applied a transparent quality appraisal process (CASP, 2018; Shier, 2001), enhancing rigour and auditability. Limiting inclusion to UK peer-reviewed studies ensured contextual relevance to NHS and education policy, though this may have excluded innovative participatory work from other countries. The combination of thematic synthesis with a structured participation framework offers a novel contribution to autism research, particularly in relation to voice, power and representation.

2.6.2.2 Limitations

Several limitations should be considered when interpreting these findings. First, although the search strategy was comprehensive and iteratively refined, it relied on database indexing and existing terminology. Given the evolving language of autism research, some relevant studies may have been missed (Cooke & Booth, 2023).

Second, excluding grey literature supported methodological rigour but may have omitted co-produced or community led work often published outside academic publishing, for instance through charities instead (Newson et al., 2024). This may have limited visibly of alternative approaches to researching autistic pupil voice.

Third, most studies involved verbally fluent participants. Autistic pupils who communicate through non-verbal modes of communication were rarely represented, and where present, these forms of expression were rarely analysed as meaningful data. This may reinforce neurotypical assumptions about what counts as valid voice (Hemmingsson et al., 2022; Taneja-Johansson, 2023).

Finally, some studies reported participatory practices only minimally. As a result, Shier ratings in this review should be seen as indicative rather than exhaustive. This reflects broader challenges in qualitative reporting, where limited methodological transparency can obscure how voice is accessed and interpreted.

2.6.3 Implications for Practice and Research

This review highlights that autistic pupil voice is not simply expressed, but co-constructed through research conditions, adult assumptions, and the depth of participation afforded. These findings carry important implications for inclusive research design, educational practice, and clinical engagement with autistic young people in mainstream schools.

2.6.3.1 Education and Clinical Practice

Autistic pupils' ability to participate meaningfully in school and research depends on emotionally safe environments, anchored in trust, predictability, and communication scaffolds. These conditions were associated with richer, more self-defined accounts of inclusion and need (e.g. Cunningham, 2022; Goodall, 2020). Educators, school-based clinicians, and Educational Psychologists' (EPs) should treat these relational dynamics as foundational, not peripheral, to enabling voice.

- Assessment frameworks should include flexible, multimodal tools, such as photo elicitation or emotion diaries, to support expression beyond verbal language. This is especially important for pupils who communicate through behaviour, metaphor, or sensory cues.
- IEPs and clinical formulations could draw on Shier’s Pathway to Participation as a reflective tool, ensuring pupils are not only consulted but actively involved in decisions about their support.
- Staff training should help practitioners recognise non-verbal indicators of distress (e.g. masking, shutdowns) as communicative acts, not as disengagement or defiance. This aligns with trauma-informed approaches to school distress.

These implications are consistent with NHS frameworks promoting Shared Decision Making (SDM), which emphasise emotional safety, power-sharing, and adapted communication. SDM recognises individuals as experts in their own experience, a principle mirrored in this review, which shows that voice is shaped not only by opportunity to speak, but by the relational and methodological conditions under which speaking becomes possible.

For clinical psychologists, these findings reaffirm core principles such as the importance of relational safety and communication diversity in formulation. They also extend these principles by evidencing how participatory depth influences what is shared, heard, and represented. This aligns with trauma-informed and neurodiversity-affirming approaches (BPS, 2013), and supports the development of co-constructed, contextually grounded formulations (Johnstone & Boyle, 2018). The findings offer a practical lens to reflect on how autistic pupils’ voices may be missed or misinterpreted, particularly when constrained by neurotypical norms or adult-led framing.

2.6.3.2 Research Design

The review found a consistent pattern: studies rated at Shier Levels 3-4 provided more emotionally grounded and co- constructed representations of pupil experience. In contrast, studies at Level 1- 2 often relied on adult interpretation, with limited reflexive attention to whose voice was prioritised.

- Design for participation: future studies should embed participation from design through to dissemination. Member checking, advisory groups, or co-analysis should be resources and treated as core components.
- Researcher reflexivity: few studies critically examined how their own positionality shaped meaning-making. Qualitative research involving autistic participants must engage with neurotypical assumptions that may influence what is seen, coded, or omitted.
- Analysing non-verbal data meaningful: symbolic forms such as drawing, silence, gesture or metaphor were often elicited but not analysed. Researchers should use frameworks (e.g. visual narrative analysis) that treat such expressions as legitimate data, not just prompts.

2.6.3.3 Contribution to the Discipline

The findings are particularly relevant for clinical psychologists working with neurodivergent young people. They call for a shift from procedural inclusion (e.g.

attending or being interviewed) to meaningful co-construction of knowledge. This aligns with the neurodiversity paradigm and the ethos of participatory research, supporting a more just, reflexive clinical psychology that centres lived experiences and challenges normative assumptions about communication, agency and credibility.

2.6.4 Conclusion

This review shows that autistic pupils voices are present but precarious: they surface most fully when research environments foster emotional safety, when researchers share interpretive space and when non-verbal communication is recognised as meaningful. Shier's framework (2001) offers a useful framework for identifying tokenism and highlighting how participatory depth directly shapes what becomes knowable. Moving from consultation to genuine co-construction is not an ethical add-on, but a methodological necessity if educational research, and by extension school based psychological practice is to be produce insights grounded in autistic lived experiences in school.

2.7 Rationale for Current Research

Autistic pupils in UK mainstream schools face disproportionately high levels of distress, exclusion, and unmet educational needs (Atkinson & Mansfield, 2024c; Sanson & Sasso, 2023). Despite growing policy emphasis on inclusion and pupil voice, much of the qualitative research in this area continues to rely on adult-led, speech-focused methods that limit how autistic perspectives are accessed and represented (Cook et al., 2018; Goodall, 2019; Lewis et al., 2023). As a result, autistic pupils are often positioned as data sources rather than as meaning-makers in their own right.

The systematic literature review conducted as part of this thesis identified three recurring patterns: although emotional safety featured prominently in pupil narratives, few studies explicitly considered it as a methodological factor, for example in researcher-participant dynamics; pupils’ perspectives were frequently shaped through adult framing; and symbolic or embodied communication was often excluded from analysis. These patterns were strongly influenced by the level of participation pupils were afforded. Most studies clustered at Levels 1- 2 on Shier’s (2001) Pathways to Participation, offering little opportunity for co-construction. No study reached Level 5, where pupils share power and responsibility for shaping the research process.

These findings align with theoretical critiques from the neurodiversity paradigm (Kapp, 2020), the double empathy problem (Milton, 2012), and the concept of epistemic injustice (Fricker, 2007). Each highlights the risk that autistic pupils’ communication, especially when non-verbal or affective, may be marginalised or misinterpreted within research settings dominated by neurotypical norms. From a CRSC perspective, pupil voice is not treated as fixed or neutral, but as something co-produced through relational, institutional, and methodological processes.

The present study responds by adopting a Photovoice methodology informed by Participatory Action Research (PAR), enabling autistic adolescents aged 14- 18 to co-construct the research focus and reflect on their lived experiences of school. Self-selected photographs served as visual scaffolds for discussion, supporting pupil-defined meaning-making while accommodating symbolic and affective expression.

Although the analysis will centre on verbal dialogue, photographs are not treated as illustrative ‘data’. Instead, they are used to support reflection, helping pupils to define what matters and how it is expressed. This design choice directly addressed gaps identified in the SLR, where visual or embodied communication was often excluded from the analysis.

While the study did not claim full co-researcher status, it aimed to achieve Shier’s Level 4 by embedding multiple points of pupil influence and collaborative interpretation. In line with neurodiversity paradigm and CRSC framework, images and captions will also be included in dissemination, extending the reach of autistic voice beyond the spoken word.

By prioritising emotionally safe interactions, supporting visual expression, and involving pupils in shaping the research process, this study addresses key gaps identified in the literature and contributes to more inclusive research practices. It offers a grounded, pupil-led account of school experience that has relevance for both educational and clinical psychology, particularly in shaping how autistic distress, belonging, and agency are understood and responded to in practice.

2.8 Aims and Research Questions

2.8.1 Aim

To co-explore with autistic pupils aged 14-18, how they make sense of their experiences in mainstream secondary school, using Photovoice (Wang & Burris, 1997) to support emotionally meaningful, participant led reflection. The study centres pupil-defined meaning, wellbeing and multimodal communication within a CRSC framework (see 1.3.2). The focus was on how autistic pupils depict and narrate moments of school life through self-generated photographs.

2.8.2 Overarching Research Question

"What are your experiences of being in mainstream school?"

This broad guiding question was developed in line with the study's overarching aims. However, it was not treated as a fixed or researcher-imposed frame. During the first preparatory workshop, participants were invited to reflect on the questions wording and relevance (see 3.3.3). They shared that it felt meaningful and a good starting point and did not wish to change it. Instead, they refined its focus through discussion and the development of focus points for photographs, which helped shape how they wanted to respond.

This process reflected both the participatory ethos of the study and its CRSC stance: voice was seen as co-constructed through interaction, interpretation and the wider research environment, not as fixed.

Chapter Three: Methodology

3.1 Chapter Overview

This chapter outlines the methodology used to explore autistic pupils' experiences in mainstream schools. Grounded in the study's CRSC stance (see chapter 1), the study sought to understand how pupils made sense of school life through their own words, images and interpretations. A participatory, visually driven design was adopted to reflect the open and exploratory nature of the research question: "what are your experiences of mainstream school?". Photovoice (Wang & Burris, 1997) was selected to support flexible, participant led expression, while Reflexive Thematic Analysis (RTA) (RTA, 2019) enabled interpretation of how those experiences were shaped by social, sensory and institutional factors.

The chapter proceeds to:

1. Justify the study's qualitative and participatory design.
2. Describe recruitment, data collection and analytic procedures.
3. Detail ethical, safeguarding and reflexive processes.
4. Demonstrate rigour using Yardley's (2000) quality criteria.

3.2 Research Positionality and Experts by Experience Involvement

As a non-autistic clinical psychologist in training, I was positioned as an outsider to participants lived experience, but an institutional insider to NHS and education systems (see Chapter 1) (Dwyer & Buckle, 2009). I therefore approached the research as a co-constructed process, aware that my interpretations would be shaped by both personal assumptions and structural power. A reflexive journal was kept throughout to document how these dynamics were negotiated across the project (Finlay, 1998). A key reflection from this journal is presented below, illustrating how early assumptions were challenged through interaction with participants and consultants. (see appendix G).

Two autistic adult consultants were involved in the study, both with prior experience in advocacy and community-based education. They were recruited through my supervisor's existing contacts within autistic led networks and were reimbursed in line with university policy. Initial meetings explored project aims, clarified expectations and ensured that the role aligned with their interests and expertise. Their involvement reflected a commitment to meaningful participation, rather than tokenistic inclusion.

The consultants contributed to the accessibility and relevance of study materials, advising on language, visual aids, and how framing. They also supported emotional safety planning and communication options (e.g., chat-based engagement). One consultant, with a background in photography, co-delivered the photography training during the preparatory workshop, which helped participants feel more confident using visual storytelling and was identified by some as a tangible skill they gained through the research.

Both consultants co-facilitated Photovoice workshops. Their presence, alongside their willingness to share personal experiences helped foster a relatable and emotionally safe group dynamic. Several participants later reflected that the consultants' involvement enhanced their engagement. By affirming the value of lived experience, the consultants reinforced the study’s participatory ethos and trauma-informed aims.

The study was informed by participatory action research (PAR) principles (Kindon et al., 2007) and aimed to embed meaningful involvement throughout. At times, session plans were adapted in response to participant energy levels reflecting the study’s iterative, responsive design (Milton, 2014).

It is important to acknowledge that while Photovoice often aspires to full co-production, especially in shaping research questions and collaboratively analysing data (Wang & Burris, 1997; Latz, 2017), this was only partially achieved in the current study. Participants helped shape the research focus and shared meaning through group discussion but were not involved in formal coding or theme construction. Similarly, consultants contributed to prompt design, co-facilitated workshops, and offered feedback on emerging interpretations, but they did not participate in transcript level analysis.

This reflected both the realities of doctoral research (including ethical and time constraints) and a deliberate choice to use RTA, which positions the researcher as the analytic instrument (Braun & Clarke, 2019). While full co-production was not enacted, the process was designed to centre participant meaning as far as possible, and to remain reflexively aware of the limits of participation. These decisions, shaped by both practical constraints and the study’s epistemological stance, are revisited in the Discussion as part of a wider reflection on participatory practice.

Table 9 below summarises how different dimensions of my positionality shaped decisions and responses:

Table 9

Dimensions of Reflexivity

Dimension	Positionality	Reflexive Action
Social/professional	NHS trainee; access to institutional systems	Shared delivery with autistic consultants; transparency in process
Epistemic	Non-autistic; outsider to lived experience	Dialogic peer-checking; reflective journaling
Affective	Anxiety about online disengagement	Flexible facilitation; pacing adjustments; camera-off options

3.3 Design

3.3.1 Rationale for Qualitative and Participatory Design

Qualitative methods support in depth exploration of lived experience, relational meaning making and contextual complexity (Denzin & Lincoln, 2011; Willig, 2013). They are particularly well suited to working with underrepresented groups, as they accommodate a diverse form of expression and foreground participant voice (Cornwall & Jewkes, 1995; Fletcher-Watson et al., 2019). Prioritising qualitative approach ensured that policy-relevant recommendations were grounded in rich first-person accounts rather than metrics that often obscure heterogeneity in autistic experience (Pellicano & den Houting, 2022).

A participatory approach was also appropriate given the history of autism research treating young people as passive subjects rather than active contributors (Galletta & Torre 2019; Milton, 2012; Wang & Burris, 1997). This study drew on PAR principles, which have been widely used in educational and mental health research to promote agency, challenge systemic exclusion and support participant led inquiry (Vaugh et al., 2020). While not fully co-produced, the design prioritised meaningful involvement across the research process (see section 3.2). Although photovoice often involves participants in generating the research questions (Wang & Burris, 1997), the overarching question in this study was developed by the researcher to meet ethics approval requirements. Shier’s (2001) Pathways to Participation framework further informed the design, offering a model of participation that spans five levels of increasing agency and shared decision making. The framework supported critical reflection on power sharing and how participant influence could be embedded at different stages of the study (Tisdall, 2017). Participants were invited to amend or reframe the guiding question and chose to keep it, noting that it was already meaningful to them. They then shaped its focus through prompt co-construction and group discussion (Level 3), selected topics to explore through photography (Level 4), and co-developed dissemination outputs (approaching Level 5). Autistic consultants contributed to design and delivery decisions, reflecting higher levels of involvement (Levels 4-5), in line with PAR principles (Vaughn et al., 2020; Cornwall & Jewkes, 1995). This helped translate participatory values into methodological decisions aligned with the study’s CRSC stance and neurodiversity-affirming approach (Milton, 2012; Botha & Frost, 2020). It also ensured continuity with the study’s SLR (Chapter 2), where Shier’s framework was used to evaluate how autistic pupils’ voices were represented in previous research.

The study’s participatory ethos also aligned with values from community psychology and critical disability research, which emphasises collaboration and ethical engagement in research with marginalised* populations (Nelson & Prilleltensky, 2010; Ozer, 2013). This alignment supported both the epistemological commitments of CRSC, and the methodological goal of centring young people lived experiences.

Photovoice (Wang & Burris, 1997) was selected as a participatory visual method that complemented these aims. It has seen extensive recent application in mental health and autism research (Liegghio et al., 2018; Povee et al., 2019).

3.3.2 Photovoice as a Participatory Visual Method

Photovoice combines participant taken photographs with dialogic reflection to support the expression of lived experience in both visual and narrative forms (Wang & Burris, 1997). Originally developed within public health, Photovoice has been used across educational and disability research to centre marginalised perspectives and inform systemic change (Brown & McDonnel, 2022; Fletcher-Watson et al., 2019; Lal et al., 2012; Povee et al., 2019)

As introduced in Chapter 1, Photovoice has theoretical roots in Freirean Pedagogy, feminist inquiry and visual ethnography, which emphasise empowerment, reflexivity and knowledge co-construction (Freire, 1970; Hesse-Biber, 2012; Pink, 2021). These

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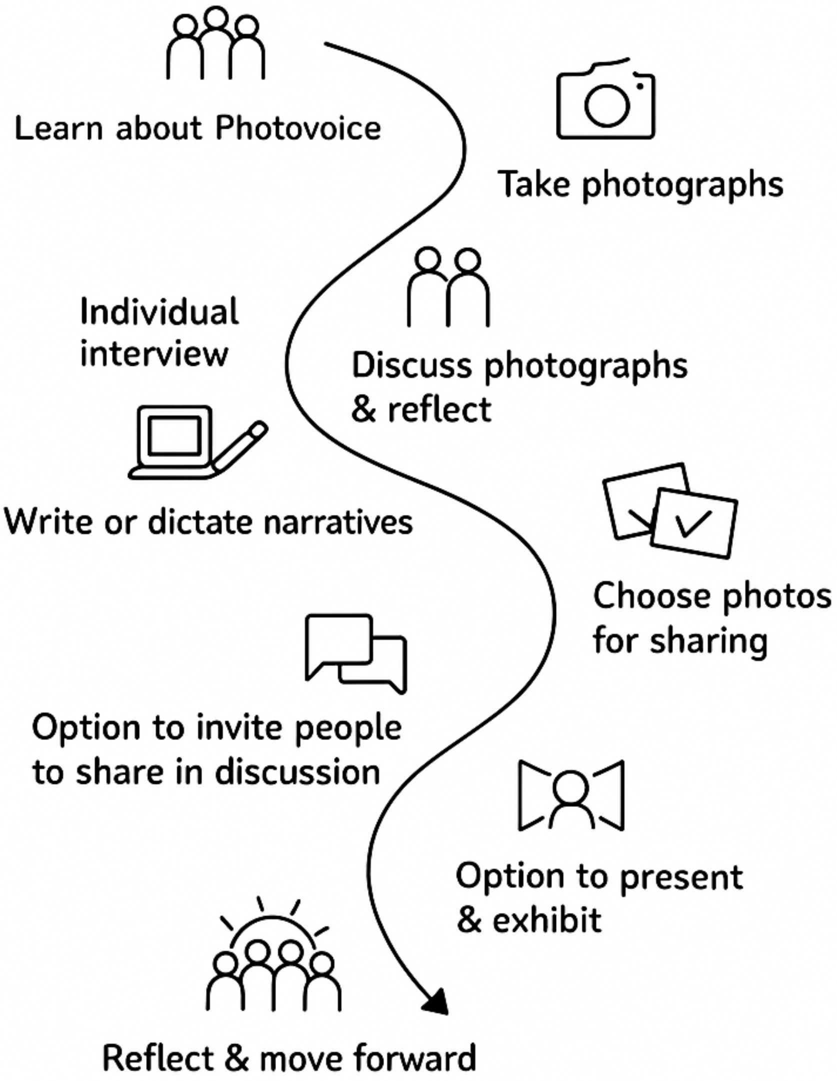
* “marginalised” refer to the structural and systemic exclusion of autistic people from educational, clinical and research contexts, rather than implying inherent vulnerability. This framing aligns with critical disability theory and the neurodiversity paradigm, which locate disadvantage in social and institutional responses to difference, rather than in individual deficit (Goodley, 2014; Kapp, 2020; Milton, 2012).

principles align with CRSC (Harper, 2011; Willig, 2012), recognising that while material structures shape pupils' experiences, meaning is constructed through interpretation, relationship and resistance. Recognising the diversity of autistic communication was central to the decision to use Photovoice, a method that values participant-led expression and supports meaning-making beyond purely verbal categories (Lewis et al., 2023; Richards & Crane, 2020).

Photovoice enabled participants to make visible aspects of school life that may otherwise be overlooked in traditional verbal methods, particularly sensory, emotional or relational dimensions. To support safe and ethical image making, participants received guidelines on ethical photography (see appendix O). Figure 3 illustrates the photovoice journey adapted for this study.

Figure 3

A Photovoice Path (adapted from Lorenz, 2005).



3.3.3 Participant Co-Production

The study was introduced to participants with a broad topic focus- exploring autistic pupils' experiences in mainstream school, rather than a fixed research question. This reflected the study's PAR informed design and commitment to participant agency (Vaughn et al., 2020).

In the first preparatory workshop, participants engaged in a visual idea-generation task to reflect on what felt important, overlooked or hard to talk about in school. The screenshot in Figure 5 reflects their ideas. Through this process, they co-produced the guiding research question: "*what are your experiences of mainstream school?".* This participant-generated phrasing was adopted as the study's formal research question.

During the same session, participants identified focus points for their photographs, including feeling safe, masking and sensory overload. The topics become informal anchors for image taking, while still allowing space for individual reflection and emerging ideas.

Participants were active collaborators across multiple stages of the project. Figure 4 summarises the stages and depth of participant contributions.

Figure 4

Participant contributions

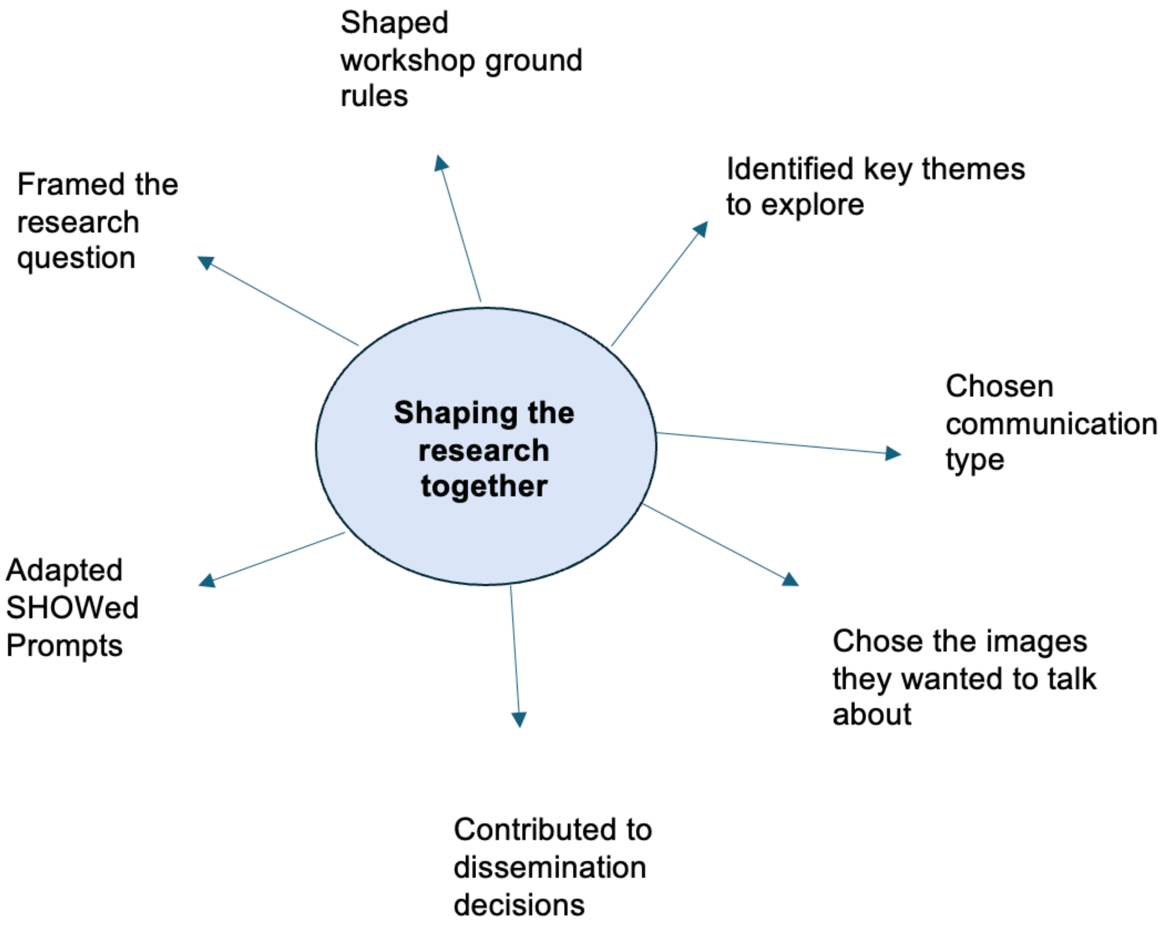


Figure 5

Participant generated focus points for Photo Prompts from Workshop

3.3.2 SHOWeD and Co-producing Interpretation

In the second preparatory workshop, I introduced the SHOWeD reflection framework (See, Happening, our lives, Why, next Steps) originally developed by Wang & Burris (1997) and widely used in contemporary photovoice studies to scaffold participation narration (Povee et al., 2019).

While the framework itself was researcher-introduced, participants contributed to adapting its wording to suit their preferences. Some of the original prompts were felt to be too abstract, and participants suggested alternative phrasings that were clearer and more relatable. The final adapted version (see Appendix H) included: “what helps you feel safe?”, “what is hard to explain?”, and “why does this situation exist?”.

These prompts were used flexibly during individual interviews to support participant-led meaning-making and were treated as optional guides rather than a fixed structure. This adaptation process reflected the study’s PAR-informed ethos and helped support emotional safety and accessibility.

Photographs were used as narrative prompts, not as standalone data. This approach emphasised participant led interpretation over researcher led coding, consistent with visual ethnographic approaches that treat images as meaning making tools rather than objective representations (Pink, 2021; Rose, 2016; Schwartz, 1989). For a detailed breakdown of each procedural step, see section 3.7 Steps were adapted from Wang and Burris (1997) to ensure accessibility and flexibility in line with autistic pupils’ communication preferences and contexts.

Two preparatory workshops supported participants to engage with the Photovoice method, explore focus areas, and shape the reflective tools used in the study. These sessions emphasised autonomy, flexible communication, and collaborative meaning making. Design decisions were directly shaped by the findings of my SLR and the ethical and relational commitments that informed the study from its inception. Table 10 summarises how participants shaped the reflection prompts and accessibility supports.

Table 10

Participant Contributions to Prompt Development

Workshop Focus	Description
Co-Developing Reflection Prompts (SHOWeD)	Re-phrased abstract prompts to be more accessible e.g. *“What does inclusion look like?”* to *“What moments at school make you feel included?”* and *“What is happening in this photo?”* to *“What does this show about school?”*. Ensured that prompts scaffolded rather than constrained expression, participant meaning making (appendix h)
Accessibility Measures	Provided visual aids and flexible pacing, simplified language to suit varied processing styles. Participants could contribute verbally, via chat, or using written responses.
Optional 1:1 Support	Participants could request additional help with reflection prompts. Follow-up support was offered via email, chat, or short calls when needed.

3.3.5 Online Delivery of Photovoice

Photovoice workshops were delivered online via Zoom to improve accessibility and reduce sensory, travel and scheduling demands (Lichty, 2019; Tanhan & Strack, 2020). Early consultation revealed a strong preference for remote engagement, informing the decision Participants joined from familiar settings and engaged through speech, chat or non-verbal reactions, depending on preference (Botha & Frost, 2020). Cameras could be turned off, and breaks were encouraged, supporting sensory regulation and autonomy. This approach aligns with Brayley’s (2023) systematic review, which recommends structured delivery to support comfort and engagement in online Photovoice.

Zoom’s professional features (e.g. waiting rooms, passwords, GDPR compliance) were used to protect participant privacy and ensure safe, ethical delivery of sessions. These measures anticipated safeguarding concerns while preserving participant comfort and privacy.

While online delivery improved accessibility, it also limited informal peer connection and embodied cues. This reflects wider tension in participatory research, where adaptations that improve inclusion can reshape the nature of engagement and meaning making (Kindon et al., 2007). Nonetheless, participants reported that the format was supportive and reflexive, consistent with the study’s CRSC and neurodiversity-affirming commitments.

3.4 Reflexive Thematic Analysis (RTA)

RTA (Braun & Clarke, 2019;2021; 2024) was selected for its compatibility with the study’s participatory and CRSC stance. RTA offers a flexible, researcher driven approach that recognises meaning as co constructed and context bound. RTA enables analysis of both semantic content and latent patterns, allowing lived experiences to be foregrounded while critically examining systemic influence (Terry et al., 2017). This was particularly important given the study’s focus on autistic pupil’s experiences in mainstream education, where dominant neurotypical narratives often shape how experiences are measured and understood (Botha & Frost, 2020; Milton, 2012). RTA also suited the dialogic and interpretative nature of

Photovoice, allowing space for symbolic meaning and relational nuance to emerge through the analytic process.

Table 11

Consideration of Alternative Qualitative Methods

Qualitative Method	**Strengths**	**Limitations**
Narrative Analysis (Riessman, 2008)	Focuses on meaning-making and stories; aligned with amplifying participant voice	Privileges structured storytelling: may not reflect how autistic people express experience, which may be more visual or emotionally driven (Milton, 2012).
Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003; Willig, 2012)	Explores lived experience in depth; well established	Researcher-led: less compatible with participatory ethos; prioritise idiographic detail over collection patterns (Eatough & Smith, 2017)
Codebook Thematic Analysis, (Fereday& Muir-Cochrane, 2006)	Structured and rigorous; useful in applied or multi researcher contexts	May impose external frameworks, limiting space for participant led meaning making
Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2019,2021)	Iterative and interpretive; enabled theme development grounded in participant meaning while allowing critical engagement with systemic factors. Strong fit with CRSC and participatory stance.	Requires ongoing researcher reflexivity; interpretive process is subjective and evolving

Treatment of Visual Data

Photographs were used as narrative prompts. They were not treated as standalone data to be coded. decision was informed by both ethical and epistemological considerations. From a CRSC perspective, meaning is co-constructed in context, and many images held symbolic significance that emerged only through participant explanation. Some were highly metaphorical (e.g., empty corridors, blurred lights), and their meaning could not be interpreted without participant insight. Coding the images in isolation risked detaching them from their intended meaning. Instead, the images were integrated into the analysis through participants' own reflections, supporting meaning-making while avoiding researcher-imposed interpretation (Pink, 2021, Rose, 2016; Schwartz, 1989).

I focused on how participants used the images to tell stories, articulate emotions and challenge existing norms. This approach aligned with both my CRSC stance and the participatory goals of Photovoice study.

To increase transparency and support replicability, Table 12 outlines the six phases of RTA (Braun & Clarke, 2006; 2021; 2024) with accompanying reflexive notes on how each stage was enacted in this study.

Table 12

Six phases of RTA with reflexive notes on how each stage was enacted

Phase	**Description**	**Reflexive Commentary**
1. Familiarisation	Transcripts were read repeatedly alongside audio recordings, with reflexive notes recorded in a research journal. Group and individual transcripts (including chat contributions) were transcribed, collated and analysed together. Data were mapped onto an excel spreadsheet to support consistent and transparent theme development.	I noticed how emotionally rich certain metaphors were and caught my instinct to under interpret those, likely due to my clinical training to 'stay neutral'
2. Generating Initial Codes	Coding was inductive, conducted on an excel sheet. This supported iterative theme development while maintaining an	My coding reflected not just what was said, but how it was

	audit trail. Both semantic and latent codes were developed iteratively. An extract and early theme map are provided in Appendix I[*] to support transparency and illustrate the analytic process.	expressed. I reflected on where I was tempted to steer interpretation toward expected categories and paused to stay with the participants language.
3. Constructing Themes	Codes were grouped into initial themes using visual maps. Participant themes were refined collaboratively.	I initially labelled one cluster ‘isolation’ but reframed it as ‘solitude as regulation’ after reflecting on how participants described its protective function.
4. Reviewing Themes	Themes were reviewed for internal coherence and distinctiveness. Dataset was revisited to ensure alignment.	I struggled with how to preserve participant voice while still offering critical interpretation, CRSC helped me see this tension as part of meaning making.
5. Defining and Naming Themes	Themes were written around central organising concepts and supported by extracts. They were mostly latent level to explore how participant meaning was shaped by underlying systemic structures (Braun & Clarke, 2022)	I shared early theme names with participants & consultant for feedback. Their language helped me refine tone and emphasis to stay close to their intentions. This was not framed as “member checking” but as part of

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[*] Full coding extract and theme map provided in Appendix J

		dialogic meaning making process. This helped avoid validation-based language and instead prioritised relational and interpretive depth (Braun & Clarke, 2023)
6. Producing the Report	Themes were written up within a CRSC informed narrative, with integrated theory	The writing process helped me understand some images as symbolic expressions (e.g. a bird alone in the sky) of unmet need, even if this wasn't explicitly verbalised.

This combined structure ensured that participant voice informed analysis while allowing critical reflexive interpretation in line with participatory and CRSC principles.

3.5 Ethical Considerations

3.5.1 Layered Consent and Capacity

Ethical approval was granted by the University of Hertfordshire Ethics Committee (ref no: 02452025Feb HSET) (see appendix N). An amendment was submitted and approved to broaden recruitment pathways partway through the study. This ensured that evolving inclusion effort remained transparent and aligned with university ethics procedures. The consent process was designed in alignment with participatory and neurodiversity affirming principles, recognising consent as a relational and ongoing process rather than a one-off event (Brady & Warren, 2019). This approach was especially important when working with autistic young people, whose communication preferences and energy levels may vary across stages of research engagement.

The study adhered to the British Psychological Society's Code of Human Research Ethics (BPS, 2021a) and Code of Ethics and Conduct (BPS, 2021b), with particular attention to autonomy, capacity, accessibility, and emotional safeguarding. Historically, neurodivergent voices have been excluded from research due to perceived challenges in obtaining informed consent, contribution to their underrepresentation in knowledge production (Boxall & Ralph, 2009; Brown & McDonnell, 2022). This study took an explicitly inclusive approach, using layered, relational consent to promote participation while maintaining ethical safeguards.

Consent and assent (see appendix L) were obtained through an initial meeting with each participant and, where required, their parent or carer. Information was provided using accessible formats, including a visual “research passport”, outlining project aims and participation rights (see appendix K). Participants and families were invited to identify personalised signs of distress and co-develop preferred responses (e.g. contacting their parent/giving them time alone). These were documented in the research passport and referred to throughout the study. Verbal and written assent were revisited at key stages (e.g. before interviews, prior to image use in dissemination), and participants were reminded of their right to pause or withdraw at any time without explanation. This supported autonomy and reduced pressure to remain involved. Figure 6 presents the layered consent process across the study. See appendix M for photo-release form.

Figure 6

Layered Consent Process Across Study Stages

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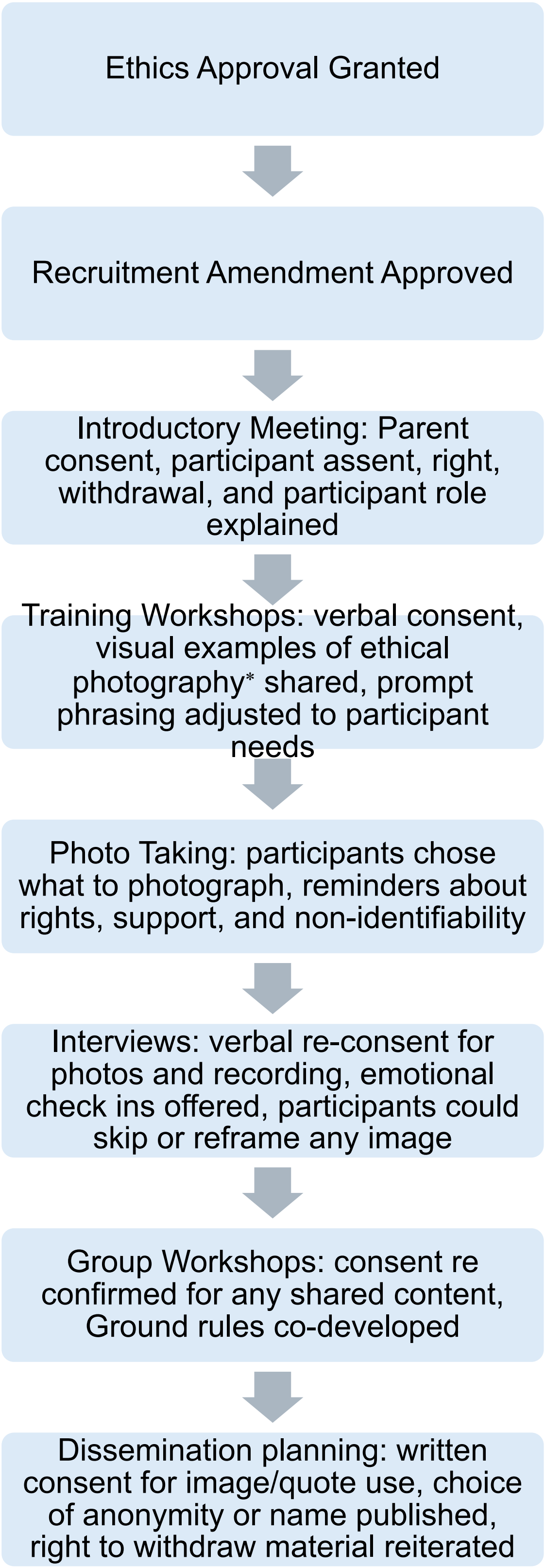

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[*] See Appendix S for Ethical Photography

Capacity to consent was not assessed using standardised tools but was informally evaluated in early meetings by explaining the project, checking understanding and encouraging questions. While parental consent was required, parents were positioned as supported rather than gatekeepers.

To protect privacy, participants were advised not to include individuals in their photographs. Images were stored on encrypted university servers and retained for two years, shorter than the five-year retention period for interview data, reflecting the greater identifiability and sensitivity of visual material.

Participants were informed that withdrawal was possible at any point until their data were anonymised and thematically coded, after which full removal was no longer feasible (Brady & Warren, 2019). This limitation was explained during the consent to support informed decision making.

3.5.2 Emotional Safeguarding

Reflecting on personal and school-based experiences through Photovoice can be both empowering and emotionally complex (Tanhan et al., 2022). While the method supports self-expression and agency, it also holds the potential to surface distressing material. Emotional safeguarding was therefore integrated throughout the study, grounded in both participatory principles and clinical duty of care expectations relevant to my role as a trainee psychologist (BPS, 2021a).

Participants were not assumed to be vulnerable but were treated as experts in their own experience, with full control over their level of engagement. They could pause, take breaks, withdraw, or skip any activity without explanation. These boundaries were reiterated at every stage including interviews and group workshops.

Emotional regulation strategies were introduced during the preparation phase, co-developed with consultants, and tailored to participant preferences. These included grounding techniques (see appendix O), co-created group norms (e.g. share only what you want to, you can come back to it later), and flexible communication options such as chat, camera off, or typed responses. The latter was particularly helpful for participants who found written interaction more accessible (Turff, 2024). Participants also received a reviewed list of mental health and advocacy services (Crane et al., 2021; see appendix Q). Emotional safety was embedded throughout: participants were encouraged to express discomfort at any stage, and adjustments were made flexibly in response. Follow up check ins were offered where needed, in line with ethical guidance for emotionally complex qualitative research (Guillemin & Drew, 2010).

Safeguarding protocols were in place in case of emotional or psychological concern. The escalation pathway was participant, research, academic supervisor and Key Contact for Participant Crisis Services, if required. The full escalation pathway is shown in Figure 7. These procedures were explained transparently during pre-screening meetings and included in the information sheet. Where possible, it was agreed that participants would be informed first.

No safeguarding concerns arose during the study. [*]However, I remained reflexively aware of the emotional risks involved. Several participants described the process as

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both validating and challenging, an emotional duality reflected in previous participatory research where self-representation can be both liberating and demanding (Oliffe & Bottorff, 2007). This highlighted the importance of balancing care with autonomy, ensuring emotional safety was not imposed but co-constructed.

Figure 7

Emotional Safeguarding Escalation Pathway

Participant discloses emotional or wellbeing concern
↓
Researcher assesses and documents concern
↓
Academic Supervisor is consulted
↓
Key Contact for Participant is informed. *
↓
Referral to Mental Health services, if required

One participant disclosed a historical experience of alcohol use and self-harm during school. This was discussed in the context of past distress, and there was no indication of current risk. In line with the safeguarding protocol outlined in the ethics application and research passport, this disclosure was reviewed in clinical supervision (see Appendix P). Carers and services were already aware of the circumstances, and therefore it did not raise a new safeguarding concern. The participant was gently reminded of their rights and offered appropriate support options.

* A “key contact” was identified for each participant to ensure safe communication if risk arose. See appendix J.

3.5.3 Dissemination Ethics

Dissemination is a core principle of photovoice, understood not only as an output but as a continuation of the participatory process, through which participants' insights challenge dominant narratives and inform systemic change (Liegghio et al., 2018; Wang & Burris, 1997). In this study, dissemination was not treated as a neutral act of reporting, but as an ethically situated practice involving questions of voice, visibility and power. Participants shaped how, where and to whom their experiences were shared, prioritising formats that felt emotionally resonant, visually accessible, and grounded in lived feeling. Some forms of dissemination will be public and visible, such as school-based exhibitions, staff training sessions and visual toolkits. Others may unfold more quietly through participants' own acts of self-advocacy, identity expression or peer connection. This layered approach reflects the core aims of Photovoice: to honour diverse ways of making meaning and to support young people in being heard on their own terms.

One participant expressed a desire to be named, feeling that anonymity diluted their advocacy. This raised an important ethical dilemma: how to honour participants right to be visible while also upholding safeguarding responsibilities (Gubrium & Harper, 2013). To address this, dissemination strategies were designed to be flexible and participant led. Individuals could opt for public recognition or anonymity and were encouraged to revisit their decisions over time. As preferences evolved, so too did consent, reinforcing the need for ongoing ethical reflexivity and dialogue. This iterative process aligns with best practices in participatory research (Daley et al., 2013; Farrell, 2021), ensuring that dissemination remained grounded in participant agency rather than researcher control.

Visual data raised specific ethical considerations related to privacy, ownership, and dissemination. Participants were instructed to avoid photographing individuals and were encouraged to use symbolic or abstract imagery (NSPCC, 2022). They retained full ownership of their images, consistent with Photovoice’s emphasis on participant control (British Sociological Association, 2017) and consent (via release forms) was re-confirmed before any material was included in the thesis and dissemination. This process upheld Photovoice’s emphasis on participant control and layered consent (Hamilton, 2007; Latz, 2017; BSA, 2017).

To support decision-making, a flexible dissemination decision tree was used (Figure 8).

Figure 8

Dissemination Decision Tree

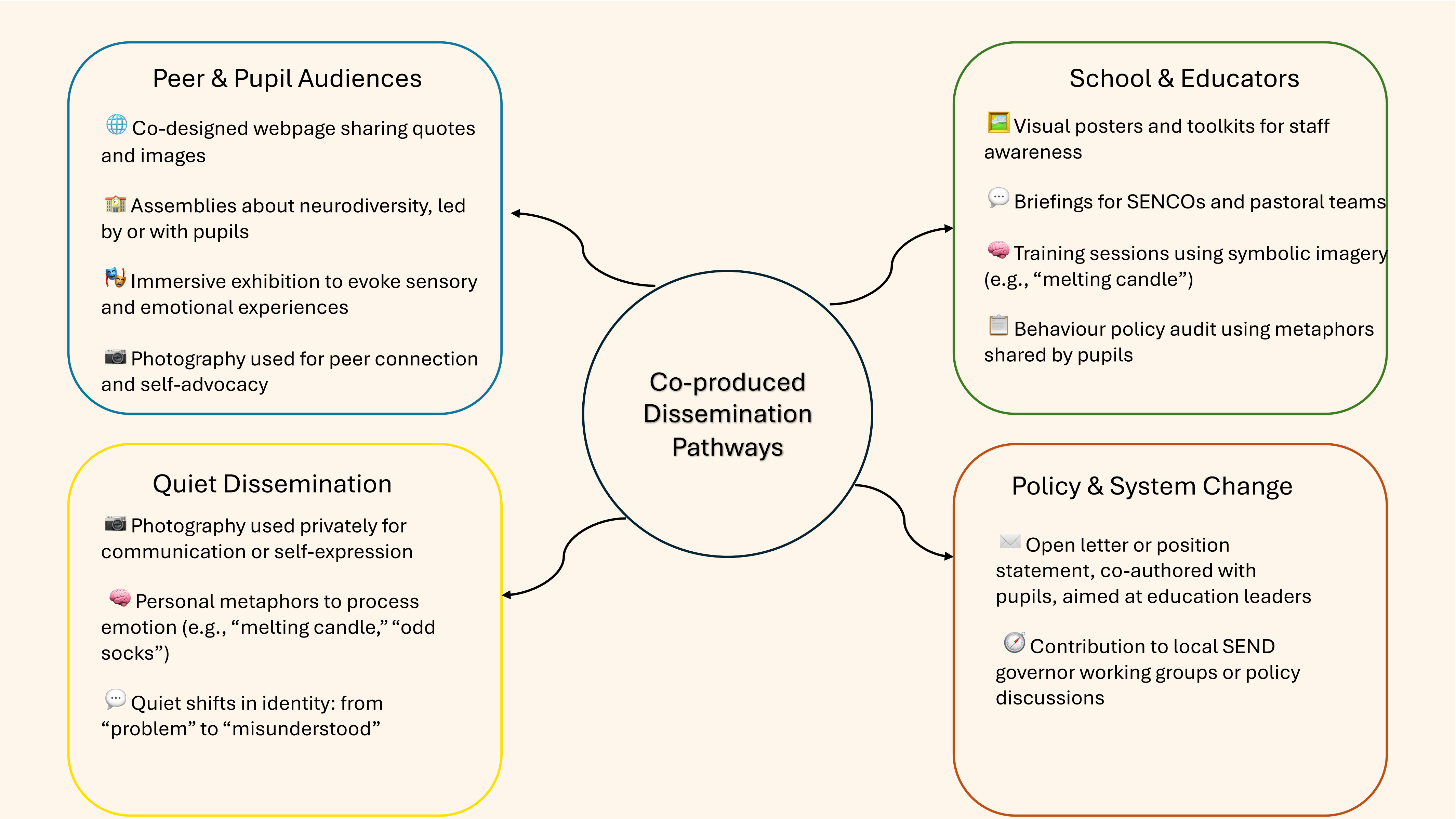
Participant submits photo / quote / caption for potential use
↓
Do they want their real name used?
→ Yes → Safeguards discussed (e.g. remove location, remove identifiers)
→ No → Use pseudonym or anonymise fully
↓
Is the content sensitive or potentially identifiable?
→ Yes → Discuss risks and revisit consent if needed
→ No → Follow participant's chosen level of visibility
↓
Re-consent checkpoints:
• During dissemination planning
• Draft content review
• Pre-launch check-in
↓
Final decision reflected in output (e.g. named quote, anonymised image, or removed if consent withdrawn)

The diagram below summarises the dissemination pathways co-produced with participants. These include formal knowledge-sharing (e.g., SENCO briefings, policy discussions), pupil led awareness-raising (e.g., assemblies, visual exhibitions), and quieter, dissemination that supports personal reflection and identity development. This layered approach reflects the relational, situated, and evolving nature of knowledge in participatory research.

Dissemination remains ongoing and responsive. Further opportunities for knowledge sharing, particularly with schools, services, and community networks, are being explored in collaboration with participants.

Figure 9

Co-Produced Dissemination Ideas



Co-produced Dissemination Pathways

Peer & Pupil Audiences

- 🌐 Co-designed webpage sharing quotes and images
- 🏫 Assemblies about neurodiversity, led by or with pupils
- 🎭 Immersive exhibition to evoke sensory and emotional experiences
- 📷 Photography used for peer connection and self-advocacy

School & Educators

- 🖼️ Visual posters and toolkits for staff awareness
- 💬 Briefings for SENCOs and pastoral teams
- 🧠 Training sessions using symbolic imagery (e.g., "melting candle")
- 📋 Behaviour policy audit using metaphors shared by pupils

Quiet Dissemination

- 📷 Photography used privately for communication or self-expression
- 🧠 Personal metaphors to process emotion (e.g., "melting candle," "odd socks")
- 💬 Quiet shifts in identity: from "problem" to "misunderstood"

Policy & System Change

- ✉️ Open letter or position statement, co-authored with pupils, aimed at education leaders
- 🧭 Contribution to local SEND governor working groups or policy discussions

3.5.4 Data Security and Confidentiality

Data security and confidentiality procedures were designed in accordance with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act (2018). All data, including transcripts, images and recordings, were handled in ways that balanced ethical obligations, institutional policy, and participants' rights to privacy and control. Full data protection procedures, including encryption, anonymisation, and retention timelines, are outlined in the information sheet (appendix J).

Limits to confidentiality were clearly explained to participants in the information sheet and during pre-screening meetings. These included the legal and ethical duty to disclose any risk of harm to self or others. Participants were reminded of these limits at each stage involving personal narrative or visual data.

Participants were also advised not to share identifying information about themselves or others during group discussion. Privacy expectations were discussed as part of the co-created group ground rules.

To protect participant identity, pseudonyms were assigned, and any identifying details were removed from transcripts and analysis. A summary of data handling procedures is provided in Table 13.

Table 13

Data handling and retention overview

Data Type	Storage Location	Retention Period	Security Measures
Audio recordings (Zoom, Teams)	Encrypted university OneDrive	Deleted within 24 hours post-transfer	Access restricted to researcher only
Transcripts	Encrypted university server	5 years	Pseudonyms assigned, identifying details removed
Photographs	Stored separately from transcripts	2 years	Avoided recognisable content; encrypted storage
Analytic notes and coded data	Excel file on encrypted device	5 years	De-identified, password-protected
Participant contact info	Secure university folder	Deleted after study completion	Not linked to transcripts or images

3.6 Participants and Recruitment

3.6.1 Inclusion and Exclusion Criteria

Participants were autistic pupils aged 14 to 18. This age range was chosen to align with developmental stages often associated with increased autonomy, emotional regulation, and symbolic meaning-making (Erikson, 1980; Piaget, 1970; Vygotsky, 1978; Steinberg, 2017). In line with the Double Empathy Problem (Milton, 2012) and the Neurodiversity Paradigm (Kapp, 2022), this study recognised that autistic adolescents may express insight in diverse ways. The photovoice method enabled participants to engage through visual and narrative expression, regardless of prior photography experience.

Participants were required to have sufficient capacity to engage meaningfully with the reflective and visual elements of Photovoice, as supported by previous participatory research (Aldridge, 2007; Overmars et al., 2018; Povee et al., 2024). This was not assessed through formal testing but through a pre- screening conversation designed to explore each participant's understanding of the study, preferred ways of communicating, and comfort with taking part. Participants were invited to ask questions, reflect on the research in their own words, and share what support might help them feel comfortable. This conversational approach offered a flexible, needs-led capacity check, aligning with participatory ethics and ensuring participants could engage in an informed, supported way.

To support this process, the following prompts guided the informal dialogue:

Table 14

Example prompts used in pre-screening capacity check

Screening Area	Example Prompt
Understanding of the study	"Can you tell me what this project is about in your own words?"
Comfort with participation	"Does this sound okay for you to take part in?"
Emotional safeguarding	"What should I do if you feel upset or want to stop?"
Practical understanding	"Would you be okay with taking photos and talking about them?"

In recognition of diagnostic disparities, especially for girls and racially minoritised young people (Russell et al., 2022), the study also welcomed self-identified autistic pupils. If a participant had no formal diagnosis but self-ascribed their identity and demonstrated a clear understanding of the study's purpose during screening, they were included. This approach reflected the study's participatory values and neurodiversity-affirming stance.

While exclusions were necessary to ensure methodological suitability, they also highlight wider concerns about accessibility in qualitative research for autistic young people with higher support needs. The inclusion and exclusion criteria are summarised in table 15.

Table 15

Inclusion and Exclusion Criteria

INCLUSION CRITERIA	EXCLUSION CRITERIA
Autistic young people aged 14-18 with a formal diagnosis or self-identification of autism.	Profound intellectual disabilities or significant communication needs that would prevent meaningful participation.
Minimum two weeks enrolled in a UK mainstream secondary school	Young people unable to provide informed consent/assent or whose parents/ guardians declined consent
Capacity to engage with photovoice (understanding the task, taking photographs and reflecting on them)	Less than two weeks enrolment Attending specialist provision Only.

3.6.2 Participant Demographics

Eight autistic young people took part in the study. Participants varied in age, gender, school context, diagnostic status and support needs, offering a diverse range of mainstream school experiences. All were involved in shaping how they participated and how their contributions were shared. All participants identified as White British. This was not an intentional sampling criterion, it reflects wider patterns in autism research and raises important questions around structural barriers to the inclusion of racially minoritised autistic young people (Russell et al., 2022). Key participant details are summarised in Table 16.

Table 16

Participant Demographics

Pseudonym	Age	Gender	Diagnosis / Self-identify	Years in Mainstream	Ethnicity	County	Additional Notes
Rue	18	Female	Diagnosed at 17	14	White British	Cornwall	Repeated a year; no formal support
Ivy	15	Female	Diagnosed at 14	Since nursery	White British	Berkshire	Receives autism-specific support
River[*]	18	Non-binary	Diagnosed at 13	≈ 15	White British	Hertfordshire	EHCP; 1:1 support
Leo	15	Non-binary	Diagnosed at 8	11	White British	Hampshire	LSA support; in Learning Support Unit
Kai	16	Male	Diagnosed at 16	Whole education	White British	Hampshire	Now in college;

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[*] One participant attended the initial workshop and contributed to prompt development and early discussions. They submitted photographs via text but could not continue due to a part-time job. Their data were not included in the final analysis due to limited engagement, though their early contributions informed the participatory design.

							previously unsupported
Pluto Blue	15	Female	Awaiting assessment	6	White British	Bristol	Adjustments in place: timetable, toilet pass, seating, inclusion base
Jasper	14	Male	Diagnosed at 4	10	White British	Berkshire	SEND support; offers school feedback
Sienna	15	Female	Diagnosed at 15	11	White British	Northamptonshire	Allowed earplugs, fidget toys, quiet space

3.6.3 Recruitment Strategy

A purposive sampling strategy was used to identify autistic young people (aged 14-18) with experience in mainstream secondary education. This approach aligned with the study's participatory and CRSC stance by enabling direct engagement with those most affected by the research focus. Recruitment occurred across three stages over a one-month period, beginning with email-based outreach to UK autism charities and autistic led networks. Recruitment then expanded to social media and, in its final stage, involved direct engagement with individual community advocates.

Initial contact involved sharing an ethically approved recruitment pack (See Appendix R) with organisations such as Ambitious about Autism, Not Fine in School and several neurodivergent-led youth networks. This strategy mirrored established approaches to recruiting neurodivergent young people through advocacy networks and social media (Townsend & Wallace, 2016). Several organisations agreed to advertise the study on their platforms and expressed support for the project. However, uptake via these routes remained limited, likely due to competing priorities and organisational capacity constraints. This reflects broader systemic barriers to research access within under-resourced advocacy sectors (e.g., staff shortages). In response to low uptake via email, an ethics amendment was submitted and approved, allowing recruitment via X (formerly Twitter), including advertisement by a well-known autistic advocate on their public page. This route yielded a higher number of direct responses, especially from parents and carers. However, it also introduced new challenges, including the need to verify the legitimacy of respondents and ensure safeguarding by checking online presence before arranging a follow-up conversation. Reliance on advocacy networks and social media may also have inadvertently reinforced existing barriers to participation for racially minoritised autistic young people, as reflected in the final sample (See Section 3.6.2).

Interested families or young people contacted the researcher directly and were offered a pre-screening conversation. This process supported accessibility, ethical transparency, and relational trust (See Figure 9 in Data Collection section for visual summary). Visual aids were shared in advance to accommodate diverse communication preferences. Eight participants were eventually recruited, reflecting strong interest while maintaining participatory depth and manageable group dynamics (Glaw et al., 2017). Small samples are typical in Photovoice studies, with seven to ten participants considered optimal, and as few as three sufficient, given the depth of visual and narrative engagement (Tanhan et al., 2022). A small degree of over recruitment was used to account for potential attrition (Sterrett et al., 2022; Wang et al., 2022).

3.6.4 Remuneration for Participants

Participation was reimbursed £15 per hour in line with university policy and community psychology recommendations on fair recognition for lived experience contributions (Cornish et al., 2023; NIHR Centre for Engagement, 2022). Payment was offered after each session to reduce any perceived obligation to remain involved. Based on feedback from advocacy organisations, reimbursement was clearly stated in recruitment materials to support transparency and avoid gatekeeping. This approach aligned with ethical commitments to treat autistic participants not just as subjects, but as co-creators of knowledge.

3.7 Data Collection

Data collection followed a multi-phase participatory process co developed with autistic consultants, foregrounding accessibility, autonomy and voice (Fletcher-Watson et al., 2019). Participants engaged in individual and group-based formats to generate rich, situated accounts of school experience. Figure 3 (Section 3.4) provides a visual summary of the full process, from initial engagement to dissemination.

Data generation occurred across three main stages. The delivery of each stage was designed to reflect CRSC principles of accessibility, emotional safety, and participatory flexibility. Table 17 summarises how these stages were facilitated and adapted.

Table 17

Data generation stages and delivery approach

Stage	**Delivery Format**	**Participant Experience & Delivery Considerations**
Preparatory Workshops	X2 online workshops introducing Photovoice, ethical image use and the SHOWeD framework (Wang & Burris, 1997). Interactive slides, chat, polls.	Prompts co-adapted for clarity (e.g. what do you think led to this?" to "" why does this situation exist?" See Appendix H for full prompt sheet. Interactive, collaboratively adapted workshops to suit processing preferences Engagement via different modes Optional 1:1 support and photography tutorial offered Ethical guidance grounded in visual research frameworks (Reavey & Johnson, 2008; Wiles et al., 2008), supporting informed, image making
Individual Interview (~60 mins)	Remote, semi structured interviews using participant selected photos	SHOWeD framework used flexibly to support participant led meaning making (Braun & Clarke, 2024).

		Allowed for private in-depth reflection including what was not captured in images Consent re confirmed No fixed limit on photographs; participants could share as many or as few images as felt manageable and depth prioritised to reduce energy demands and pressure Participants invited to reflect on whether their photos represented their experience
Group workshop (~90 mins)	Online group session for shared photo discussion and meaning making	Collective sharing and collaborative reflection Peer dialogue "finally getting to talk about school in a way that actually makes sense" illustrating value of peer dialogue Having these after individual interviews helped reduce conformity pressure, particularly relevant during adolescence. They could develop their own interpretations first
Optional Debrief	Informal unrecorded follow up after group session	Offered emotional closure, feedback or clarification of contributions Some participants used this to reprocess their input Participants were invited to stay involved in shaping dissemination over time. (resource sheet in appendix M)

On average, 1-2 weeks passed between each stage, allowing participants time for reflection and flexibility around fatigue or competing demands, while also minimising attrition (Tanhan et al., 2022). Notably, the group workshop format was particularly valued by participants and may hold future relevance for clinical and educational contexts supporting autistic young people’s reflection on school-based distress (Milton, 2012)- a point explored further in the Discussion. The full process from recruitment to dissemination planning, is also mapped visually in Figure 9.

Figure 9

Data Collection Process Overview

1 ENGAGEMENT & PREPARATION

Relational trust, co-construction & accessibility into the research process

Recruitment Support

3rd Sector Organisations & Autism advocates approached to support recruitment

Expression of Interest

Participants/parents expressed interest directly.
Selected 8 willing people based on inclusion criteria

1st Meeting & Consent

Rapport building, informal capacity check, consent/assent discussion, ethical packs & "research passports" emailed

Workshop 1: foundation

Co-facilitated with an autistic consultant & autistic photographer. **Ground rules co-created**; Photovoice method and ethical photography introduced.

Workshop 2: Prompt & Practice

Participants co-developed the guiding question:
"What are your experiences of mainstream school?"
SHOWeD framework introduced through role-play; task structure explained.

2 DATA-GATHERING & REFLECTION

Exploring lived experience through visual & narrative expression

Photography Period (2 weeks)

Participants encouraged to capture abstract/symbolic images
Flexible timeline; optional support
Cameras posted or phones used
Reminded of ethical photography

Individual Interview (online)

Links & reminders sent in advance
Photos submitted beforehand; consent re-recorded
Semi structured using SHOWeD; **participant narratives guided meaning-making**
Participants selected & captioned final images for group workshop, release forms signed

Group Sharing Workshop

Participants shared selected images in co-faciliated group setting
SHOWeD framework supported discussion; ground rules revisited
Shared & divergent meanings explored
Early theme development supported through participant led dialogue

3 DISSEMINATION

Supporting Real World Impact

Dissemination Planning

Collective discussion on how, where & to whom their work would be shared
quotes, captions & photos selected
Dissemination co-designed (immersive exhibition)
Vouchers provided

Optional follow up

Informal 1:1 follow-up offered for feedback, emotional closure & clarification of final contributions

RTA initiated post-workshop; grounded in participant dialogue

3.8 Reflexive Thematic Analytic Procedure

3.8.1 Analytic Process

The analytic process involved two interrelated phases: participant led reflection and researcher led interpretation (See appendix I for initial coding and theme development). Rather than treating participants as passive data sources, their early reflections during group workshops were treated as analytic material. This discussion surfaced key concerns, shared themes, and emotionally resonant language that shaped the direction of subsequent analysis. However, the study also required me, as the researcher, to move beyond participants framing and engage in interpretive sense making consistent with my CRSC stance. Themes were not ‘discovered’ but were developed through iterative, relational meaning making across stages (Braun & Clarke, 2024). This process is summarised in Table 18.

Table 18

Development of Themes Across Two Analytic Phases

Phase	Description	Reflexive Notes
Participant-led reflection	Group workshop discussions focused on participant meaning making and surfaced topics like “safe spaces” and “invisible struggles.” These reflections informed the analytic direction but were not formally coded. Individual interviews, held after this group session, enabled deeper exploration of personal themes	I journaled concerns about unintentionally steering the discussion. Participants’ language grounded early theme directions, foregrounding lived experience.

	such as self-harm and unmet social needs. When photos were later shared in the 2nd workshop, participants began reflecting on each other's experiences, deepening collective meaning making.	
Researcher-led RTA	Full transcripts (group, individual and chat) were analysed inductively using RTA (Braun & Clarke, 2006, 2019; 2021). Theory (social model, neurodiversity paradigm) helped me to interpret both individual narratives (micro) and broader systemic barriers (macro) (note. Not used as coding frame)	I reframed "isolation" as "solitude as regulation" based on participant tone. Similarly, "sensory overwhelm" became a critique of systemic design, not personal deficit. Themes remained open to reinterpretation throughout.
Visual data integration	Photos were used as narrative prompts to support symbolic, emotional, and multi layered meaning making. Images were not formally coded (Wiles et al., 2012).	E.g. An empty corridor was described as both refuge and exclusion. I resisted literal interpretation and focused on the relational meaning constructed in dialogue.

3.8.2 Reflexive Learning Through Analysis

Throughout the analytic process, I remained reflexively aware of my interpretative power. I drew on peer debriefing, discussion with consultants, and theoretical frameworks such as the social model of disability (Oliver, 1999), and the neurodiversity paradigm (Kapp, 2020) to support critical engagement. These perspectives enabled a shift away from individualised explanation and toward a systemic understanding of distress, regulation and belonging.

Extended reflexive notes and examples of coding shifts are included Appendix I.

3.9 Quality, Validity and Self Reflexivity

The reflexive learning process was not limited to analysis but shaped by early assumptions and real time dilemmas. A reflection on researcher expectations and emotional learning is presented below.

Figure 10

Reflexive Commentary post workshop (planning and early data collection stages)

Early in the project, I encountered moments of self-doubt and bias, particularly prior to the workshops. I initially worried participants might disengage or struggle with online tasks, assumptions that, in hindsight, these worries may have reflected an unconscious deficit framing, shaped by dominant narratives about autistic disengagement or difficultly with abstract tasks. Although not deliberate, this framing positioned participants as potentially limited, rather than capable co-researchers. Recognising this helped me reflect on how even well-meaning researchers can internalise societal assumptions, and how participatory methods can be accompanied by reflexivity to avoid reproducing them.

In practice, participants exceeded expectations. Their reflections using the SHOWeD framework were thoughtful, layered and emotionally expressive. Their engagement shifted my lens- not just about autistic participation, but about how power, voice and method are co constructed.

Logistical challenges also offered learning opportunities. For example, low attendance at the dissemination workshop prompted reflection on the need for consistent reminders, - particularly for neurodivergent participants who benefit from structure and consistency. While follow up ensured all voices were included, the experience highlighted the relational and practical demands of truly inclusive research. It also meant that when I didn't hear back during dissemination planning, I didn't assume disinterest. Instead, I followed with gentle reminders which supported continued inclusion.

3.9.1 Navigating Power and Positionality

As a non-autistic researcher, I was critically aware of the power dynamics embedded in participatory analysis, particularly in deciding whose voices are centred and how meaning is constructed. In a field shaped by medicalised and deficit-based discourses, I made a conscious effort to centre autistic perspectives and avoid interpretive bias (Braun & Clarke, 2023; Jacobson & Mustafa, 2019).

Reflexive practices, including peer debriefing and dialogue with neurodivergent colleagues, helped challenge some of my early assumptions, such as when I unconsciously framed certain coping strategies as “problems” rather than as adaptive responses (Tufford & Newman, 2012). Their input supported a shift toward a strength based, participant- informed lens.

At the same time, the realities of doctoral research required me to move beyond participants’ framing and offer my own interpretative analysis. While many narratives could have been aligned with academic categories, doing so too quickly would have risked flattening their complexity. This highlighted the discord between honouring participant meaning and meeting the analytic expectations of scholarly work.

These tensions reflect broader challenges in participatory research, whether the balance between authentic voice and institutional demands requires ongoing transparency, humility and critical reflexivity (Farrel, 2021; Klocker, 2012).

3.9.2 Quality Assessment

Evaluating qualitative quality requires alignment with a study's epistemological and ethical stance (Yardley, 2000). This research is situated within a CRSC position, which assumes that while material realities exist, our understanding of them is shaped by discourse, lived experience, and social power (Bhaskar, 1975; Harper; 2010, Willig, 2012). Yardley's (2000) framework was selected for its emphasis on contextual sensitivity, reflexivity and methodological flexibility, making it particularly suited to participatory, CRSC-aligned research. Alternative frameworks such as Tracy (2010) were considered but Yardley offered a better fit with the study's epistemological commitments and analytic approach. Table 19 details how each criterion was addressed.

Table 19

Application of Yardley's (2000) Quality Principles

Principle	Application in This Study	Reflexive Considerations
Sensitivity to Context	Grounded in a CRSC stance; informed by literature on autistic experience and inclusive practice. Autistic consultants co-designed aspects of the method (e.g., prompts, consent, delivery) (Botha & Frost, 2020). Ongoing reflexivity supported	Balancing participatory responsiveness with institutional structures (e.g., ethics forms, consent framing).

	awareness of power dynamics and helped centre participant voice throughout the study.	
Commitment and Rigour	Reflexive Thematic Analysis was applied iteratively. Data triangulated across photos, narrative, and observation (Liegghio et al., 2018). Participant feedback shaped theme naming.	Time and word constraints limited more sustained member involvement post-analysis.
Transparency and Coherence	Documented procedures across recruitment, analysis, and dissemination. Reflexive notes and coding decisions were tracked and are summarised in Appendix I. Participant feedback and flexible engagement strategies supported reflexive theme refinement and sustained involvement.	Full transparency was sometimes constrained by anonymity requirements, especially during dissemination planning.
Impact and Importance	Participants co-led dissemination planning and selected outputs- agreed for it to be shared with stakeholders (school SENCO etc). Some reported increased self-advocacy. Findings have potential to inform school practice and participatory research.	The emotional resonance of findings may not easily translate into policy impact without further collaborative work.

Yardley’s (2000) framework was not used as a checklist, but as a reflexive guide throughout the research process e.g. sensitivity to context guided the co-adaptation of SHOWeD prompts. Conflicts emerged between ethical transparency and the need to protect anonymity, and between academic structure and participant responsiveness (Stenfors et al., 2020). Nonetheless, the study aimed to enact quality through its participatory commitments, contextual sensitivity, and critical engagement with power, meaning and voice.

3.9.3 Reflexivity as a Marker of Research Quality

Reflexivity is central to ensuring credibility in qualitative research, particularly in participatory methodologies like photovoice, where researcher-participant power dynamics must be continuously negotiated (Stenfors et al., 2020). In RTA (Braun & Clarke, 2021), the researcher is not a neutral observer but an active meaning-maker, whose interpretations are shaped by their positionality, assumptions, and reflexive engagement with the data (Finlay, 2003). Rather than a limitation, subjectivity is treated as an analytic resource that enhances depth and interpretive insight (Braun & Clarke, 2024).

Throughout this study, I engaged in ongoing self-examination to uphold transparency, ensure participant perspectives informed analysis, and maintain researcher accountability. This aligns with the study's CRSC stance**,** which recognises that knowledge is not passively discovered but co-constructed within social and institutional contexts (Harper, 2010). Reflexivity was not an isolated exercise but a continuous, evolving process**,** shaping both methodological decisions and analytical interpretations (Braun & Clarke, 2021).

The methodology aimed to support meaningful autistic pupil participation while maintaining epistemological and ethical coherence. The design balanced participatory values with academic rigour, reflecting the study's CRSC stance and commitment to co-constructed knowledge.

Chapter Four: Findings

4.1 Chapter Overview

This chapter presents five themes developed through Reflexive Thematic Analysis (RTA) of Photovoice material, exploring how autistic young people experience mainstream secondary schooling. The analysis draws on both verbal and visual accounts, with photographs used as prompts to support pupil-led meaning making.

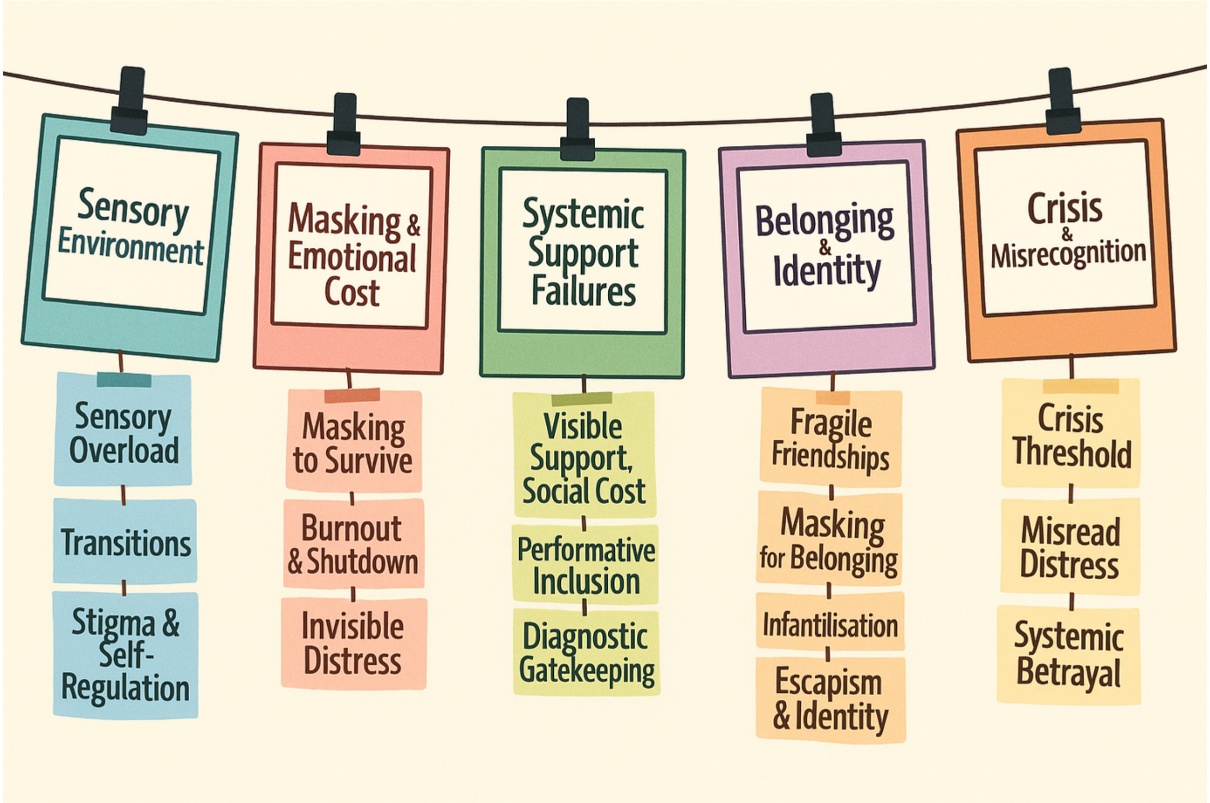
The themes reflect different but interconnected aspects of participants' experiences. These include the sensory and physical demands of school, the emotional effort of appearing to cope, difficulties accessing meaningful support, the impact of being misrecognised by others, and the consequences of being unheard.

Although presented individually, the themes often overlapped in practice. For example, sensory overload frequently contributed to emotional exhaustion, and the absence of appropriate support often made it harder for pupils to feel included or understood. Together, the themes suggest a cumulative pattern in which unmet needs build and intensify, moving from survival to emotional distress, and for some, to crisis.

Figure 12 presents the thematic map, reflecting the overlapping nature of pupil experiences.

Figure 12

Thematic Map



4.2 Theme 1: “Too Loud, Too Bright, Too Much”- Surviving the Sensory Landscape of School

This theme explores the relentless sensory demands of mainstream school as described by participants. These accounts were conveyed both verbally and visually, with photographs often used to express what was difficult to put into words. Pupils used metaphor, imagery and lived examples to describe how sensory overwhelm shaped how they engaged with learning, regulated emotions, and accessed support. These were not isolated experiences, but ongoing conditions of school life.

4.2.1Subtheme: Sensory Overload as Background and Emotional Noise

Participants described school as a space of constant sensory overload, particularly classrooms, corridors, and transitions. Sound, light and movement were experienced as inescapable and exhausting. Rather than being able to regulate or escape these experiences, pupils described enduring them, often silently, and at emotional cost.

"It was like having very powerful headphones on at full volume all the time. Completely inescapable." – Pluto blue
"The volume button on a remote... you can turn it up or down. But I had no way to turn it down. It was always stuck on the highest setting." – Ivy

Figure 13

The Stuck Remote

[7]

"Always stuck on the highest setting, even when you're just trying to think" Ivy

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[7] In photovoice, participants often pair images with titles or captions that reflect their intended meaning. These captions, where presented in boxed form are treated as part of the image, excluded from the thesis word count.

Ivy submitted this photo of a remote control to represent the experience of having no way to turn down the sensory volume at school. During a group session, Jasper reflected on Ivy's image, saying: *"That's exactly how it feels… like you're holding it, but none of the buttons do anything".* Their shared interpretation reinforced the inescapability of sensory overwhelm and the absence of responsive support, a persistent and often unacknowledged feature of classroom life, that often went unacknowledged.

Figure 14

Noise-cancelling headphones

One participant submitted an image of headphones placed on schoolwork, symbolising an attempt to regulate sensory input while trying to remain academically engaged. Pupils were expected to learn in environments that compromised their capacity to do so.

Pupils described what could be called internalised survival strategies, the effort to appear regulation in environments not built for them. They spoke of managing distress silently, rather than environments adapting to reduce harm. As one participant said: “*you just try to get through the day.”.*

In these accounts, school became a place of survival rather than growth, a structure that individualised distress, rather than recognising it as relational or environmental.

4.2.2 Subtheme 2: Transitions and the Emotional Fallout

Although school followed a timetable, the moments between structures, such as moving between lessons, spaces or expectations, were described as emotionally disorganising. These transitions often lacked predictability, containment, or sensory calm, leaving pupils abruptly exposed to noise and shifting social demands, with no time to prepare or recover.

“Sometimes it’s like having cold water shock going from such different situations so quickly.” - Rue

Rue’s metaphor captured the jarring effect of unsupported transitions. Participants emphasised that it wasn’t change itself that caused distress, but unsupported change; moments where sensory and relational needs went unacknowledged.

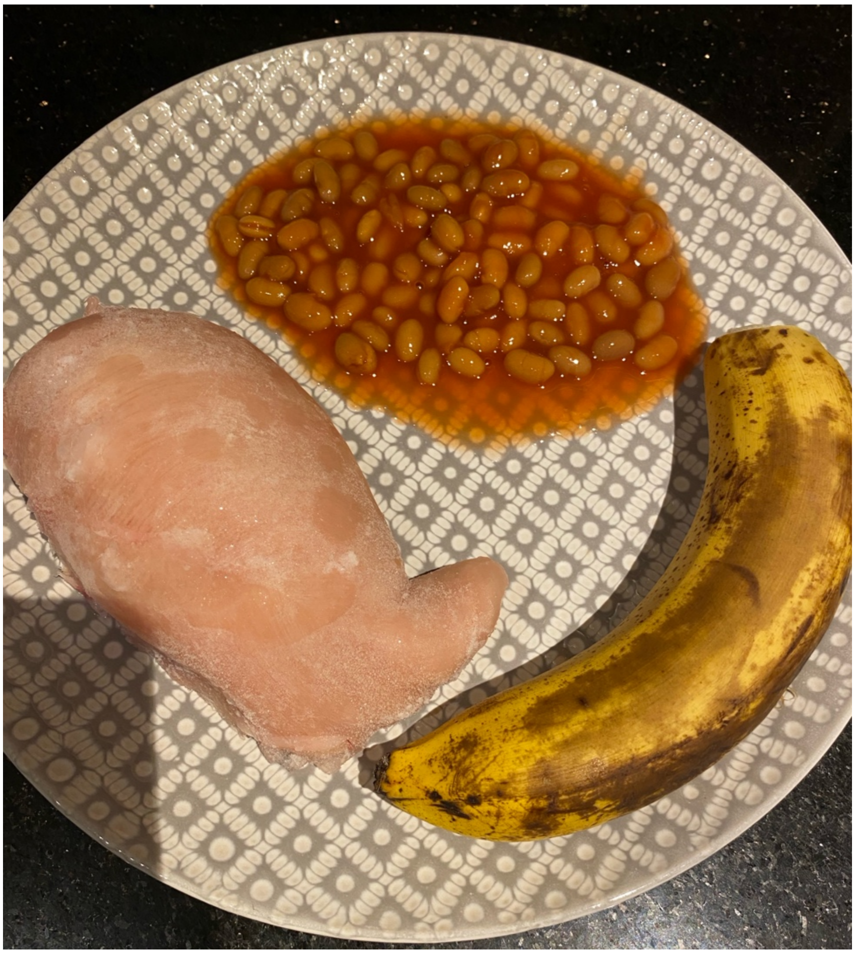
Overload often triggered shutdown, withdrawal or visible distress, which was rarely recognised as a form of communication.

"*The school kept complaining to my mum about the fact that I'd suddenly start screaming and crying and hiding myself under tables when they went from one lesson to another without giving me any warning*." - Kai

These moments were not understood as expressions of need or regulation but were framed by staff as behavioural disruption. Pupils described having to manage transitions alone, often without teachers or sensory support.

Figure 15

Raw and Unprepared



Ivy submitted this photo to symbolise how transitions felt abrupt and incoherent, “things that don’t belong together.” The image captured how sudden shifts left her emotionally disoriented, especially when sensory and social demands collide without warning.

“It’s such a challenge. I have to take an extra 5 minutes at the end and start of back-to-back lessons to readjust and avoid the crowds and chaos.” - Leo

Leo developed their own approach to reduce transition stress, describing how they gave themselves extra time to decompress between lessons. Like others, the strategies they used were self-devised rather than supported by the school.

Sienna described this slow emotional build-up:

“It’s like all day you’re collecting little stresses, and then it spills out. You go home and you’re done… can’t talk, can’t think, just done.” - Sienna

This form of *quiet burnout* was rarely recognised or supported. While this quote powerfully illustrates emotional load, the cumulative impact of persistent misrecognition and internalised coping is explored in more depth in Theme 5.

Transitions were not incidental; they were structurally embedded stress points. Pupils who held it together were often seen as coping, while those who showed distress were misread as disruptive. In both cases, the emotional meaning behind behaviour was missed. The system interpreted surface behaviour but overlooked what was being communicated underneath.

4.2.3 Subtheme 3: Coping with Stigma- Self-regulation, Shame, and Resistance

In the absence of responsive support, pupils developed their own strategies to manage distress, including stimming, zoning out, leaving class, or using sensory tools. These helped with emotional regulation but often came with social cost. Many described hiding or avoiding these strategies to avoid standing out.

"I still feel a lot of shame for using fidget toys or headphones… I feel like I'm making myself look more stereotypically autistic." - Ivy

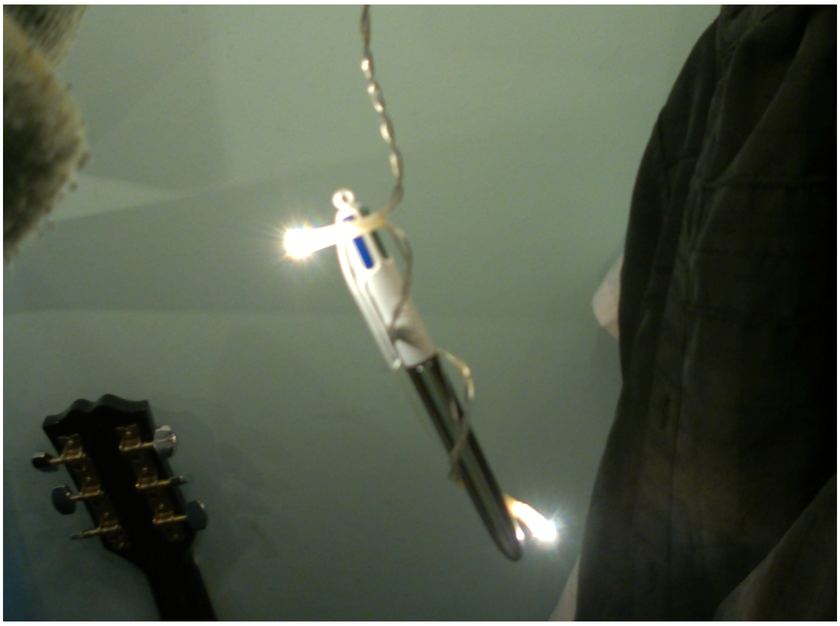
"I have a pass to leave the classroom if it gets too much, but I don't want to use it because everyone would ask me where I'm going. It's not really a solution if it just makes things worse in another way." - Pluto Blue

Participants spoke of weighing emotional safety against the risk of peer judgement. Even when others weren't overtly critical, the pressure to appear "normal" shaped how they expressed their needs. Using visible support often meant being visibly different, and that felt riskier than masking.

Writing and solitary creative practices became important ways to cope. Pluto Blue submitted a photo of a pen in soft light, describing writing to process emotions, a way to *"peel back the layers"* without fear of being seen. Several participants described writing as structured, constrained, and freeing, a place where they didn't need to mask.

Figure 16

The light to me



"The pen is like the light to me… I want to be a writer… it's how I can let out how I feel and make how I feel something kind of beautiful." Pluto blue

Other strategies like crochet or fidgeting were also described as helpful, but only when socially accepted:

"When I crochet during a film, I focus so well… it helps me concentrate." - Pluto blue

"I was trying to show fidgeting… like the vibrating guitar string." Pluto blue

These weren't just ways to cope, they were subtle forms of resistance. Pupils used them to reclaim focus and autonomy in classrooms where these needs were rarely recognised.

Some also described emotionally "clocking out" or withdrawing, not from apathy, but as self-protection. In settings that felt emotionally unsafe, disengagement became a way to preserve autonomy when authentic expression wasn't possible.

4.2.4 Theme Summary

This theme showed how autistic pupils coped in school by finding their own ways to manage stress. But these strategies often came with a cost. Pupils worried about being judged, standing out or looking “too autistic”, so some hid their needs or stopped using support altogether. Despite this, they found small ways to look after themselves, not just to get through the day, but to hold onto a sense of control. These weren’t just coping strategies, they were quiet ways of saying, “I know what I need,” even when the school didn’t listen.

4.3 Theme 2: “I’m Just Trying to Get Through the Day” - The Emotional Cost of Camouflage

This theme explores the emotional and psychological toll of appearing to cope in schools where it didn’t feel emotionally or physically safe to be themselves. While inclusion is often framed around curriculum access, participants described the effort of “being fine” as a more significant barrier. Pupils spoke about masking, hiding distress, and performing neurotypical norms; not to deceive, but to protect themselves. Over time, this constant self-monitoring led to exhaustion, disconnection, and a loss of fragile sense of self. These responses were not due to internal deficit, but to school systems that demanded regulation without providing support.

4.3.1 Subtheme 1: Masking as Survival - Cognitive Labour and Disconnection

Masking was described as a habitual often subconscious strategy, a strategy for appearing regulated and socially acceptable in environments that felt unsafe.

“Masking is a subconscious thing that you do every day without even thinking.” ……

“Hiding is actively trying to hide the fact that we are under stress… hiding happens when the mask fails.” Leo

This distinction showed how self- presentation was shaped by external pressures rather than personal choice. Participants moved between appearing composed and breaking down, often without recognition or support.

The cognitive toll of this labour was significant:

“I’d say that about 60% of an autistic person’s mindset in a classroom is on not breaking down and not having a horrible time, and only 40% is on actual learning.” - Leo

“That’s generous. If you’re having a bad day, that could go up to 90% on just trying to cope and only 10% on learning.” - Sienna

Pupils weren’t avoiding learning; they were using their energy to stay regulated in environments where participation didn’t feel safe.

“I feel like I have to hide stuff, hide parts of myself, in order to be liked… and I would really rather it wasn’t like that.” - Pluto Blue

"I don't know who I actually am sometimes." - Sienna

These accounts pointed to the impact of sustained masking on pupils' sense of identity. Some described not knowing who they were beneath the version of themselves they showed at school. Their sense of self was shaped by how they were seen by others, and by the ongoing effort to appear a certain way in spaces that didn't make room for difference. For many, especially during adolescence, this pressure blurred the boundary between what felt performed and what felt authentic, leaving pupils uncertain not just about how to act, but who they were allowed to be.

Figure 17

The flame that faded

"When support is missing, burnout takes over" Rue

Rue submitted this image of a melted candle to symbolise how she felt after a day of masking, not just tired, but emotionally depleted. Pupils described the need to "recover from being perceived," a phrase that captured the emotional labour of managing how they were seen. Participation became something to endure, not something that nourished connection.

4.3.2 Subtheme 2: Burnout and Shutdown- A System That Exhausts You

Pupils described a slow build-up of exhaustion from sustained masking, sensory overload and unmet needs, often resulting in burnout or shutdown.

"It's a spiral effect… one thing happens, it gets worse, and then something else gets worse. You fall behind, get stressed, fall behind more… it's just a constant loss of control." Leo

"By the end of the school day, I was so drained from dealing with it all. I'd go home and just fall asleep. Then I couldn't do my homework, and I'd get behind." - Ivy

These reflections described not disengagement, but depletion. When overwhelmed, pupils found little flexibility within school systems to pause, recover or ask for what they needed.

Burnout wasn't caused by a single event, but by the cumulative strain of emotional self-monitoring in unsupportive environments. Just getting through the day left no energy for learning or connection.

"I couldn't even speak… it wasn't defiance, I just literally couldn't answer her question." - Kai

Shutdowns were often misunderstood. Several participants described how even small adjustments, like earplugs, were only offered after crisis. One pupil shared that she was only given them following a serious mental health event, reinforcing the pattern that distress had to become visible to be believed.

Figure 18

Can’t Just Turn Off

“I didn’t know who I actually was sometimes… it was like I’d forget how to be me.” - Sienna

Sienna submitted this photo of a quiet park path, describing her walk home as "decomposing school." For her, it wasn't a break, it was recovery. The metaphor captured how masking throughout the day built up pressure that only released afterwards. "Decomposing" reflected not collapse, but the slow breakdown of emotional containment, a return to feeling after hours of performance.

Figure 19

Falling

"This shows how I started out doing okay but eventually everything just kind of fell apart."

Leo submitted this image of a wooden mannequin mid-collapse: "*like falling without anything to hold onto."* The image symbolised a quiet collapse, not dramatic, but slow, disorienting, and hard to name. The emotional toll extended beyond tiredness. Some described related to this image as moments of dissociation and shutting down.

These weren't signs of weakness, they were survival strategies. This was like a slow erosion of capacity under sustained pressure.

These accounts challenge the assumption that disengagement is about effort. Pupils weren't giving up; they were responding to systems that demanded constant regulation without providing the support to sustain it. Burnout wasn't a personal failure; it was a signal of being left unsupported for too long.

This subtheme shows how the structure of mainstream education can produce autistic burnout and then be misread as apathy or resistance. Pupils paid a high emotional cost to stay composed. When they could no longer manage it, the system often saw them as the problem, rather than recognising its own role in what they were coping with.

4.3.3 Subtheme 3: Hidden in Plain Sight- When Emotional Distress is Invisible

Masking often meant pupils' emotional needs went unseen. Teachers tended to equate silence, academic performance, or classroom presence with wellbeing.

"No one ever asked me what would help… only when my grades dropped did, they step in." - Ivy
"I felt like they spoke about me but not to me. Like I wasn't even there." - Ivy

Ivy's words reflect a deeper kind of invisibility, being observed, but not recognised as someone who could speak for herself. Staff often related to pupils through their diagnosis or support plan, rather than through conversation or connection. Distress was rarely noticed unless it became measurable, usually through failing grades.

“The first time it happened, it made it look like I was blanking my English teacher, so I had to send her an email to apologise and explain that I physically couldn’t answer her question.” - Kai

Kai’s account shows how shutdowns were often misunderstood. Although she couldn’t speak in the moment, she felt responsible for repairing the interaction, highlighting how the burden of recognition fell on the pupil.

Some pupils withdrew entirely, seeking quiet corners, toilets, or libraries; not as acts of defiance, but as ways manage in emotional unsafe spaces.

“I spent most of my time in the toilets. It was the only place I could be left alone.” - Rue

Because these strategies were quiet and non-disruptive, they often went unnoticed. Without visible disruption, internal distress rarely triggered support.

Figure 20

Lonely Days

“a playground would usually look like fun... but a lot of children with autism, like me, would have to watch other kids and know that no one wants to play with us... because we talk too much or about the wrong thing”-Kai

Kai submitted this image of a quiet park, a space where they could decompress after school. This space was the only place they could "*breathe.*" For Kai, it wasn't about avoiding school, but recovery from the effort of appearing fine.

Later, Kai shared that the image also reminded them of being younger, before they realised how their difference was judged. As that awareness grew, so did the sense of being emotionally alone.

These reflections point to the long-term impact of misrecognition. When distress is missed or misunderstood, pupils may begin to question whether their struggles are valid at all.

Some also described how difficult recognising their own feeling until things became overwhelming. This suggests that distress can be both missed by others and muted by pupils themselves, especially in environments that do not make emotional expression feel safe or welcome.

This subtheme highlights how distress, when masked behind apparent coping, often remained invisible. Support usually came only after falling grades or visible breakdown. Pupils whose distress was quieter were often left to manage alone. Participants called for a broader understanding of distress, one that takes silence, withdrawal, and internal struggle seriously, and trusts pupils to show what they need in their own ways.

4.3.4 Theme 2 Summary:

Across this theme, pupils described masking not as deception, but to stay safe. The effort to appear fine came at a high cost: exhaustion, identity confusion, and missed support. Their distress was often minimised or ignored unless it became disruptive. These accounts challenge behaviour led systems and the assumption that calm means coping. Pupils needed to be recognised, not just when they broke down, but when they were quietly holding it all together.

4.4 Theme 3: Support That Hurts - The Social Cost of Being Seen

This theme explores how support in mainstream schools, even when available, often created new vulnerabilities for autistic pupils. Participants described support as exposing, stigmatising or misaligned with what they need, leading to emotional risk rather than emotional safety.

. Across subthemes, they spoke about the social consequences of visible support, the frustration of rigid procedures and the challenges of accessing help without a formal diagnosis. These accounts show that support wasn’t just about what was offered, but how it was delivered, and whether it felt safe and responsive.

4.4.1 Subtheme 3.1 Visibility, Stigma, and Social Consequences

Pupils reflected on how using visible forms of support, such as break cards, headphones, or quiet areas, often came with a cost. Though these tools were meant to help, they could draw attention, highlight difference or feel emotionally unsafe.

“There are plenty of spaces…but there’s always different people every day. I don’t know where I’ll sit…the lights…the noise…. It smells different every day”. Leo

Even quiet rooms were unpredictable and overstimulating. But more than that, visible support often felt like a public signal, something that marked pupils out as struggling.

“I decided I wasn’t going to tell anyone I was trying to get a diagnosis… I didn’t want to jeopardise my chance to make friends.” -Rue

“It felt like I was announcing that I couldn’t cope.” - Ivy (on using support)

Support was rarely offered through trust. As Rue put it: *“Support only ever comes after your grades drop. It’s not about wellbeing, it’s about performance.”*

Figure 21

Different but the Same

"This isn't about celebrating difference. It's about how being marked out makes you vulnerable." Leo

Leo submitted a photo of a red soldier surrounded by green ones. The image captured the tension pupils felt; needing support and being exposed by it, a visual metaphor for enforced visibility in a system built around sameness.

"It's not really a solution if it just makes things worse in another way." - Ivy

These moments were emotional trade-offs: Using support meant standing out, and for many, that felt riskier than masking. In school where different wasn't normalised, tools like break cards or headphones came signals of otherness. Inclusion, in these moments, felt conditional, something to be earned by fitting in, rather than supported through trust and relationship.

4.4.2 Subtheme 3.2: Performative Inclusion- When Support Exists on Paper Only

Participants described how schools presented themselves as inclusive in policy or language but rarely delivered support in ways that felt flexible, timely or connected to their actual needs.

"They only ever offer help once everything has already gone wrong." – Sienna

Support was rarely proactive. Participants described having to reach crisis before their needs were acknowledged. Adjustments were framed not as rights, but as emergency responses, placing the burden on pupils to endure until help was justified.

This created a system where support was granted not by need, but by proof, especially when distress matched what school expected to see. Pupils who masked or withdrew were often overlooked, while those who visibly broke down were finally offered help. This created a harmful paradox: pupils had to demonstrate breakdown to be believed.

"I was given a break card but only allowed 5 minutes, not the 10 I needed." – Ivy

Even when tools were available, they were often delivered in rigid ways. Time limits, fixed routines, or rules around when and how support could be used meant that help didn't always meet the reality of pupils' needs. School prioritised policy consistency over relational understanding, reinforcing a version of inclusion that looked good on paper, but didn't feel supportive in practice.

Academic performance often acted as a gatekeeper. Pupils who maintained high grades were seen as coping, even when that performance came at a high emotional cost.

"I asked to drop computing… they said no, my grades were too high." - Ivy

Pupils described feeling stuck between keeping up appearances and asking for change. Inclusion was often conditional: if you were doing well, you didn't "deserve" support, and if you needed help, you had to prove it.

Figure 22

Stuck at the Barriers

"Teachers say it's like train barriers have come down when they try to talk to me… but there's a footbridge right there. It's not impossible" *Rue*

Rue submitted this photo of a level crossing and explained how it represented *"Navigating a World Where We Don't Speak the Same Language."* She explained that although staff said they could not “get through” to her, the problem was not her, “there’s a footbridge right there, it’s not impossible”.

symbolised how timely, relational forms of support were visible but routinely ignored, bypassed in favour of one-size-fits-all procedures.

This image captured how pupil could see viable, simple alternatives, but schools seem to miss them. These weren’t cases of no support, but of overlooked opportunities for timely care. Often, they would experience a one-size-fits all approach.

Participant didn’t question whether inclusion mattered. They questioned how it was delivered. Too often, inclusion was reduced to paperwork and procedures, something that existed in documentation, not in relationships. Pupils were expected to adapt to inflexible systems, rather than systems adjusting to support them. For many, this meant help came late, or not at all.

4.4.3 Subtheme 3.3: Diagnostic Gatekeeping and the Burden of Proof

Participants described how access to support often hinged on having a formal diagnosis. Without it, they were misunderstood, excluded from adjustments, or judged based on behaviour. But even with a diagnosis, understanding wasn’t guaranteed.

“I wasn’t allowed extra time because I didn’t have my diagnosis yet… I ended up with lower grades.” - Ivy

“I was trying to get my diagnosis, and my school refused to help my mum because they didn’t want to ‘put a label on things’… but they then labelled me as ‘difficult’ because they didn’t understand what I was doing.” -Kai

This contradiction, avoiding formal labels while still applying informal judgment, left pupils in a bind. Without a diagnosis, they were denied support; with one, they were reduced to it. Diagnosis acted both as a key and a cage, opening access, but narrowing how pupils were seen.

Even after diagnosis, participants said they had to keep explaining their needs and fighting for support:

“Teachers don’t read my support plan. I have to explain my needs over and over again.” – Ivy

“We have student support, but sometimes they make it harder. Like, you have to prove you need the help before you get it. But if you’re struggling, that’s the last thing you want to do.” – Ivy

For many, support didn’t come through trust or dialogue, it had to be earned through repeated self-justification. The emotional strain of proving their distress left pupils feeling doubted, not supported. In a culture where labels were applied either way, formally or through assumptions, what mattered was not the label itself, but how it was interpreted and used.

Figure 23

Systems

"It's meant to help, but really it just traps you more" Leo

Leo submitted this image of a toy figure wrapped in a soft toy snake. At first glance, the figure looks comforted, but its limbs are pinned in place. For Leo, it showed how support could feel performative or even restrictive when imposed without real understanding.

They added, "*Teachers want to help, but the system makes it hard."* Pupils weren't blaming individuals but point to a wider structure that made support conditional, delayed, or disconnected from their actual needs.

Across this subtheme, participants challenged the idea that diagnosis guarantees meaningful inclusion. What they called for was not support that had to be earned, but support that was flexible, relational and built on trust- not proof.

4.4.4 Theme 3 Summary

This subtheme explored how support, even when available, often came with emotional risk. Pupils described feeling judged and forced to prove their distress before being taken seriously. Across subthemes, they showed how visible support could carry stigma, how rigid systems delayed help, and how diagnosis, while necessary for access, often introduced new limits. What they asked for wasn't just formal recognition, but support that felt responsive, human and grounded in trust.

4.5 Theme 4: "Different, Not Inferior" - Belonging, Identity, and the Cost of Acceptance

This theme explores how autistic pupils made sense of identity, visible and connection in school. Many wanted friendship and belonging but described how school culture often made being themselves feel unsafe. Social inclusion was often conditional, dependent on masking, following, performing neurotypical behaviours, or minimising difference.

Across their reflections, pupils explored what it meant to be accepted, and what that acceptance cost them. Some found comfort in private spaces or trusted friends.

Others felt excluded or misread, even when they were physically present. This theme explored what it took to belong in environments that prioritised sameness over understanding.

4.5.1 Subtheme 4.1: Friendship, Fragility, and Social Uncertainty

Participants described friendship as important but often fragile. Connection required ongoing effort, self-monitoring and guessing what others meant. While some had close friends, many spokes of feeling on the edge of social groups, unsure how to fully join in.

“Some friends stay; some leave. It’s like a contest to see who sticks around” - Jasper

Jasper’s metaphor captured how friendship didn’t always feel stable. For many, being part of a group meant having to manage yourself constantly, watching what you say, what you do and how other might respond.

Even small classroom moments, like pair work, could feel uncertain:

“When they say, like, talk to your partner… I don’t know what to say. Even if the person next to me is literally my friend, I won’t know what to say.” - Sienna

Being friends with someone didn’t mean the social part got easier. Several pupils said they weren’t sure how to start or keep up conversations, even with people they like and trusted.

Friendship didn’t always protect against exclusion. Some pupils felt like they were “sort of” part of a group but still unsure if they were wanted. Others described breaktimes as the hardest part of the day, not because they were alone, but because they didn't know where to go or how to join in.

"There wasn't anywhere I felt I could go… even break wasn't really a break."

"I used to feel kind of invisible, like people just looked through me… they didn't see anything." – Pluto Blue

The fear of being "looked through" came up more than one. Pupils weren't just wanting social time, they wanted to be recognised for who they were, not ignored or seen only through assumptions about autism.

Figure 24

The Odd One Out

Ivy submitted this photo of a group of soft toys and described the bright odd one out as one turned away from the rest. While soft toys are usually linked to comfort, this arrangement showed how even in safe looking spaces, exclusion can still be felt.

Across this subtheme, friendships were not absent but often came with effort and uncertainty. Pupils wanted connection, but not one that depended on hiding their needs or pretending to be someone else. Their struggles weren't about lacking social skills but about trying to connect in places where it wasn't always safe to be themselves.

4.5.2 *Subtheme 4.2: Masking for Belonging: Identity, and Self-Presentation*

In mainstream school, the desire to belong often conflicted with the need to self-protect. Participants described masking, concealing aspects of identity or feelings, as something they did every day to manage how others saw them. While earlier themes framed masking as a response to overwhelm, here it was used to avoid judgement, rejection or being seen as different.

"I like being me, but school makes it hard." Jasper

"I feel like I have to hide parts of myself in order to be liked." Jasper

"I just wanted to be normal… I thought if I could fake being normal, maybe I wouldn't struggle as much"- Rue

These reflections showed how hard it was to stay true to yourself in spaces where difference felt unsafe. Pupils weren't ashamed of who they were, they were adapting to environments where being authentic didn’t feel possible. Masking wasn’t just about surviving the school day; it became a condition for being accepted.

Several participants said that even after diagnosis, misrecognition continued. In some cases, it introduced new assumptions. They described managing not just their own feelings, but how others read them, especially when support made them stand out.

“They see autism, not me… they’re still looking through you because they’re looking through the lens of autism.” Pluto blue

“I’ve always felt like I have ‘true sight’… I can see things about people that others don’t.” Pluto Blue

These reflections reframed misunderstanding as relational, not individual. Pupils weren’t lacking awareness; they were in spaces where their ways of connecting weren’t seen, valued or reflected back.

Figure 25

Between Darkness and Light

Jasper submitted this photo of a sunset behind a security camera. It symbolised the pressure to look “fine” while feeling watched. The light in the background, he said, was the part of himself that didn’t feel safe to show.

This sense of internalised vigilance was echoed across accounts. Pupils described adapting how they spoke, moved, or expressed emotion, not to connect, but to stay safe. Masking, in this context, wasn’t about avoidance, it was a relational strategy in a school where difference was tolerated only when hidden.

Figure 26

The Impossibility of Camouflage

"No matter how much I try and hide stuff, you can still see it underneath… like my odd socks." Pluto Blue

One pupil shared this image of her school shoes and mismatched socks. She explained that the socks were a deliberate act of self-expression- something small that made her feel more like herself within the constraints of school uniform. The photo reflected how even when pupils appeared to blend in, parts of their difference were always present.

Across this subtheme, pupils described the emotional cost of trying to belong in places that asked them to hide. Inclusion, when tied to sameness, came at the expense of being known. Pupils were not asking to join in, they wanted to be seen for who they were, not as a diagnosis or a problem to fix.

4.5.3 Subtheme 4.3: Infantilisation and the Experience of Being Underestimated

While earlier subthemes explored how pupils masked to fit in, this subtheme focuses on a different kind of misrecognition: being seen as less capable, less mature or emotionally naïve. Pupils described being spoken down to, over-accommodated or excluded from decisions, not because they lacked insight, but because others assumed they did.

Even when pupils shared their diagnosis or showed they could cope, they were often met with responses that felt patronising. Emotional distress was misread as immaturity. Coping strategies like sensory tools or special interests were seen as signs of delay. Some described meltdowns being treated as tantrums, rather than expressions of need.

"I haven't regressed in age, I'm autistic." – Leo

Leo's words pushed back against that logic. They were not rejecting support; they were challenging the idea that needing help meant they were not capable. i.e. drawing a line between support that empowers and support that diminishes.

Several pupils described how support, even when well meant, felt controlling. Instead of being asked what would help, they were managed.

"I've never been asked, even since having my diagnosis, "so what can we change in the school?"-

This reflected a core feature of infantilisation: the assumption that autistic pupils don't know what they need. Yet many had clear insights into what would make school more accessible, and several felt that trust and communication was missing in schools.

Support didn't feel collaborative. It felt imposed, given without conversation, based on assumptions rather than relationship. What made it disempowering wasn't always what was offered, but how it was delivered: decisions made for them, not with them.

Figure 27

Seen but Unnoticed

Pluto Blue submitted an image of a wire mannequin casting a shadow. She explained it symbolised how she felt at school; that while her physical presence was noticed, her thoughts, feelings and individuality were often invisible. The shadow suggested a gap between how she was perceived and who she really was.

During a group discussion, another participant reflected:

"Even those that know you have autism and try and support your autism, they're still looking through the lens of what they know about autism, rather than you and your autism"

This exchange captured a shared feeling: that pupils were not against diagnosis, but against being reduced to it. What they wanted wasn't less help, it was support shaped by relationship, curiosity and respect.

Inclusion was not just about being present. It was about being recognised on your own terms. Infantilisation, even when well-intended, created emotional distance. It left pupils feeling managed, not met.

4.5.4 Subtheme 4.4: Escapism and Authenticity: Solitude, Special Interests, and Self-Preservation

When school felt overwhelming, invalidating, or socially exposing, participants described withdrawing, not to avoid, but to protect themselves. These quiet moments of solitude were ways to recover, hold onto identity, and feel in control in environments where being authentic felt risky.

"I would go to the park after school and just swing for an hour. It helped me block everything out and just breathe again." - Jasper

For Jasper, time alone was not isolation, it was recovery. Other participants described similar routines: crocheting or listening to music. These weren't distractions, they were how pupils regulated and reset.

“What helps me focus when I’m watching something in class… it’s not distracting, it’s the opposite.” Ivy

Special interests did not take pupils away from learning, they often made it possible. But these tools were frequently misunderstood or discouraged, pushing pupils to hide the very things that supported their wellbeing.

“I’d just go sit in the toilets during break… not because I wanted to, but because there was nowhere else where I could be alone without questions.” -Rue

Being alone wasn’t a sign of failure, it was a way to decompress, to exist without having to perform emotional regulation for others.

Online spaces also emerged as key places of refuge and connection:

“I feel like I know more neurodiverse people online than in real life. Like, people I can actually talk to.”

Several participants wished they had more opportunities to connect with other autistic young people in school. While online spaces offered that sense of recognition, it was often missing in their everyday environments, reinforcing the need to seek authenticity elsewhere.

Figure 28

Perched of the Edge of Belonging

"It's like being alone but still connected. I'm doing my own thing, but I'm not cut off from the world." Rue

Rue submitted an image a small bird alone on a wire. She explained that the photo represented self-directed solitude, not as retreat, but as autonomy. It captured a quiet refusal of misrecognition, a reclamation of control and identity.

Across this subtheme, escapism was not disengagement. It was a form of self-preservation, a strategy for surviving environments that demanded constant performance. Whether through special interests, sensory regulation or time alone, pupils found ways to stay connected to who they were, even when school did not make space for it.

4.5.5 Theme 4 Summary

This theme explored how autistic pupils made sense of identity, belonging and self-expression in schools where being themselves often felt unsafe. While many wanted connection, they described how masking, misrecognition and social ambiguity made that hard.

Pupils used masking not just to manage overwhelm, but to shape how they were seen, often to avoid stigma or being misunderstood. For some, the pressure to fit in created a growing disconnection from themselves. Others found comfort and control in quiet acts of self-preservation, through solitude, special interests or online spaces where they didn’t have to perform.

Inclusion, they showed, was not just about being present, it was about being recognised and supported in ways that felt safe, meaningful and real.

4.6 Theme 5: “They Only Listen When It’s Too Late” - Exclusion, Risk, and the Cost of Being Misunderstood

While the earlier themes explored the daily emotional effort of surviving school, through regulation, masking, and adapting, this theme explores what happens when that effort becomes unsustainable. Participants described the consequences of prolonged misrecognition, where distress was consistently overlooked or misunderstood until it escalated into shutdown, withdrawal, self-harm, or crisis.

Although “school refusal” is often framed as avoidance, pupils reframed these responses as survival, reactions to cumulative overwhelm and unmet need. Support was often delayed, conditional, or reactive, offered only when distress became too visible to ignore. These accounts reflect not just frustration, but emotional and relational betrayal, a sense of being left to navigate risk alone in systems that positioned themselves as supportive. This theme explores the emotional toll of being unheard, the misreading of distress and the erosion of trust that followed when pupils were repeatedly met with silence.

4.6.1 Theme 5.1: Emotional Invisibility and the Crisis Threshold

The subtheme focuses on what happens when distress remains unseen, until it becomes crisis.

“Sometimes school feels like my feet are glued to the tracks and I’m just waiting for the train to come.” Rue

Rue’s metaphor captured the quiet helplessness many participants described, being trapped in systems that noticed behaviour, but missed emotional need.

“I told them I wasn’t coping, and they said I just needed to be more resilient.” - Kai

Resilience, in this context, was a code for compliance, a pressure to keep going in environments that were not build with neurodivergent pupils in mind.

“It was only after my second overdose that they gave me earplugs.” Ivy

Ivy’s reflection exemplifies the delayed nature of support. A basic, low-cost adjustment was withheld until visible crisis occurred, reinforcing a system that acted only when distress became unignorable. Pupils described needing to deteriorate before being believed.

Ivy described how normalised distress had become:

“I didn’t notice how bad the lights were until the teacher turned them off to show a video, then when they went back on, it hit me.”

Without contrast, discomfort had become background noise, part of school life. Several pupils only recognised their distress in hindsight. This helped explain why early signs were missed, not just by teachers, but sometimes by pupils themselves.

Figure 29

Withering Away

“What happens when no one checks in… you can’t grow if no one waters you” Pluto Blue

Pluto Blue submitted this image of a plan with dry curling leaves, except for one green stem. It symbolised gradual erosion, the kids that often goes unnoticed because it doesn’t look like crisis. Several participants described not only the absence of proactive support, but the exhaustion of having to constantly self-advocate. Over time, this led to emotional detachment, from others, from school, and from their own internal world. Some described going dumb, withdrawing of giving up on asking for help altogether.

As one participant said earlier in the study: *“There’s a footbridge right there. It’s not impossible.”*

Pupils weren’t rejecting support. They needed it earlier, offered differently, not just after something had gone wrong. These accounts raise urgent questions about how schools recognise emotional suffering, whose distress is believed, and when care becomes accessible. Pupils were not lacking resilience. They were navigating environments that required endurance and proof before offering help.

The pattern was clear: distress was not met with curiosity but only acknowledged once it disrupted. Pupils were not lacking resilience; they were navigating systems that responded only when pain became visible. These accounts raise urgent questions about how schools recognise suffering, whose distress is believed, and when care becomes accessible.

4.6.2 Theme 5.2: Misreading Distress: When Behaviour Masks Emotional Need

While the previous subtheme focused on distress that went unseen, this subtheme explores a related pattern: distress that was visible but misread. Pupils described shutdowns, withdrawal, or emotional overload that were interpreted not as expressions of need, but as rudeness, defiance or disruption.

“The school kept complaining to my mum about the fact that I’d suddenly start screaming and crying and hiding myself under tables.” – Kai

Kai’s account reflects a pattern in which visible distress was met with behavioural judgement rather than curiosity. Her meltdowns, often triggered by overwhelming transitions or sensory strain, were framed as misconduct, despite clear signs of distress.

Rue submitted a photo of train barriers to represent how teachers responded to her during moment of shutdown or emotional overload:

“I’ve been told a lot of times by specific teachers that when they try and talk to me, it’s like the train barriers have come down. For me, I’ve always thought- just because you can’t pass the barriers, doesn’t mean you can’t communicate with me. There are extra hurdles because I may communicate differently, but that doesn’t mean it’s impossible’.

Rue’s metaphor challenged the assumption that communication must look one way to be valid. She reframed shutdown not as refusal but as an alternate mode of expression, one that required them to understand her rather than punishment reflecting how neurodivergent forms of communication are often misinterpreted when systems rely on narrow norms of emotional expression.

Participants described how emotional or sensory overload could lead to involuntary responses, freezing, dissociating, retreating. Yet instead of support, these moments were often met with discipline or demands for verbal explanation after the fact. The burden of understanding was placed on the pupil, not the environment.

Figure 30

Daydreaming

“Sometimes school can be so much that the only way we can get through is to dissociate and disengage. Teachers get angry and wonder why we aren’t present and engaging but fail to understand that the sensory reality and demands we are under are so intense that we can barely stay in the classroom, let alone engage fully in the lesson we ironically usually would love to do. E.g. I loooove F maths but F maths lessons are torture, and I could describe every marking on the wall I sit next to.” Rue

Rue’s account captured the dissonance between external behaviour and internal experience. Her withdrawal wasn’t disinterest; it was a survival strategy. Her love for the subject didn’t protect her from shutdown; the conditions of the classroom made participation emotionally and sensorily unsafe.

Across these accounts, pupils emphasised that their behaviour was not misbehaviour, it was communication. But schools frequently interpreted distress through a behavioural lens that stripped it of context and meaning. Pupils were left managing both their internal dysregulation and others’ misreading of their actions.

When autistic expressions of distress were labelled as disruption or defiance, it denied pupils access to timely, compassionate support. Instead, it deepened their sense of shame and isolation, reinforcing the idea that they had to appear calm or composed to be understood.

4.6.3 Theme 5.3: Powerlessness and Systemic Betrayal

This subtheme explores the deeper emotional toll of being repeatedly misread, unsupported, or left to manage distress alone. While the previous subtheme focused on misinterpretation of distress, this subtheme highlights what happened when pupils were promised care, but support was delayed, withdrawn, or never materialised. For many, this produced not just exhaustion, but a profound sense of betrayal.

"A lot of the times I've been like screaming for help… and teachers have just, because I haven't been saying 'I need help', ignored it or not recognised it." - Rue

Rue's reflection captures a wider dynamic reported across accounts: to be taken seriously, pupils had to express distress in calm, verbal, neurotypical ways. When they couldn't, they were ignored or misunderstood. Overtime, this eroded trust, school no longer felt emotionally safe.

Figure 31

Unseen Pain

"Alcohol made me feel normal… I could relax...". Ivy

Ivy submitted a photo of a gin bottle wrapped in a plaster, placed beside pills and a lighter. The image combined symbols of harm and repair, offering a stark metaphor for superficial responses to deep emotional need.

"I didn't know how to talk about how I felt… self-harm showed it without having to say it.". Ivy

This reflected how, in the absence of relational safety, crisis became the only language the system seemed to recognise. These actions were not manipulative or attention seeking, they were survival strategies. Ivy later shared, with a touch of humour, that alcohol helped her feel "normal", exposing the extent to which pupils had to self-manage distress in environments that didn't offer meaningful help.

Even with formal support plans in place, many described being excluded from key decisions. Pupils were often expected to repeatedly explain their needs yet rarely included in shaping how support was delivered.

"*They spoke about me, not to me"* Ivy

Support was frequently withdrawn once pupils appeared "calm", reinforcing the assumptions that regulation meant recovery. Instead of prompting stability, these left pupils feeling destabilised and disbelieved. For many, the experience was not just of unmet need, it was of being managed rather than understood, a sense of objectification.

Participants described carrying the burden of self-advocacy while holding emotional pain that few recognised. Overtime, many stopped asking for help, not because they no longer needed it, but because they had learned it rarely arrived when it mattered.

4.6.4 Theme 5 summary

This theme explored the cumulative cost of being misrecognised, misinterpreted, or left unsupported in school. While earlier themes explored the emotional of appearing “fine”, this theme captured what happened when that effort could no longer be sustained. Pupils described being misunderstood even in moments of visible distress and reflected on the loss of trust that followed when helped arrived too late, or not at all.

Rather than rejecting care, pupils learned that support was often conditional: offered only when pain became disruptive and rarely grounded in relationship or repair. These accounts challenge the idea that risk only emerges at the point of crisis. For many, the harm had already been done by the time anyone noticed.

Figure 32

Reflexive note:

Sitting with Ivy’s photo of the gin and pills was the hardest for me. I felt a mix of anger and helplessness. I wasn’t particularly shocked and that’s what moved me the most. How many other children are going through the same right now and not being seen?

In my journal I wrote ***“to sedate yourself to survive school just shows desperation!!”***

School should be a place where you feel safe to learn and grown. And despite all this, Ivy didn’t give up and continued to strive!

It surprised me that what caught me most wasn’t the overdose, it was the fact she went to school drunk. That’s where I noticed my bias come in. I think I was drawn to the idea that she hadn’t given up that she still wanted to learn. But it also made me reflect on how easily perseverance gets praised, even when it’s rooted in pain. I realised I’ve been trained to notice certain types of risk but I’m still learning to recognise what it means when a system lets someone down quietly. And in Ivy’s case, that was already happening.

During the familiarisation stage the feeling of injustice resurfaced again... I kept circling back to the idea that a child shouldn’t have to numb themselves to access education.

That line stayed with me. It reminded me that Ivy wasn’t flagging live risk but was trusting me with something retrospective and real. And that changed how I approached the coding. I slowed down. I revisited the theme to check whether my own emotional response was starting to take over the interpretation.

I spoke to a colleague, went back to Ivy’s exact words, and spent time reflecting on how she chose to show this not just what she showed. I didn’t want this part of the analysis to be overpowered by my own sense of advocacy. I wanted the theme to reflect what she shared, on her terms. This reflection prompted a new latent sub theme- “quiet acts of survival” and ensured ivy’s photo was coded under systemic invisibility rather than individual crisis.

Chapter Five: Discussion

5.1 Chapter Overview

Each of the five analytic themes developed through Reflexive Thematic Analysis (Braun & Clarke, 2021) are discussed in relation to existing theory, empirical research, and the systems that shape everyday school life.

Photovoice (Wang & Burris, 1997) supported pupil-led meaning-making through images and verbal reflection. Experiences were understood as relational, and co-constructed, shaped by interactions with peers, staff, routines, and environments. While themes are presented individually, they are conceptually linked. For example, sensory overwhelm often co-occurred with masking (Theme 2) and misrecognition (Theme 5).

The analysis is framed by a Critical Realist Social Constructionist epistemology (Harper, 2010) and informed by the neurodiversity paradigm (Kapp, 2020) the social model of disability (Oliver, 1996), epistemic injustice (Fricker, 2007; Byrne, 2022), and trauma-informed lens (Fisher, 2022). These frameworks helped illuminate how schools often respond to distress behaviourally, offer support reactively and overlook the relational conditions needed for genuine inclusion and to support the mental health of autistic pupils (Billington et al., 2024).

Themes are not treated as objective discoveries, but as interpretive tools, developed through reflexive engagement with participants' spoken and symbolic contributions. They reflect what was said, what was withheld, and how meaning was visually or emotionally conveyed. This analysis understands inclusion not simply as presence, but as recognition, safety, and the freedom to be oneself without penalty.

This chapter uses each theme to explore how autistic pupils make sense of school, before concluding with methodological reflections, implications for clinical psychology and education, and recommendations for future research.

5.2 Theme 1: Surviving the Sensory Landscape of School

Participants described the school environment as relentlessly overwhelming, loud, unpredictable, and overstimulating. The entire environment was not just physically uncomfortable but emotionally unsafe. Sensory distress was not peripheral to school life but shaped how pupils encountered, interpreted, and endured each day.

For some, the classroom became a space of threat rather than learning. One participant described school as “always watching, always noise,” while another said, “if you’re having a bad day that could go up to 90% on just trying to cope and only 10% on learning.” Rather than being addressed proactively, sensory needs were often only accommodated reactively, if at all. These accounts support existing research highlighting sensory sensitivities as core to autistic experience (Robertson & Simmons, 2015; Tsuji et al., 2023; Uljarević et al., 2017) and align with recent findings that sensory accessibility is rarely prioritised in mainstream schools (Al Qutub et al., 2024; Ambitious about Autism, 2024). This study adds depth by showing how sensory overwhelm impacted pupils’ cognitive, emotional, and relational capacities throughout the school day. Energy accounting (Murray & Lawson, 2022) may offer a useful framework here, highlighting how sensory overload depletes internal resources, reducing pupils’ capacity to engage socially or academically.

Regulation was experienced as a private, unsupported task (Padilla, 2024). Participants described self-directed coping strategies for example, hiding in toilets, as essential for surviving the day. Yet these strategies were often misread as rudeness or disengagement. One participant reflected that they had to choose between being overwhelmed or being punished, describing what several called a “double bind”: the expectation to self-regulate without drawing attention, but with social or disciplinary consequences when distress broke through (Halsall et al., 2021).

These strategies also resonate with Monotropism theory (Murray et al., 2005), which conceptualises focused engagement, not as distraction, but to regulate affect, maintaining a sense of control in overwhelming environments. For example, through doodling. Rather than avoidant, these acts were adaptive and protective. This interpretation demonstrates a shift away from non-compliance to self-directed regulation, and an embodied attempt at coping.

This dynamic reflects a deeper epistemic concern. Drawing on Fricker’s (2007) concept of epistemic injustice, participants’ embodied distress was frequently disqualified as valid knowledge unless communicated verbally or through disruptive behaviour. Calm was often misread as coping. Quiet withdrawal was praised, while visible distress was more likely to be sanctioned. This echoes critiques of behaviour-focused inclusion models, where surface-level compliance is privileged over internal wellbeing (Fisher, 2022; Goodall, 2020). The findings here extend this critique by illustrating how behavioural assumptions undermine the credibility of non-verbal or sensory-based communication.

Participants accounts reinforced these themes powerfully. One participant submitted an image of a teddy bear wearing headphones, symbolising both vigilance and sensory overload. This image conveyed how distress could be both constant and invisible, and how the need for safety was often managed through suppression. This study builds on recent visual and participatory work (O'Hagan & Byrne, 2023), illustrating how sensory experience is communicated symbolically when verbal options are not possible.

From a neurodiversity-affirming perspective, these findings challenge the assumption that wellbeing can be achieved without sensory safety. The neurodiversity paradigm views sensory difference not as deficit but as a valid form of embodied experience (Botha et al., 2022; Kapp, 2020). While this paradigm calls for a redefinition of access, this study adds nuance by showing how schools not only overlook sensory needs but often reward the suppression of discomfort (Billington et al., 2024a). This echoes what Fisher (2022) and what Goodall and MacKenzie (2019) describe in a conference as the logic of “resilience-as-compliance,” where adaptation is expected from the pupil, rather than the system.

This theme also intersects with trauma-informed approaches, which emphasises predictability, relational safety, and sensory regulation as prerequisites for learning (Cunningham, 2022; Perry & Szalavitz, 2017). This lens argue that emotional regulation cannot be externally imposed without internal safety. The findings here extend this argument by showing how autistic pupils internalise stressors and appear compliant while experiencing cumulative dysregulation.

These findings address the research question by illustrating how autistic pupils' experiences are shaped not just by social and academic dynamics, but by sensory and embodied realities. Sensory distress shaped how pupils engaged, how they were perceived, and what support they received. When schools fail to recognise sensory needs as genuine, wellbeing is not prioritised. Sensory regulation must therefore be understood not as a separate access need, but as central to how autistic pupils experience school, and how experiences are felt through the body, not just through policy.

5.3 Theme 2: The Emotional Cost of Camouflage

Masking was not described as deception, but as a habitual, often unconscious survival strategy to avoid judgement, punishment, or social exclusion. While the immediacy of masking was beneficial, however, long term costs including exhaustion, identity confusion and uncertainty in relationships. Participants described masking as necessary to "get through the day." Strategies included staying quiet, copying peers, hiding sensory needs, or pretending to understand. These behaviours were sometimes praised by staff described as "well-behaved", reinforcing the message that compliance equalled success.

These findings extend work linking camouflaging with anxiety, burnout, and disrupted identity development (Botha & Frost, 2020; Hull et al., 2017; Raymaker et al., 2020; Botha & Frost, 2020) and support recent studies showing that masking mediates the relationship between low belonging and elevated distress in autistic students (Halsall et al., 2021; Roberts & Milner, 2024). Masking, in this context, is not a personal deficit, but a systemic response to environments that invalidate distress.

Several participants described masking even with close friends, unsure whether they themselves were liked or just the version performed. This reflects research on relational masking in adolescence, where the pressure to conform intensifies (Cook et al., 2021; Hull et al., 2020). Bernardin-Mason et al. (2023) found that high levels of camouflaging correlated with poor self-concept and depressive symptoms, particularly in contexts of peer observation. In this study, pupils described feeling drained, emotionally disconnected, and unsure of their own identities, a pattern also reported by Halsall (2021) who found sustained camouflaging predicted lower self-concept. One image submitted depicted soft toys turned toward each other, with one facing away, symbolising isolation rather than connection. This builds on Leonard and Smyth's (2022) work with autistic girls who mask to avoid exclusion, and with Woodhouse et al. (2023), who demonstrate masking an embodied negotiation of identity. The current study contributes further by demonstrating how masking was sustained as a protective response to anticipated misrecognition. The neurodiversity paradigm frames masking as a systemic response, rather than an internalised trait (Kapp, 2020; Leadbitter et al., 2021). This study supports this position.

Masking also involved epistemic labour. Drawing again on Fricker's (2007) concept of testimonial injustice, pupils anticipated that their inner distress would not be believed unless it conformed to neurotypical standards- what Chapman and Carel (2022) call an autistic "credibility deficit". As one participant put it: "It's not support if I have to break first." This reflects the findings of O'Hagan and Byrne (2023), where pupils reported concealing emotional pain to avoid disbelief or dismissal.

These findings show how emotional suppression is often misinterpreted as resilience. Pupils described how appearing calm came at the cost of authenticity. This reflects growing evidence that camouflaging is strongly associated with anxiety, depression, and psychological distress autistic people (Cook et al., 2022; Perry et al., 2022; Lewis & Monk, 2022). Lamb et al. (2024) concur staff often interpreted shutdown or distress as defiance, further undermining emotional safety. The current findings deepen this critique by highlighting the cost of being *believed only when visibly in crisis*, a process that erodes confidences and reinforces emotional invisibility.

Masking impacts pupils’ identities and sense of self. Several pupils said they no longer knew “who I really am,” echoing Halsall et al. (2021) and Cassidy et al., (2022), who found that sustained masking leads to disconnection and identity erosion. What emerged was not a clear distinction between coping and crisis, but a persistent state of disconnection: being physically present, emotionally withdrawn, and socially uncertain.

From a trauma-informed perspective, these findings highlight how chronic masking mirrors survival responses to emotionally unsafe environments (Perry & Szalavitz, 2017; Cunningham, 2022). Pupils were not disengaged out of apathy, but because they had learned that safety required invisibility. Such adaptations, while often pathologised in behavioural models, should be recognised as protective responses to systems that invalidate distress.

Cumulatively, these findings respond to the research question by showing that emotional visibility in school was often conditional. Pupils masked not because they were coping, but because they felt unable to express distress without negative consequences. This theme underscores that masking is a survival strategy in systems that invalidate distress. To avoid a mental health crisis, schools must begin by understanding what pupils need to express themselves safely (Cassidy et al., 2023).

5.4 Theme 3: The Gap Between Policy and Practice

Participants described how systems such as EHCPs, break passes, and quiet spaces existed in theory but were often delayed, conditional, or accompanied by stigma. These findings challenge the assumption that formal provision creates emotional safety or belonging (Goodall, 2018; EHRC, 2017). Instead, participants described support that arrived too late, felt too rigid, or increased their visibility and vulnerability (NOA, 2023; Padilla, 2024).

Many participants attended schools officially labelled as inclusive. Several had EHCPs, named support staff, or access to designated spaces. However, support was often described as symbolic or tokenistic. One pupil reflected: “It’s not support if it makes things worse,” referring to a break card they were too embarrassed to use. This double bind, between visible need and social judgement, resonates with what Kelly et al. (2023) call “performative inclusion,” in which inclusive practices serve bureaucratic or reputational purposes rather than pupils’ lived experience.

Supports were often inflexible or procedurally delivered, therefore not mirroring people’s needs. These findings align with Kelly et al. (2023), who examined 150 EHCP’s found that most were generic, deficit-framed, and rarely co-produced with the young person. In this study, even when accommodations were available, they were implemented in ways that felt unhelpful.

A consistent pattern was delay. Pupils often received support only after visible breakdown, school refusal, grades dropping, or self-harm. One said: “No one noticed until I stopped coming.” These experiences align with what researchers have termed a “wait for crisis” approach: a reactive pattern in which support is typically offered only once distress becomes overt or disruptive (Ashworth et al., 2024; Crane et al., 2019; McClemon et al., 2023). These systems tended to overlook internalised signs of distress, such as masking or emotional withdrawal, responding only when risk became measurable. Participants’ accounts suggest that this logic was mirrored in school settings, where pupils’ needs were only acknowledged once their distress became outwardly visible.

This also intersected with narratives of deservingness (Carroll & Lodge, 2023; Fricker, 2007). Pupils who performed well academically were told they “Didn’t need support,” while others were disbelieved due to verbal fluency or effective masking. Some were told they weren’t “autistic enough” to warrant accommodations. These findings extend work by Carroll and Lodge (2023), who showed how EHCP eligibility and access were often shaped more by diagnostic presentation than lived experience. Here, participants’ accounts highlight how institutional norms of credibility and recognition shaped access to support (Fricker, 2007).

Some pupils described the emotional contradictions embedded in symbolic efforts at inclusion. One school ran neurodiversity week but ignored requests for sensory adjustments. These findings support Kelly et al.’s (2023) framing of “aesthetic inclusion,” where visible gestures of inclusion mask the absence of relational or systemic change. As one pupil put it: “The pass exists, but it doesn’t open anything.” The metaphor captures how formal provision that does not align, can heighten vulnerability rather than reduce it.

Collectively, these findings challenge the assumption that formal support is inherently protective. Its impact depends on how it is delivered, received, and embedded within schools. Participants called for support that was flexible, responsive, and co-developed, not generic, administratively driven, or dependent on visible breakdown.

5.5 Theme 4: Belonging, Identity, and the Cost of Acceptance

Participants described peer relationships as emotionally complex, where acceptance felt conditional and visibility carried social cost, heightened by their age and need for peer acceptance (Chemery & Colley, 2023; Cook et al., 2021). Drawing on Critical Disability Theory and the Double Empathy Problem, this theme frames inclusion as a relational process shaped by social norms, institutional expectations, and efforts to avoid stigma.

School was described as a space of continuous identity management. One pupil asked, “Do they like me or the school me?” Others shared how they altered their tone, posture, or interests to fit what peers seemed to expect. This aligns with Howe et al.’s (2023) photo-elicitation study, where pupils described switching between social “masks” in different settings. Camouflaging was not seen as deception, but as emotional labour, necessary to maintain social safety.

Pupils in this study wanted the environments to meet them halfway. Yet belonging often required suppressing traits central to their identity. One pupil said, “If I stim in front of them, they’ll think I’m weird. If I don’t, I feel like I’m not being me.”

This tension is captured in Botha’s (2020) and Williams et al.’s (2022) work on relational masking, and in Halsall et al.’s (2021) findings on identity fragmentation. In the current study, pupils were not unsure of who they were, they were aware but learned quickly that authenticity came at a relational cost. Masking was not only a strategy for avoiding disruption, but a response to social dynamics that equated difference with rejection.

These findings challenge deficit-based assumptions about autistic sociality. Drawing on Milton’s (2012, 2022) double empathy framework and adding to recent findings on neurotype-matching in peer interaction Chen et al., (2022), this theme reframes communication difficulties as reciprocal. Pupils described actively trying to connect, but feeling misunderstood or dismissed, particularly by neurotypical peers. Descriptions of being “looked through” highlight the absence of reciprocal understanding. Without adaptive relational practices, enforced inclusion may add to school distress. As one participant put it: “When I talk about my interests, they zone out. But if I stay quiet, I get asked why I’m so quiet.”

Belonging, then, was not just about presence, but recognition. Lebenhagen’s (2022) study, drawing on Critical Disability Theory, found that autistic adolescents defined inclusion as being “welcomed as autistic,” not simply allowed to be present. Participants in this study echoed this through both words and images. One shared a photo of a wire mannequin symbolising how she is often seen through despite being physically present. These findings align with recent work linking identity suppression to mental health impacts. Research shows that sustained masking and stigma-related vigilance are associated with elevated anxiety, depressive symptoms, and reduced self-concept in autistic adolescents (Cook et al., 2022; Lewis & Monk, 2022; Perry et al., 2022). Pupils in this study described not only emotional fatigue, but a retreat from social engagement, a strategy for protecting themselves from rejection.

This reflects a shared theme: symbolic inclusion without emotional safety (cf Kelly et al., 2023). Pupils learned they could be tolerated when they conformed but not accepted when they were fully themselves. As Lebenhagen (2022) and Goodley (2014) argue, inclusion without relational justice reproduces marginalisation. Participants described this not as personal failure, but as school neglect of their need for identity-safe spaces.

Collectively, these findings contribute to the research question by showing that emotional safety was often experienced as conditional belonging, acceptance granted only when difference was hidden. Pupils described navigating complex identity trade-offs, weighing authenticity against social protection. These dynamics were not rooted in autistic deficits, but in environments that failed to provide mutual understanding or emotional safety.

Masking emerged most explicitly in Theme 2 as an involuntary, habitual strategy of emotional survival. In Theme 4, however, it appeared as a more deliberate way of managing identity and social perception. Here, masking was not simply about avoiding overwhelm but about controlling how others, particularly peers, perceived them in classrooms and social spaces. Pupils described masking to avoid being labelled as “weird” or excluded from friendship groups.

This shift, from unconscious survival to conscious strategy, reflects masking’s dual role as both safety and cost (Atkinson et al., 2024b; Fisher, 2022). As one participant put it: “Masking is a subconscious thing that you do every day without even thinking… hiding happens when the mask fails.” This quote illustrates both the automatic nature of masking and the emotional toll of being seen. Participants described wanting to connect with others, but fearing that expressing themselves authentically, through stimming, showing emotion, or communicating sensory needs, would lead to rejection. These layered uses of masking help explain why autistic pupils’ identities often shifted how they presented themselves across settings, managing how much of their authentic selves to show to appear socially acceptable. This was particularly evident in classrooms where accommodations such as wearing headphones were overlooked or misinterpreted as disengagement, reinforcing the pressure to suppress difference to be accepted.

5.6 Theme 5: Exclusion, Risk and the Cost of Being Misunderstood

Participants described being overlooked, misread, or disbelieved until their emotional needs became disruptive, diagnosable, or academically consequential. The findings illustrate how institutional norms shaped who was seen as needing help, when, and under what conditions.

Many pupils described support as reactive, offered only after ‘school refusal’ or self-harm. They shared that referral for help occurred only after weeks of withdrawal or emotional shutdown. These accounts echo findings by Ashworth et al. (2025), who documented how families often face credibility challenges, with services waiting for crisis before intervening. Even when staff noticed something was wrong, participants said distress was often attributed to “just autism,” not to co-occurring anxiety or emotional pain.

This reflects testimonial injustice (Fricker, 2007): participants’ interpretations of their own experiences were often dismissed unless corroborated by behaviour that staff recognised as “serious.” As in Theme 1, calm was mistaken for coping. But here, misreading had a compounded cost, not only was distress invisible, but it also delayed access to intervention. One pupil reflected, “I had to break for them to see it.”

Support was often withheld until a formal diagnosis was in place, and even then, pupils were told they were “too high functioning” to qualify. These findings extend critiques of diagnostic gatekeeping, which reflect neuro-normative assumptions about what distress should look like (Knott & Taylor, 2024). Knott and colleagues found that the average delay between first concern and autism diagnosis was over two years, increasing when co-occurring conditions were present. These delays compound risk, amplifying distress long before help arrives. Gatekeeping, through referral thresholds and diagnostic legitimacy, becomes a structural form of harm (NAU, 2023; Equality & Human Rights Commission, 2017).

Participants shared images symbolising isolation, surveillance, and being watched without being understood. One pupil submitted a photo of a wire mannequin and described it “being seen but not noticed.” These symbolic images conveyed how distress, when overlooked or misunderstood, becomes epistemically erased. Do et al. (2024) frame such symbolic communication as a form of epistemic resistance, an attempt to reassert meaning when verbal expression is dismissed.

Pupils described staff responses focused on behaviour, rather than underlying distress. They recalled being praised for good grades or calmness, while their emotional state went unacknowledged. One participant said, “They made a plan without asking me.” Another added, “They thought I was fine because I was still getting good grades.” This reactive, performance-first focus mirrors post pandemic behaviour policies that praise compliance over wellbeing (Padilla, 2024; Thompson, 2022). It also aligns with Ashworth et al.’s (2025) call to shift from behaviour-led thresholds to relational, early recognition. These findings challenge the idea that external disruption is the most reliable indicator of need.

For many, trust in adults eroded by the time support arrived. Some pupils spoke of emotionally “checking out,” or withdrawing from conversations about their needs. Others stopped asking for help altogether. As Do et al. (2024) argue, when speaking up is repeatedly met with disbelief or dismissal, silence becomes a protective strategy. What was not seen in behaviour was not seen at all.

Overall, these findings show how school systems often rely on reactive, diagnosis-dependent models that fail to recognise early, non-verbal, or non-normative expressions of distress. Participants challenge the assumption that visible breakdown is the best indicator of support need. Instead, they call for a model of inclusion that listens earlier, validates pupil testimony, and responds before crisis emerges. These findings make visible the emotional and epistemic cost of delayed recognition, and the urgent need for systems to hear distress before it becomes harm.

Across all five themes, a cumulative pattern emerged: autistic pupils were expected to cope invisibly, perform emotional composure, and suppress distress until it became legible to others. These patterns inform the practice recommendations outlined in section 5.8.

5.7 Strengths and Limitations

5.7.1 Strengths

One of the study’s key strengths was how the chosen approach supported pupils in expressing their experiences in ways that felt natural, layered, and meaningful to them. Pupils feedback reflected this (See appendix P). Rather than reducing their accounts to “barriers and facilitators,” this study sought to reflect how school is *felt*, and how meaning is co-constructed across difference.

By embedding autistic perspective across all stages of design, this study aimed to move beyond researching “on” autistic people toward researching “with” them, reinforcing its commitment to inclusion, accessibility and ethical participatory practice. The use of photos not just as illustrative tools but as meaning making, prompting new interpretations and emotional understandings that shaped their narratives. Both individual and group-based sessions supported emotional expression, validation, and shared understanding. This structure offered space for relational reflection as well as private meaning-making, an approach less common in existing literature but potentially valuable in school-based or therapeutic settings.

The co-produced SHoWED prompt structure supported accessibility and layered reflection. Several chose to share meaning through metaphor, humour, or silence. By allowing these contributions to remain open rather than pushing for clarity, the study upheld an ethic of care and honoured neurodivergent ways of knowing. Silence was not treated as disengagement, but as a potential form of agency.

Framed within Shier's (2001) Pathways to Participation, this study reached between Levels 3 and 4: participants were meaningfully involved in design and dissemination but not in analysis. While interpretive authority rested with me as clinician-researcher, participants influenced how accounts were generated and how insights were shared. This level of involvement exceeded that of many studies reviewed in my SLR, where autistic pupils were often positioned as informants rather than collaborators.

5.7.2 Limitations

While the study upheld key indicators of qualitative rigour, including transparency, reflexivity and coherence (Yardley, 2000) there were limits to what this methodology could access. These do not undermine the study's contribution but help define its scope.

All participants were verbal and recruited through either charities or via social media. As a result, the study reflects the experiences of pupils who remained, to some extent 'accessible' within existing systems. Disengagement from education, being non-verbal or having inconsistent representation, were barriers to inclusion in the study. One young person, for example, was unable to participate due to inpatient admission, highlighting how those most excluded from education are often excluded from research. This echoes wider concerns in autism research about structural exclusion and the underrepresentation of marginalised voices (Botha & Cage, 2022c)

Despite its participatory ethos, full co-analysis was not feasible within the scope and timeline of doctoral research. However, pupils were still involved at Shier Levels 3-4, going beyond the consultative approaches still common in recent reviews (Newson et al., 2024; Pickard et al., 2022). In line with Reflexive Thematic Analysis (Braun & Clarke, 2021), interpretation remained researcher led. However, participant meaning making shaped the early analytic process through photo discussions, captions, and group reflections, which informed how themes were developed.

It is also important to reflect on the balance between participatory aims and the methodological requirements of RTA, particularly in relation to analysis and the development of research questions. Photovoice often aspires to full co-production, including participant led development of research questions and collaborative data analysis (Wang & Burris, 1997; Latz, 2017). In this study, the overarching research question was developed by the researcher in line with ethics approval requirements, while participants helped shape the focus of their contributions through co-constructed prompts and group discussion. Similarly, while participants shaped the focus of group discussions and consultants provided feedback on the analysis, coding and theme development remained researcher led. This was a deliberate choice, aligned with RTA’s interpretive stance, which positions the researcher as the analytic instrument and does not seek consensus (Braun and Clarke, 2019). While this falls short of full co-production, it was consistent with the epistemological stance in which meaning is co-constructed through interaction but interpreted by the researcher using theoretical insight. These boundaries are acknowledged as limitations, but they ensured methodological coherence and ethical integrity within the doctoral context. Future work could explore more collaborative approaches to question setting and analysis, provided there is sufficient time and funding to make such involvement meaningful.

Several community organisations expressed interest in supporting recruitment but were unable to participate due to staff shortages and funding constraints. This reflects broader structural barriers within the autism advocacy sector, where under-resourcing can restrict access to participatory opportunities, particularly for marginalised or underrepresented groups.

Finally, this study does not claim generalisability. However, the findings may be transferable to other mainstream school contexts where distress is overlooked until crisis, or where inclusion remains contingent on masking, performance, or diagnostic status. These limitations reflect not only the boundaries of this project, but the wider patterns of access, power and knowledge production in autism research (Leadbitter et al., 2021).

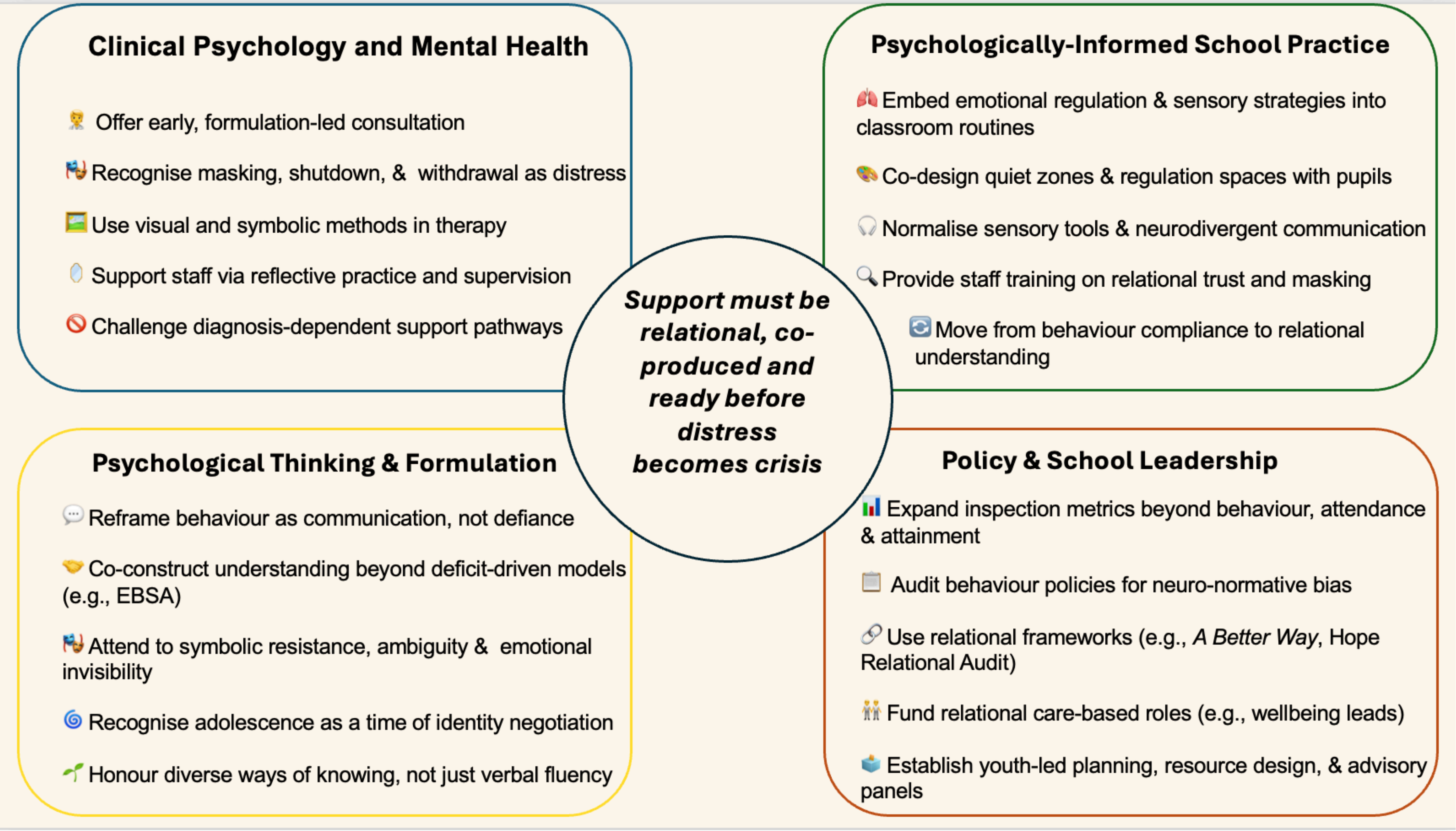
5.8 Clinical Implications and Future Research

5.8.1 Implications for Clinical Psychology, Education, and Policy

The following diagram summarises implications across clinical psychology, psychologically informed school practice, psychological formulation, and policy leadership. It calls for early, relational, neurodiversity informed support before distress escalates into psychological crisis. The following figure is a snapshot of preliminary insight of recommendations that came out of the study.

Figure 32

What Needs to Change? A Visual Summary of Key Implications



Clinical Psychology and Mental Health

- Offer early, formulation-led consultation
- Recognise masking, shutdown, & withdrawal as distress
- Use visual and symbolic methods in therapy
- Support staff via reflective practice and supervision
- Challenge diagnosis-dependent support pathways

Psychologically-Informed School Practice

- Embed emotional regulation & sensory strategies into classroom routines
- Co-design quiet zones & regulation spaces with pupils
- Normalise sensory tools & neurodivergent communication
- Provide staff training on relational trust and masking
- Move from behaviour compliance to relational understanding

Support must be relational, co-produced and ready before distress becomes crisis

Psychological Thinking & Formulation

- Reframe behaviour as communication, not defiance
- Co-construct understanding beyond deficit-driven models (e.g., EBSA)
- Attend to symbolic resistance, ambiguity & emotional invisibility
- Recognise adolescence as a time of identity negotiation
- Honour diverse ways of knowing, not just verbal fluency

Policy & School Leadership

- Expand inspection metrics beyond behaviour, attendance & attainment
- Audit behaviour policies for neuro-normative bias
- Use relational frameworks (e.g., *A Better Way*, Hope Relational Audit)
- Fund relational care-based roles (e.g., wellbeing leads)
- Establish youth-led planning, resource design, & advisory panels

While these recommendations reflect participant experiences, they also align with emerging practices in clinical psychology, inclusive education, and participatory policy. Models such as *A Better Way*, (Steinberg & Oades, 2022) illustrate how local authorities can fund proactive, co-produced supports, and formulation led consultation (Johnstone & Dallos, 2013) already exist in some settings, yet their current implementation remains inconsistent and under resourced.

Findings challenge referral cultures reliant on visible crisis or diagnosis. Clinical psychologists have a key role in advocating for needs-led, creative, and formulation-driven approaches (Johnstone & Dallos, 2013; BPS, 2023). Masking, withdrawal, and symbolic resistance should be recognised as communicative acts. Photovoice demonstrated how imagery, metaphor, and affect can surface insights often missed in verbal approaches (Wang & Burris, 1997; O’Hagan & Byrne, 2023). This affirms the value of multimodal, participatory work with young people who have been historically misunderstood.

Schools and policymakers must also reframe inclusion beyond presence or performance. Staff development, curriculum design, and policy frameworks should centre relational safety, pupil voice, and diverse expressions of need. Participants wanted schools to normalise sensory difference, represent neurodivergence affirmatively, and embed support into everyday life, not as a reaction, but as a right (Newson & Quinn, 2023; Botha & Frost, 2020).

5.8.2 Future Research Directions

The following suggestions identify ways future research could extend this work and address gaps in representation, methodology, and epistemic justice. There is a need to centre the perspectives of autistic pupils who are typically excluded from research. All participants in this study were White British, verbal, and engaged with education or community support. As a result, this project does not reflect the perspectives of pupils who are nonspeaking, disengaged from formal education, or without stable adult advocacy, groups often doubly marginalised by systems that exclude them from both schooling and research participation (Pellicano et al., 2014). Future research should also prioritise the perspectives of racially minoritised autistic pupils, who must navigate the intersectionality of racism and neurodivergence in education.

Future studies should develop low-demand, flexible methods, such as digital storytelling, journaling, or visual elicitation, that broaden access and challenge dominant assumptions about what constitutes “valid” data. Additionally, research should explicitly engage with questions of epistemic justice. For example, building on this study by involving autistic pupils as co-analysts and recognising ambiguity, humour, silence, and resistance as legitimate forms of meaning-making. A shift from extracting verbal content to interpreting contextually grounded meaning could support richer understandings autistic experience and challenge the deficit framings that continue to shape both research and practice (den Houting & Pellicano, 2022)

Longitudinal research is also needed to explore how autistic pupils’ school experience shape their identity and psychological wellbeing overtime. Tracking their experiences over key developmental points, for example, from Year 9 to Year 11, could shed light on different approaches necessary to mirror their evolving needs; recent UK follow ups show such design reveal shifts missed in one-off studies (Anderson & Butt, 2023).

5.9 Final Reflections

This project began from a place of care for autistic young people navigating a school system that often misunderstands them, and for the hidden emotional labour that such navigation demands. I was drawn to this work not only as a researcher, but as a trainee clinical psychologist working with young people in distress, many of whom had shared stories of feeling unsafe, unseen, or misread in educational settings. The aim of this study was never to “give voice,” but to hold space to listen, to honour, and to reflect critically on what that listening required of me.

Throughout this research, I held multiple roles: researcher, psychologist-in-training, non-autistic adult, and participant-listener. Each of these roles carried power. I became increasingly aware of how my clinical training and personal values shaped what I noticed, what I interpreted, and what I prioritised. I entered the project with a strong belief in the neurodiversity paradigm and a desire to challenge deficit-based framings. But I also needed to be cautious not to impose meaning or celebrate resistance without acknowledging its emotional cost. I held a deep respect for the intelligence and creativity of autistic people, a belief I still hold, but I came to realise that the forms of resistance I admired often came at great emotional cost. What looked like strength on the surface was, at many times, a strategy for survival. It felt ethically uncomfortable to celebrate resistance without also recognising the toll it took. This insight asked me to slow down and to hold space for both resilience and exhaustion at once. This research challenged me to ask not “How do we build resilience?” but “What are we asking young people to be resilient to?”

When interpreting participants’ accounts of teacher misunderstanding or overlooking their distress, I was mindful not to reduce these encounters to individual blame. Several participants themselves acknowledged this complexity, holding both the harm they felt and the structural pressures their teachers faced. I shared these feelings, recognising the emotional costs of being misread, while also seeing the realities of under-resourced systems. A CRSC stance enabled me to situate meaning not within individual roles of ‘teacher’ or ‘school’, but within relational dynamics shaped by policy, funding and systemic strain. Teachers, too, were often navigating environments with little room for connection. This helped me stay grounded in the authenticity of participants’ accounts, not dismissing their pain, but understanding it within the wider systems that shaped those experiences.

Finally, there were moments when participants pushed back, gently but clearly. They challenged the language I used or reshaped by questions in ways that made me pause. I came to see these not as misunderstandings, but as intentional signals that meaning isn’t something I can construct alone. These moments reminded me that discomfort can be part of knowledge making, and that understanding must be built together, not imposed. I’m leaving this project with a stronger sense of responsibility, and a commitment to keep asking, as participants did: what are our school experiences, and what needs to change?

5.10 Conclusion

This study set out to hear autistic pupils’ experiences of navigating school. The findings revealed that many survived by masking their needs, regulating emotions alone, and withholding their authentic selves to avoid judgement. Participants described being praised for appearing calm while struggling internally or denied support because their distress didn’t fit expected forms. Instead of receiving help for sensory or emotional distress, they were expected to remain composed until breakdown. These accounts reflect not a lack of resilience, but a lack of proactive care from the systems around them.

This research contributes to literature on autistic pupil experience by centring meaning-making around masking, burnout, diagnostic delay, and emotional invisibility. It also offers a methodological contribution through visual, metaphor-rich accounts and a participatory approach. While based on a small and demographically limited sample, the findings echo wider concerns about misrecognition and delayed support (Ashworth et al., 2025).

Participants were clear: they didn’t want more interventions. They wanted support that was attuned, co-produced, and respectful of how they experience the world. These findings raise critical questions for future research, especially with pupils who are nonspeaking, have disengaged from school, or are less likely to be invited into research spaces. Participants also reflected on the process itself as meaningful- see appendix T.

Beyond its empirical and methodological contributions, this study reflects a set of values: those autistic perspectives matter; that silence and resistance can be meaningful forms of communication; and that change doesn’t come from asking individuals to adapt, but from holding systems accountable. As participants reminded me, inclusion isn’t about fitting in, it’s about being recognised, supported, and able to show up as yourself.

Together, these findings respond to the research question by illustrating how autistic pupils experience school through relationships, regulation, recognition, and the systems that support or constrain them.

“Hope that a random person like me may be able to change things for the next autistic student that starts school next year” Photovoice **Participant**

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Appendices

Appendix A: Rationale for Identity First Language

This thesis adopts identity-first terminology (e.g., *autistic pupils*) in line with growing consensus among autistic-led research and neurodiversity-affirming practice. Survey data suggests that many autistic individuals prefer identity-first language, which recognises autism as an integral part of identity rather than a disorder to be separated (Botha et al., 2023).

This choice also aligns with the neurodiversity paradigm, which frames autism as a natural variation in cognition, communication, and sensory experience (Kapp, 2020; Walker, 2021). Throughout this thesis, person-first language (e.g., “pupils with autism”) is used only when directly quoting or referring to sources that adopt that terminology.

The use of identity-first language reflects a broader ethical and epistemological stance: one that seeks to honour autistic ways of knowing, resist deficit-based narratives, and promote linguistic consistency with community-led research values.

Appendix B: Reflexive Journal Extract- Research Positionality

As I begin this project, I’m holding multiple roles: trainee clinical psychologist, non-autistic researcher, and someone still learning how to do participatory work well. I’ve supported autistic young people in services, but this is different. I’m not offering a formulation or intervention this time, I’m here to listen. Though I worry about how much I’ll shape what I hear. I keep asking myself: what power do I bring into the room? Whose voice am I lifting, and whose might I miss?

I don’t want to fall into the same patterns this project is trying to challenge, where autistic pupils’ voices are filtered by adult assumptions or reshaped to fit familiar narratives. I want to stay true to what participants choose to share. That means being honest about my lens but not putting myself at the centre. It means catching my clinical instincts when they want to ‘fix’ or ‘make sense’ of things that might just need to be heard as they are…

Appendix C: UK Attendance and Inclusion Policy Timeline

This timeline summarises key legislation and guidance frameworks relevant to inclusion, support and attendance of autistic pupils in English UK mainstream secondary schools. It prioritises policies cited in the thesis.

Year	Policy / Guidance	Issuing Body	Key Focus
2010	*Equality Act 2010*	UK Parliament	Consolidated anti-discrimination law; introduced duty to make *reasonable adjustments* for disabled pupils.
2011	Green Paper *Support and Aspiration: A New Approach to Special Educational Needs and Disability*	DfE	Proposed reforms leading to EHCPs and greater parental choice.
2014	*Children and Families Act 2014*	UK Parliament	Enacted statutory Education, Health & Care Plans (EHCPs); extended SEND support 0-25.
2015	*SEND Code of Practice (0–25 years)*	DfE & DoHSC	Operational guidance for implementing the 2014 Act.
2018	*Mental Health and Behaviour in Schools* (updated 2022)	DfE	Behaviour-first approach to emotional wellbeing; emphasises individual “risk factors”.
2018	*Emotionally Based School Avoidance (EBSA) Guidance*	West Sussex EPS	Non-statutory guidance for identifying and managing EBSA.
2019	*Ofsted Education Inspection Framework*	Ofsted	Introduced “Behaviour & Attitudes” judgement; attendance as performance metric.
2020	*Coronavirus Act 2020* (temporary SEND modifications)	UK Parliament	Suspended some EHCP duties during COVID-19.
2021	*National Audit Office Report: Support for pupils with SEND*	NAO	Identified funding shortfalls, EHCP delays, inconsistent practice.
2022	*Working Together to Improve School Attendance*	DfE	Statutory guidance; emphasises parental responsibility and legal enforcement.

2022	Green Paper *SEND Review: Right Support, Right Place, Right Time*	DfE	Proposed national SEND standards, early help and AP reforms.
2023	*Special Educational Needs and Disabilities & Alternative Provision Improvement Plan*	DfE	Sets out implementation of 2022 Green Paper proposals.
2023	*Behaviour in Schools: Advice for Headteachers and Staff* (update)	DfE	Re-emphasises zero-tolerance behaviour policies and attendance drives.
2024	*Education (ParentPenaltyNotices) (England) Regulations 2024*	DfE	Increases fines for persistent absence.
2025	*Ambitious about Autism: Persistent Absence Briefing*	AaA	Reports 166 % rise in persistent absence among autistic pupils; calls for systemic reforms.

Appendix D: SLR Database Search Strategies

Database	Platform	Search Date	Search String	Limits Applied
APA PsycArticles	APA PsycNet	20 April 2025	(autism OR autistic OR "autism spectrum disorder" OR ASD OR asperger OR neurodivergent) AND (school OR "mainstream school" OR "inclusive education" OR classroom OR education) AND ("student voice" OR "pupil voice" OR experience OR perspective OR opinion OR narrative OR insight OR participat* OR agency) AND (qualitative OR interview OR "focus group" OR ethnography OR "case study")	English; Peer-reviewed journal articles; 2010–2025
ERIC	EBSCOhost	20 April 2025	(autism OR autistic OR "autism spectrum disorder" OR ASD OR asperger OR neurodivergent) AND (school OR "mainstream school" OR "inclusive education" OR classroom OR education) AND ("student voice" OR "pupil voice" OR experience OR perspective OR opinion OR narrative OR insight OR participat* OR agency) AND (qualitative OR interview OR "focus group" OR ethnography OR "case study")	English; Peer-reviewed; 2010–2025
Scopus	Scopus	20 April 2025	TITLE-ABS-KEY(autism OR autistic OR "autism spectrum disorder" OR ASD OR asperger) AND TITLE-ABS-KEY("mainstream school" OR "inclusive education" OR classroom OR school) AND TITLE-	English; Journal articles; Subject areas: Soc Sci, Psych, Arts & Hum; 2010–2025

			ABS-KEY("student voice" OR "pupil voice" OR experience OR perspective OR participation OR opinion OR insight OR narrative OR agency) AND TITLE-ABS-KEY(qualitative OR interview OR "focus group" OR ethnograph* OR "case study")	
CINAHL	EBSCOhost	20 April 2025	(autism OR autistic OR "autism spectrum disorder" OR ASD OR asperger) AND ("mainstream school" OR "inclusive education" OR classroom OR school) AND ("student voice" OR "pupil voice" OR experience OR perspective OR participation OR opinion OR insight OR narrative OR agency) AND (qualitative OR interview OR "focus group" OR ethnograph* OR "case study")	English; Peer-reviewed; 2010–2025

Appendix E: Reflexive Log Extracts

Date	Decision Point / Observation	Reflexive Note & Rationale
20 April 2025	Final database search completed	I felt uneasy that terms like “autism spectrum condition” might miss identity-first language. A final test adding “ASC” and “autist*” found no new UK studies, confirming saturation. I documented this and stored the final strings in Appendix D.
25 April 2025	CASP scoring - reflexivity consistently weak	Most studies were rated “No” or “Can’t tell” for reflexivity, echoing my concern that autistic voice is often filtered through unexplored neurotypical assumptions. I flagged this in the Limitations to show how it affects the credibility of thematic interpretation.
29 May 2025	Interpreting Theme 2 -clinical parallels	While coding Theme 2, I was struck by how tokenistic participation in studies resembled school settings I’ve seen on placement. It prompted reflection on my own practice and informed the Clinical Implications, reinforcing that safety and power-sharing is vital, not optional.

Appendix F: SLR Theme Source Table

	Theme 1 Conditions Framing Pupil Participation			**Theme 2 Adult Framing & Limits**		**Theme 3 Recognising Atypical / Embodied Voice**	
Study	**1.1 Trust as pre-condition**	**1.2 Suppressing voice**	**1.3 Inclusion as feeling**	**2.1 Adult framing / lack reflexivity**	**2.2 Participation framed, not shared**	**3.1 Symbolic expression minimised**	**3.2 Mis-interpreting behaviour**
Cook et al., 2016		✓		✓		✓	
Cook et al., 2018		✓			✓	✓	✓
Costley et al., 2021				✓	✓		✓
Cunningham, 2022	✓		✓			✓	
Dillon et al., 2014		✓		✓			
Fox & Asbury, 2024	✓	✓		✓	✓	✓	✓
Goodall, 2018	✓	✓		✓		✓	
Goodall, 2019				✓			✓
Goodall, 2020	✓			✓		✓	
Hummerstone & Parsons, 2021	✓		✓			✓	
Neal & Frederickson, 2016	✓		✓				

Appendix G: Reflexive Journal Extract- Workshop 2

I used the phrase "coping strategies" when referring to sensory breaks. One participant immediately replied, "It's not a strategy, it's a need." That moment made me realise how much my language was still shaped my clinical training. I acknowledged this in the group, and asked what terms felt more accurate to them. Several participants suggested "accessibility tools," which we then used going forward. It was a small shift, but it reminded me how language can reinforce or resist power dynamics, and how important it is to let participants define the terms that describe their own experiences.

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Appendix H: Adapted SHOWeD Prompts

These prompts were co-refined during preparatory workshops with autistic consultants and participants. The aim was to improve accessibility and resonance, supporting the use of the Photovoice in a neurodivergent-affirming participatory framework. The final set of six prompts was used flexibly, allowing participants to select or adapt those that felt meaningful, or to narrative their photos freely.

Original SHOWeD Prompt	Adaptation
S – See: What do you see in this photo?	*What is in this picture?* or *What did you take a photo of?*
H – Happen: What is really happening in this photo?	*What was going on when you took this?* or *What does it show about school?*
O – Our lives: How does this relate to your life or your community?	*Does this photo show something that affects you a lot?* or *how is this part of your school life?*
W – Why: Why does this situation exist?	*Why do you think this happens?* or *What makes this happen at school?*
E – Empowerment: How can understanding this help you feel more empowered?	*Did taking this photo help you understand anything about school? Does this show something you want other people to understand better? Is this something important for adults to hear?*
D – Do: What can we do to change or improve this?	*If you could change something, what would it be? If a teacher saw this photo, what would you want them to change? If you were in charge of school, what would you do about this?*

Appendix I

This appendix provides an example from one participant to illustrate how early coding informed the development of the final themes. It shows how I moved from initial descriptive coding to interpretations using RTA. Excel was used to track codes, reflections and emerging patterns.

Transcript	Semantic Code(s)	Latent Code(s)	Initial Impressions	Reflexive Notes
"The barriers were down… nothing can get past… everything's just kind of blocked."	Blocked expression, Restricted participation	Systemic silence, Emotional stuckness	The photo reflects feelings of being stuck or blocked.. a metaphor for school and communication.	their use of the barrier as metaphor really struck me .. did my questions help their reach that connection, or was it already there?
"Teachers say it's like the train barriers have come down when they try to talk to me… but there's a footbridge right there… it's not impossible."	Communication barrier, Misunderstood needs	Alternative communication overlooked	Powerful metaphor for communication barriers.	loved the metaphor- need to make sure I don't 'gloss' their struggle, but stay focused on what its criticising
"I've been screaming for help… but because I haven't been saying 'I need help' teachers ignore it."	Invisible distress, Non-verbal communication	Misrecognition of need, Epistemic injustice	Highlights invisible struggles and the failure of staff to notice non-verbal expressions of distress.	I felt emotional hearing this, reminds me how much schools rely on neurotypical communication. Makes me think abuse!!
"It feels like I'm in a pot of boiling water… I know I'll reach meltdown but I can't stop it."	Sensory overload, Escalation	Loss of control, Emotional vulnerability	Strong metaphor for sensory overload and lack of environmental support.	how little control they feels .. how often are these minimised in practice?

“I switch off completely in lessons… if I don’t understand, I get so frustrated I almost cry.”	Cognitive overload, Academic strain	Coping conflict, Shame at difficulty	Reveals the emotional toll of trying to cope.. trapped between wanting to succeed and constant barriers.	connected with their frustration a lot.. need to make sure I’m not only focusing on their struggle, but recognising her intent too.
“It’s like being the spokesperson for your difference… having to explain yourself constantly.”	Tokenism, Emotional labour	Being ‘the example’, Institutional burden	Speaks to tokenism and emotional labour always having to justify personal needs.	I realised I was part of this dynamic, asking their to explain the photo... felt conflicted about it.
“Teachers could just turn the lights off… small changes would make a big difference.”	Practical solutions, Environmental sensitivity	Neglected adjustments, Structural inertia	Suggests simple, practical accommodations that are often overlooked.	their practical suggestions show how minor changes can be impactful... are schools overlooking these due to deeper systemic issues?
“I think it kind of encapsulates the stigma around us stimming and doing what we need to do to regulate ourselves… It shouldn’t be a big statement to meet our needs.”	Self-regulation, Stigma of needs	Stigmatised visibility, Need as resistance	stimming becomes a public statement due to stigma.	struck by their description of a personal act, becoming politicised.. Come back to this
“It’s like using a tangle is a political statement… when really I’m just trying to accommodate myself.”	Misread self-care, Control and judgement	Support politicised, Medicalised difference	Highlights tension between personal need and external judgement.	words made me reflect on how schools may unintentionally politicise difference.
“I still feel a lot of shame for using fidget toys or	Stigma, Internalised masking	Masking for acceptability, Shame in visibility	Reveals internalised stigma and masking. Even	I felt their vulnerability here, important to capture but

headphones… I feel like I'm making myself look more stereotypically autistic."			using supports causes self-consciousness.	not over-sensationalise.
"I started counselling… that's when I learned I could go to quiet spaces, but I felt guilty using them."	Quiet spaces, Undeserving guilt	Service inaccessibility, Emotional cost of help	Highlights hidden resources and poor communication in schools. Guilt stems from feeling undeserving.	why do systems make students feel like a burden for using what's provided?
"We need more autistic characters in books and TV… it normalises things subconsciously."	Representation, Advocacy through media	Empowerment through cultural visibility	suggests media representation as a tool to reduce stigma.	felt hopeful... important to highlight agency, not just struggle.
"I've always thought it's so weird that the birds sit on the electric lines… how are they not electrocuted?"	Isolation, Disconnection	Metaphoric discomfort, Emotional exposure	connects to bird's position to feelings of vulnerability.	attention to small details reflects their self-awareness.. reminds me that everyday scenes can hold powerful metaphors but also how much- they know their experiences well and a shame they are never asked about them
"It kind of ties into social isolation… the bird is very alone, but it's not necessarily lonely."	Solitude, Reframing loneliness	Redefining aloneness, Navigating stigma	Uses the lone bird as a metaphor for their experience, isolation without loneliness.	I was struck by their distinction between being alone and lonely... it challenges typical deficit narratives.

Appendix J: Participant Information Sheet

UNIVERSITY OF HERTFORDSHIRE

FORM EC6: PARTICIPANT INFORMATION SHEET FOR PARENTS/CARERS

Study title:

An exploration of the school experiences of Autistic young people using a photovoice methodology

Primary Researcher:

Zineb Belouadah (Trainee Clinical Psychologist)

Principle supervisor:

Dr Barbara Rishworth (Clinical Psychologist)

Introduction

Part 1- to give you first thoughts about the project

We would like your child to help us with our research study about the experiences of Autistic young people in mainstream schools and how it might be made better. Please read this information sheet carefully and discuss it with your child. Ask us if there is anything that is not clear or if you want to know more. Take time to decide if you want your child to take part. It us up to you and your child if they want to do this. If they don't, that's fine, and it will not affect them in any way.

Why are we doing this research?

We want to understand the experiences of Autistic young people in mainstream schools and how they can be improved. We will use photos and stories to allow young people to share their perspectives. We hope that this will spark discussions that lead to positive changes in how schools support autistic people.

Who can participate?

We are looking for young people aged 14-18 who are diagnosed or identify as being autistic and have some experience in mainstream schools.

Do they have to take part?

No, it is entirely up to you and your child. If your child does decide to take part:

- You will be asked to sign a consent form to say you agree for your child to participate.

- Your child will be asked to sign an assent form to say they agree to participate.

- You will be given this information sheet and a copy of your signed consent form to keep.

Your child is free to stop taking part at any time during the research without giving a reason.

What will happen to my child if they take part? If your child chooses to join this study, they will:

- Attend an initial workshop where they'll learn about photography and how to express their thoughts through pictures. We will provide cameras.
- Take photos over a fixed period of time to show aspects of their school life
- Have an individual interview to share their photos and thoughts with the researcher
- Participate in a discussion session to talk about their photos and experiences with other young people.
- A final interview to reflect on the photovoice process and provide feedback.

What will my child be asked to do?

- Your child with be asked to take photos that represent their experiences in mainstream school.
- They will then share these photos in an individual interview where we will talk about the photos and their meanings and identify which photos they would be happy to share in the group discussion.

- They have the choice to make these photos anonymous if they do not wish for them to be identified by others in the group.
- They don't need to worry about making the pictures perfect; it's more about what these pictures mean to them.

By sharing the meaning being the photos, we can explore common experiences and differences among participants. These conversations will help us understand how schools can better support autistic young people. The insights gained from this study will be used to advocate for positive changes in educational settings.

Food and Snacks:

- Cold food and snacks will be provided during some in-person workshops and group discussions.
- We will ask for your child's dietary requirements and any food allergies before the meetings to ensure we cater to their needs safely.
- Only approved food vendors will be used.
- Your child is welcome to bring their own snacks or meals if they prefer.
- In case of any adverse reactions to the food, medical assistance will be provided immediately.

What are the possible disadvantages or risks of taking part?

- There are minimal risks involved. Your child may find discussing their experiences emotionally demanding. If so, we will provide support to make sure they are comfortable. They can also choose to stop participating at any time and will be offered breaks throughout the meetings.
- Our aim is to create a safe and supportive space where they can share what they feel comfortably sharing. We will agree on some principles to ensure discussions feels safe and helpful. At the end of each meeting, time will be set aside to check how they are feeling and to ensure they have the support they need.

- We will provide photos and details of the workshop location to help your child prepare and feel comfortable.

What are the possible benefits of taking part?

Participating in this project offers an opportunity for your child’s voice to contribute to enhancing the way schools accommodate to autistic young people. The process of taking photos is creative and can be enjoyable. The insights from this study aim to influence policymakers about the realities often not seen in the daily lives of autistic young people in mainstream schools. Their views will hopefully count towards significant change and the findings can be shared with professionals who hold the power to make valuable changes.

- We may write to parliament, create information sheets, or offer a photography exhibition to share findings with others. Your child will decide how the findings are shared.
- Any photographs or quotes from your child will only be used with their consent.
- We value their time to participate and to thank them would like to offer a voucher of a value of £15 per hour for each meeting.

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

Everything they share will be kept private, and we will use pseudonyms for any photos or stories they provide. Only the research team will have access to the original data, which will be securely stored.

What will happen to the data collected within this study?

The photographs, discussion, and any other data your child provides will be central to understanding the experiences of autistic young people in mainstream schools. Here is what will happen with the data:

1. All data will be anonymised before storage. Your child’s name or any identifying details will not be connected to the information used in the analysis or reports.

2. The anonymised data will be stored electronically in a password-protected environment. Only the research team will have access to this data to ensure your child’s privacy is maintained.

3. These electronic records and any hard copy of data will be kept for 5 years. After this period, they will be permanently destroyed securely.

4. The data may be shared in anonymised form for research purposes, such as in academic publication or presentation. No personal identifiers will be revealed. We will explain how and where the data will be shared and you will always retain the right to agree or disagree with the use of your images or information before it is shared publicly.

5. Contributors release form: This form is your agreement that allows us to use the anonymised images or quotes, ensuring that you are comfortable with how they will be used to represent the study’s findings.

Please remember that confidentiality is paramount throughout the study. If you have any concerns or issues during the study, do not hesitate to contact the researcher or the supervisor to discuss them.

Contact information:

If you have any questions about this project, or if your child would like to take part, please contact:

Primary researcher:

Zineb Belouadah (Trainee Clinical Psychologist) at z.belouadah@herts.ac.uk.

If you have any concerns or questions about how the project is being conducted, please contact:

Principal Supervisor:

Dr Barbara Rishworth, at B.Rishworth@herts.ac.uk or the University of Hertfordshire Research Ethics-Sub Committee Chair at hsetecda@herts.ac.uk.

Thank you very much for reading this information.

PARTICIPANT INFORMATION SHEET
FOR 16-18 YEAR OLDS

Study title

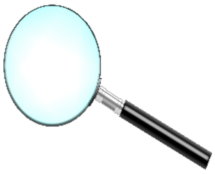
An Exploration of the School Experiences of Autistic young people using a Photovoice Methodology

Part 1 – to give you first thoughts about the project

1. Invitation paragraph

We would like you to help us with our research study about the experience of Autistic young people in mainstream schools. Please read this information carefully. If you have any questions or need more information, feel free to ask us. Take time to decide if you want to participate. It is completely your choice. If you decide not to participate, that's perfectly okay and it will not affect you in any way.

2. Why are we doing this research?



We aim to:

- Understand the experiences of Autistic young people in mainstream schools.
- Explore ways to improve these experiences.

3. Why have I been asked to take part?

You have been chosen because:

- You identify as Autistic or have an Autism diagnosis,
- You have experience in mainstream schools.
- We are asking a group of young people like you to participate in this study.

4. Do I have to take part?

No, participation is entirely voluntary. If you decide to participate:

- You will be asked to sign a consent form to confirm your agreement. ✓
- You will be receive a copy of this information sheet and your signed consent form to keep.
- ✗ You can stop participating at any time during the research without giving a reason.

5. What will happen to me if I take part?

If you choose to join this study, you will:

- Attend an initial workshop where you'll learn about photography and how to express your thoughts through pictures.
- Take photos over a two-week period to show aspects of your school life
- Have an individual interview to share you photos and thoughts with the researcher
- Participate in in a discussion session to share the photos with others and see other participants photos.

- A final interview to reflect on the photovoice process and provide feedback.

Food and Snacks:

- We will have some snacks and cold food available during our in-person workshops and group meetings.
- Please let us know if you have any food allergies or dietary needs so we can make sure the food is safe for you.
- We will only use food from approved vendors to keep everything safe.
- If you prefer, you can bring your own snacks or meals.
- If you feel unwell after eating, we will get medical help right away.

6. What will I be asked to do?

You will be asked to:

- Take photos that represent your experiences in mainstream school.
- Share some of your photos during the discussion session.
- Don’t worry about making the pictures perfect; focus on what these pictures mean to you.

7. Is there anything else to worry about if I take part?

- Discussing personal experiences may be emotionally challenging at times.

- If you feel uncomfortable, we will provide support, and you can take breaks or stop participating at any time.
- We will provide photos and details of the workshop location to help your child prepare and feel comfortable.

8. Will the study help me?

- While the study might not directly benefit you, participating in photovoice can offer several personal benefits:
- It provides a platform for you to express your thoughts and experiences through photography.
- It can help you develop new skills in photography and storytelling.
- It offers an opportunity to share your experiences and be heard by others, which can be empowering.
- The information we gather might help improve the experiences of Autistic young people in mainstream schools in the future.

9. What happens when the research study stops?

- We will analyse the information gathered from the photos and discussions.
- This will help us understand the experiences of Autistic young people in mainstream schools and identify potential areas for improvement and inclusivity.

10. Contact for further information

If you would like any further information about this study you could contact:

A Photovoice Study Exploring Autistic Young People's Experiences of Mainstream School

Principal researcher: Zineb Belouadah (z.belouadah@herts.ac.uk)

Principal supervisor: Dr Barbara Rishworth (email) Zineb Belouadah

Thank you for reading so far - if you are still interested, please go to Part 2:

PARTICIPANT INFORMATION SHEET
FOR 14-15 YEAR OLDS

Study title:

An Exploration of the School Experiences of Autistic Young People Using a Photovoice Methodology

Part 1 – Introduction to the Project

11. Invitation:

- We would like you to help us with our research study about the experience of Autistic young people in mainstream schools.
- Please read this information carefully and talk to your parents or carer about this study.
- Ask us if you have questions or need more information.
- Take time to decide if you want to take part. It's your choice to join or not. If you decide not to, it's totally fine and won't affect you.

12. Why are we doing this research?

- To learn about the experience of autistic in mainstream schools.
- To find ways to improve these experiences.

13. Why have I been asked to take part?

- You have been chosen because you identify as Autistic or have an Autism diagnosis

- You have experience in mainstream schools.
- We are asking a group of young people like you to join.

14. Do I have to take part?

- No, it’s completely your choice.
- If you decide to join:
  - You will sign a form saying you agree.
  - You will get this information sheet and a copy of your signed form.
- You can stop anytime without giving a reason.

✓ ✗

15. What will happen if I take part?

/

- Attend an initial workshop where you’ll learn about photography and how to express your thoughts through pictures.
- Take photos that reflect your school life
- Have an individual interview to share your photos and thoughts with me
- Participate in a discussion session to talk about your photos and experiences with other participants
- A final interview to reflect on the study process and provide feedback.

Food and Snacks:

- We will have some snacks and cold food available during our in-person workshops and group meetings.

- Please let us know if you have any food allergies or dietary needs so we can make sure the food is safe for you.
- We will only use food from approved vendors to keep everything safe.
- If you prefer, you can bring your own snacks or meals.
- If you feel unwell after eating, we will get medical help right away.

16. What will I be asked to do?

- Take photos that show your experiences in mainstream school.
- Share your photos and stories during discussions.
- Don’t worry about perfect pictures; focus on what they mean to you.

17. Is there anything to worry about?

- Talking about personal experiences might be hard sometimes.
- We will support you if you feel uncomfortable.
- You can take breaks or stop at any time.
- We will provide photos and details of the workshop location to help you prepare and feel comfortable

18. Will the study help me?

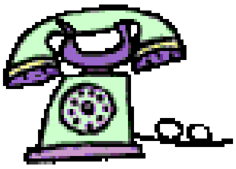
- The study might not help you directly, but we hope it does have some positive changes for you.
- It can help improve school experiences for other Autistic young people in the future.

9. What happens when the research study stops?

- We will analyse the photos and discussions.
- This will help us identify potential areas for improvement and inclusivity.
- We will use this information to understand and improve school experiences for Autistic young people.

19. Contact for further information

If you would like any further information about this study, you could contact:



- Name: Zineb Belouadah
- Position: Trainee Clinical Psychologist
- Email: z.belouadah@herts.ac.uk

Thank you for reading.

if you are still interested, please go to Part 2:

Part 2 - more detail – information you need to know if you still want to take part.

20. What if I don't want to do the research anymore?

- Just tell your parents, carer, or the researcher.
- No one will be upset, and it won't affect you in any way.

21. What if there is a problem or something goes wrong?

- Tell us if there is a problem, and we will fix it.
- Your parents or carer can also contact the researcher or the study's supervisor.

Name: Zineb Belouadah

or Principle supervisor

Dr Barbara Rishworth

22. Will anyone else know I'm doing this?

- The research team will know.
- All your information will be kept private.
- You will be given a fake name for the study.
- Any information about you that is shared will have your name and personal details removed so that you cannot be recognised from it.
- Information from the study will be securely stored for 5 years and then destroyed.

23. What will happen to the results?

- We will share the findings with professionals and organisations.
- Results may be published in academic journals or presented at conferences. You will be able to decide where else you want the results shared.

- Results will be anonymous, which means that you will not be able to be identified from them.

24. Who is organising and funding the research?

- The study is conducted by the University of Hertfordshire.
- It is part of Clinical Psychology Doctoral Training.
- The university is funding the research.

25. Who has checked the study?

- The study was reviewed by a Research Ethics Committee at the University of Hertfordshire. This a group of people who make sure that the research is OK to do.

26. How can I find out more about research?

- Contact the researcher or the study's principal supervisor for more information (contacts details provided).

Thank you for taking the time to read this – please ask any questions if you need to.

Part 2 – More Details – information you need to know if you still want to take part.

27. What if I don’t want to do the research anymore?

- You can stop participating at any time. Just let the researcher know.
- No one will be upset, and it will not affect you in any way.

28. What if there is a problem or something goes wrong?

- If there is a problem, tell us and we will try to fix it immediately.
- You or your parents can contact the researcher or the study’s main supervisor (contact details provided)

29. Will anyone else know I’m doing this?

- The research team will know you are participating.
- All information collected about you will be kept strictly confidential.
- You will be given a fake name for the study.
- Any shared information will have your name and personal details removed so you cannot be recognized.
- Once the study is complete, all information will be securely stored for 5 years and then permanently destroyed.
- Please note that confidentiality may be broken if there are concerns about your safety or the safety of others.

30. What will happen to the results of the research study?

- When the study is finished, we will present our findings to relevant professionals and organizations.
- The results may be published in academic journals or presented at conferences.
- We may create exhibitions or displays showcasing the photos and stories, which can be shared in schools, community centers, or online galleries.You will be able to decide this.
- The results will be anonymous, meaning you will not be identified from them.

31. Who is organising and funding the research?

- This study is being conducted by researchers at the University of Hertfordshire as part of the Clinical Psychology Doctoral Training.
- The research is being funded by the university.

32. Who has checked the study?

- This study has been reviewed and approved by the University of Hertfordshire Research Ethics Committee.

33. How can I find out more about research?

- Contact the researcher or the study's principal supervisor for more information (contact details provided).

Thank you for taking the time to read this – please ask any questions if you need to.

Appendix K: Research Passport

Autism Passport

Name: **I like to be called:**		**Pronouns:** **Date of Birth:**	
Email:		**Telephone:**	
Please select as many as apply:	☐ I have an official diagnosis of autism I was diagnosed at age: ____________________ ☐ I self-identify as autistic I started to self-identify at age: ________________ ☐ Other (please specify): ________________________	**I prefer this type of language:**	☐ Identity first (i.e. an autistic person) ☐ Person first (i.e. a person with autism) ☐ Combination/I don't mind ☐ Other (please specify): ______________________

Are there any interests of hobbies you would like to share?			
I am happy to be contacted in the following ways:	☐ Text ☐ Phone ☐ Email ☐ Letter	**I prefer to receive information in the following ways:**	☐ Text ☐ Phone ☐ Email ☐ Letter ☐ Face to Face ☐ Easy Read ☐ Other:
I find these ways of communicating easier:	☐ By Telephone ☐ In Person (Face to Face) ☐ Via Computer (ie Zoom) ☐ Writing or Text ☐ Gestures ☐ No Preference	**I find these ways of communicating difficult:**	☐ By Telephone ☐ In Person (Face to Face) ☐ Via Computer (ie Zoom) ☐ Talking ☐ No Preference
Are you comfortable speaking in a group setting?	☐ Yes ☐ No ☐ No preference		
I consent to information being shared with the following people:			

Communication needs I would like to share:	Here are some examples of what you may wish to include here: I can be very literal/ I need time to process and respond/ I prefer direct questions or open-ended questions.	
The following can cause anxiety and make an appointment more difficult:	☐ Unfamiliar Places ☐ New people ☐ Travelling to the appointment ☐ Unexpected Events ☐ Waiting ☐ Unexpected Changes ☐ Crowds	☐ Lighting ☐ Busy patterns or clutter ☐ Background noises ☐ Unexpected noises ☐ Certain smells or aromas ☐ Certain Textures ☐ I would appreciate being warned if you need to touch me

	☐ Busy Places	Other:

What do I need to know before we have an appointment/How to prepare me for an appointment

(multiple options can be chosen):

☐ Details of venue ☐ Details of Car Parking Arrangements ☐ Who I am meeting (and their roles) ☐ Appointment duration ☐ A appointment agenda ☐ Any information we are discussing sent out in advance	☐ Details of information needed from me / questions you will be asking (i.e. medications) ☐ Appointment Reminder (Including reminder of what I have been asked to bring) ☐ Other:

For face-to-face appointment I will find the following useful:

☐ A quiet space to wait (or wait outside and be called in) ☐ An agenda	☐ I may find the following difficult in any waiting room/appointment room: bright lighting, dim

☐ Supporting written material ☐ Supporting Diagrams / Visual Material ☐ Additional time to respond to your questions	lighting, background noise, too many people, certain smells, some textures, being touched. ☐ I may use any of the following to reduce sensory distractions: dark glasses, noise cancelling headphones, fidget toys. ☐ Other:

How to present information to me to support my understanding:		
☐ Written Text ☐ Bullet Points ☐ Diagrams ☐ Dyslexia friendly font	☐ Information on coloured paper ☐ Mind Mapping ☐ Supporting Evidence ☐ Information on paper	☐ Information on phone ☐ Easy Read Information ☐ Other:

Are you comfortable sharing photos as part of the study?	☐ Yes ☐ No ☐ No preference

Do you have any experience using a camera or taking photos?	☐ Yes ☐ No
After an appointment I would find the following useful:	
☐ 'Take away' information of anything we have discussed: ☐ List of key research tasks or actions	☐ Recap of previous appointment ☐ Details of next Appointment ☐ Information about next Appointment ☐ Other:
How would we know if you were becoming distressed of finding participating in the study difficult?	**How can we best support you if you become distressed or find participating in the research difficult?**

Appendix L: Consent/Assent Forms

UNIVERSITY OF HERTFORDSHIRE
PARENTAL CONSENT FORM FOR PARTICIPANTS AGED 14-15

Title: An Exploration of the School Experiences of Autistic Young PeopleUsing a Photovoice Methodology

Researcher: Zineb Belouadah

Introduction: This research is part of the Clinical Psychology Doctoral Training at the University of Hertfordshire. We aim to use Photovoice, a method combining photography and discussion, to explore school experiences of autistic adolescents. We are co-designing the research with your child, to ensure their voices and experiences are central to the study, helping to shape its direction and outcomes.

Participant Information: Before you and your child decide whether your they should participate, please read and ensure your child reads the Participant Information Sheet provided. It contains detailed information about the study purpose, aims, methods, potential risks and benefits.

Consent Checklist:

Please indicate your agreement with each statement by ticking the boxes below:

1. I have read the Participant Information Sheet and understand the purpose and aims of this project.

   ☐ Yes ☐ No

2. I have had the opportunity to ask questions about the project and my child's participation, and I am satisfied with the answers provided.

   ☐ Yes ☐ No

3. I understand that the discussions and photography sessions will be recorded visually and audibly and will be transcribed for analysis. I agree to this as part of the study.

   ☐ Yes ☐ No

4. I am aware that only the researchers involved in the project will have access to identifying data. I understand that recordings of the discussions will be deleted at the end of the research project, and that anonymised transcripts will be kept in a secure, password-protected folder for 5 years.

   ☐ Yes ☐ No

5. I understand that my child's participation is entirely voluntary and that they can withdraw at any time until the data has been analysed, without needing to give a reason, and without facing any negative consequences.

   ☐ Yes ☐ No

6. I understand that my child's contributions to this study will remain strictly confidential, except in cases where there are concerns about immediate safety.

   ☐ Yes ☐ No

7. I understand that the anonymised data will be included as part of a thesis for the University of Hertfordshire Doctoral Programme in Clinical Psychology. It will be written up into an anonymised paper and published. I understand that no names will be used in publications, but quotations may be included.

   ☐ Yes ☐ No

8. I will ensure that my child understands and follows the photo-taking rules that will be taught in the workshop.

   ☐ Yes ☐ No

9. I consent to allow my [Child's Full Name: _________________] to participate in this research voluntarily and agree to sign and date this informed consent form.

   ☐ Yes ☐ No

Optional Future Contact

Please choose a box to tick Yes or No:

1. I wish to be contacted in the future with further information about the results or dissemination of this project.

   ☐ Yes ☐ No

2. I am happy to be contacted by:

   Email: ☐ Yes ☐ No

   If yes, please provide your email address:

   Telephone: ☐ Yes ☐ No

   If yes, please provide your telephone number:

   Note: The participant’s decision regarding future contact will take precedence over the parent’s decision.

Contact Information

If you have any further questions or concerns, please contact Zineb Belouadah at Z.belouadah@herts.ac.uk

Signatures

Name of Participant (Please Print): ________________________

Signature: ________________________

Date: ________________________

A Photovoice Study Exploring Autistic Young People's Experiences of Mainstream School

Name of Researcher (Please Print): Zineb Belouadah

Signature: ______________________

Date: ______________________

UNIVERSITY OF HERTFORDSHIRE

CONSENT FORM

PARTICIPANTS AGED 16-18 AND PARENTS.

Title: An Exploration of the School Experiences of Autistic Young People Using a Photovoice Methodology

Researcher: Zineb Belouadah (Trainee Clinical Psychologist)

Introduction: This research is part of the Clinical Psychology Doctoral Training at the University of Hertfordshire. We aim to use a Photovoice, a method combining photography and group discussions, to explore your school experiences. We are working together with you to make sure your experiences and ideas shape this study.

Participant Information: Before you decide to participate, please carefully read the Participant Information Sheet provided. It contains detailed information about the study’s purpose, aims, methods, potential risks, and benefits.

A Photovoice Study Exploring Autistic Young People's Experiences of Mainstream School

Consent Checklist:

Please choose a box to tick Yes or No:

1. **I have read the Participant Information Sheet and understand the purpose and aims of this project.**

   ✓ ☐ Yes ✗ ☐ No

2. **I have had the opportunity to ask questions about the project and my participation and I am satisfied with the answers provided.**

   ✓ ☐ Yes ✗ ☐ No

3. **I understand that the discussions and photography sessions will be recorded visually and audibly and will be transcribed for analysis. I agree to this as part of the study.**

   ✓ ☐ Yes ☐ ✗ No

4. **I am aware that only the researchers involved in the project will have access to identifying data. I understand that recordings of the discussions will be deleted at the end of the research project, and that anonymised transcripts will be kept in a secure, password-protected folder for 5 years.**

   ✓ ☐ Yes ✗ ☐ No

5. **I understand that my participation is entirely voluntary and that I can withdraw at any time until the data has been analysed, without needing to give a reason, and without facing any negative consequences.**

✓ ☐ Yes ✗ ☐ No

6. **I understand that my contributions to this study will remain strictly confidential, expect in cases where there are concerns about immediate safety.**

✓ ☐ Yes ✗ ☐ No

7. **I agree to follow the photo-taking rules that will be taught in the workshop.**

✓ ☐ Yes ✗ ☐ No

8. **I understand that the anonymised data will be included as part of a thesis for the University of Hertfordshire Doctoral Programme in Clinical Psychology.**

✓ ☐ Yes ✗ ☐ No

9. **I understand that the information from this project may be written up into an anonymised paper and published. I understand that no names will be used in publications, but direct quotations may be included.**

✓ ☐ Yes ✗ ☐ No

10. I agree to participate in this study.

✓ ☐ Yes ✗ ☐ No

Optional Future Contact

Please choose a box to tick Yes or No:

3. I wish to be contacted in the future with further information about the results or dissemination of this project.

✓ ☐ Yes ✗ ☐ No

4. I am happy to be contacted by:

Email: ✓ ☐ Yes ✗ ☐ No

If yes, please provide your email address:

Telephone: ✓ ☐ ✗ Yes ☐ No

If yes, please provide your telephone number:

Contact Information.

If you have any further questions or concerns, please contact Zineb Belouadah at Z.belouadah@herts.ac.uk

Signatures

Name of Participant (Please Print): ________________________

Signature: ________________________

Date: ________________________

Name of Researcher (Please Print): Zineb Belouadah

Signature: ________________________

Date: ________________________

Parental Acknowledgment.

As a parent/guardian of the participant, I acknowledge that I have read the Participant Information Sheet and understand the purpose and aims of this project. I consent to my child's participation in this research.

Name of Parent/Guardian (Please Print): ________________________

Signature: ________________________

Date: ________________________

UNIVERSITY OF HERTFORDSHIRE

PERMISSION FORM

PARTICIPANTS AGED 14-15

Title: An Exploration of the School Experiences of Autistic Young People Using a Photovoice Methodology

Researcher: Zineb Belouadah (Trainee Clinical Psychologist)

Introduction: This research is part of the Clinical Psychology Doctoral Training. It uses photovoice (combining photography and discussions) to explore your school experiences. We are working together with you to make sure your experiences and ideas shape this study.

A Photovoice Study Exploring Autistic Young People's Experiences of Mainstream School

Participant Information: Before you decide to participate, please read the participant information sheet. It explains the study's aims, methods, risks, and benefits.

Permission Checklist:

Please choose a box to tick Yes or No:

1. **I have read the Participant Information Sheet and understand the study.**

   ✓ ☐ Yes ✗ ☐ No

2. **I have had the chance to ask questions and I am happy with the answers.**

   ✓ ☐ Yes ✗ ☐ No

3. **I understand that discussions and photos will be recorded and written down for analysis.**

   ✓ ☐ Yes ✗ ☐ No

4. **I understand that only researchers will see my data. Recordings will be deleted after the study, and anonymised transcripts will be kept securely for 5 years.**

   ✓ ☐ Yes ✗ ☐ No

5. **I understand that participation is voluntary, and I can stop at any time before the data is analysed without any problems.**

✓ ☐ Yes ✗ ☐ No

6. **I understand that my information is confidential unless there are safety concerns.**

✓ ☐ Yes ✗ ☐ No

7. I agree to follow the photo-taking rules that will be taught in the workshop.

✓ ☐ Yes ✗ ☐ No

8. **I understand that data may appear in a thesis and anonymised paper. No names will be used; quotes may be included.**

✓ ☐ Yes ✗ ☐ No

9. **I agree to participate in this study.**

✓ ☐ Yes ✗ ☐ No

Optional Future Contact

Please choose a box to tick Yes or No:

10. I wish to be contacted in the future with further information about the results or findings of this project.

✓ ☐ Yes ✗ ☐ No

11. I am happy to be contacted by:

Email: ✓ ☐ Yes ✗ ☐ No

If yes, please provide your email address: ______________________________

Telephone: ✓ ☐ Yes ✗ ☐ No

If yes, please provide your telephone number: __________________________

Contact Information

If you have any further questions or concerns, please contact Zineb Belouadah at Z.belouadah@herts.ac.uk

Signatures

Name of Participant (Please Print): _________________________

Signature: ________________________

Date: ________________________

Name of Researcher (Please Print): Zineb Belouadah

Signature: ________________________

Date: ________________________

Appendix M: Photo Release Form

Participant Photograph Release Form

Title: An Exploration of the School Experiences of Autistic young people Using a Photovoice Methodology

Researcher: Zineb Belouadah (Trainee Clinical Psychologist)

Purpose: This form seeks your consent to use the photographs you have taken and the captions you have written for the following purposes. Your contributions are really helpful, and your rights and privacy will always be respected.

Please indicate your consent for the following uses by ticking the appropriate boxes:

Use	Description	Please Tick
Photography Exhibition	Display of photographs in public or private exhibitions	[ ]
Peer-Reviewed Article	Inclusion in academic journals	[ ]
Doctoral Thesis	Use in the researcher's doctoral dissertation	[ ]

Conference Presentations	Presentation at academic or professional conferences	[ ]
Educational Materials	Use in educational resources or training materials	[ ]
Public Awareness Campaigns	Use in campaigns to raise awareness about autistic experiences in schools	[ ]
Other (Please Add)	___________________________________	[ ]
Other (Please Add)	___________________________________	[ ]

Withdrawal of Consent: I understand that I can withdraw my consent at any time without any negative consequences.

Confidentiality: Your personal information and identity will be protected. Any use of your photographs and captions will be anonymised unless you give explicit permission otherwise.

If any further information is required or it would be helpful to discuss any details, please contact the researcher at Z.belouadah@herts.ac.uk

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Name of Participant (Please Print):

____

Signature:

____

Date:

____

Name of Researcher (Please Print):

____

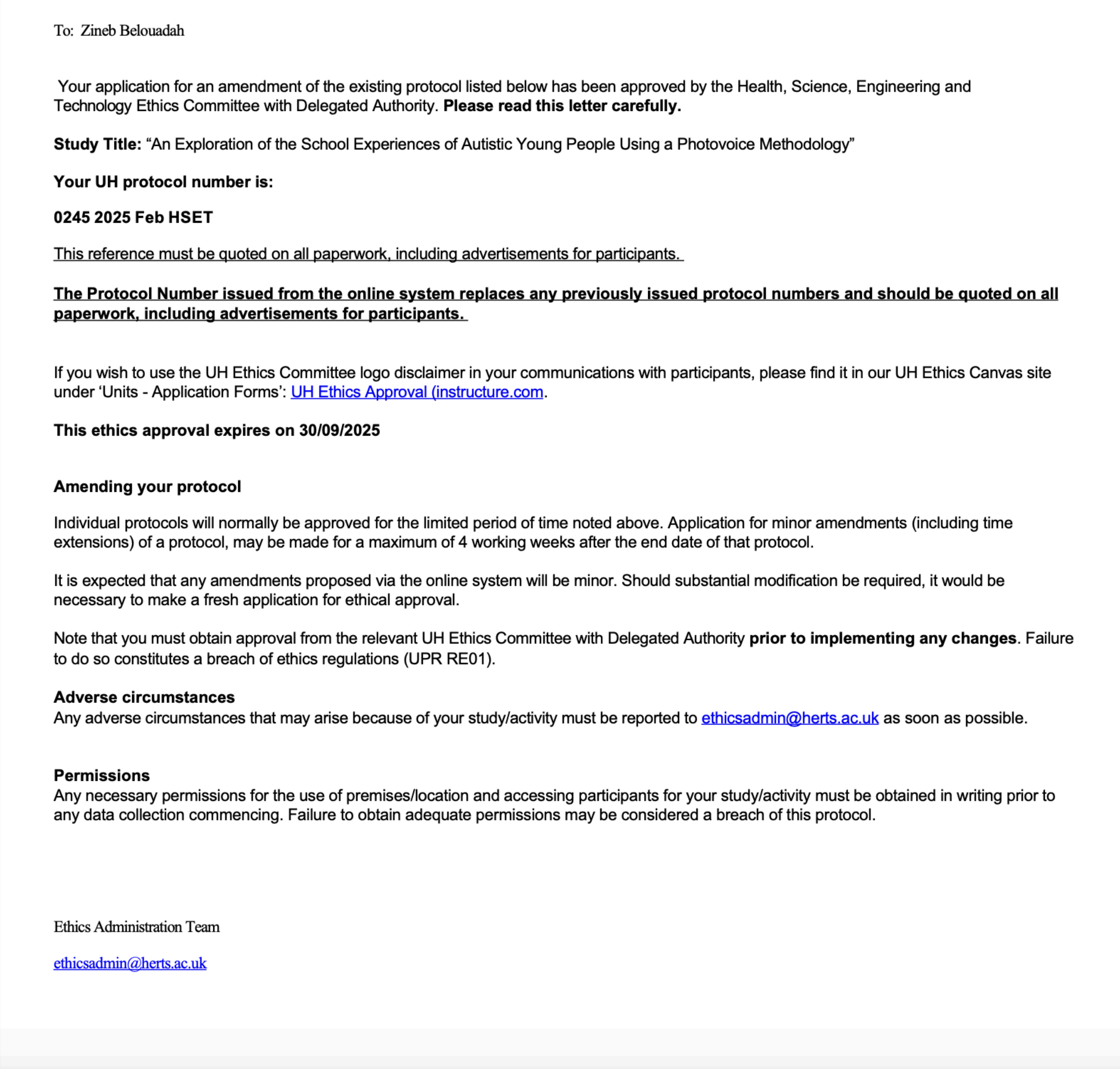
Signature:

____

Date:

____

Appendix N: Ethics Approval Documentation



To: Zineb Belouadah

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: "An Exploration of the School Experiences of Autistic Young People Using a Photovoice Methodology"

Your UH protocol number is:

0245 2025 Feb HSET

This reference must be quoted on all paperwork, including advertisements for participants.

The Protocol Number issued from the online system replaces any previously issued protocol numbers and should be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval (instructure.com.

This ethics approval expires on 30/09/2025

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

Note that you must obtain approval from the relevant UH Ethics Committee with Delegated Authority **prior to implementing any changes**. Failure to do so constitutes a breach of ethics regulations (UPR RE01).

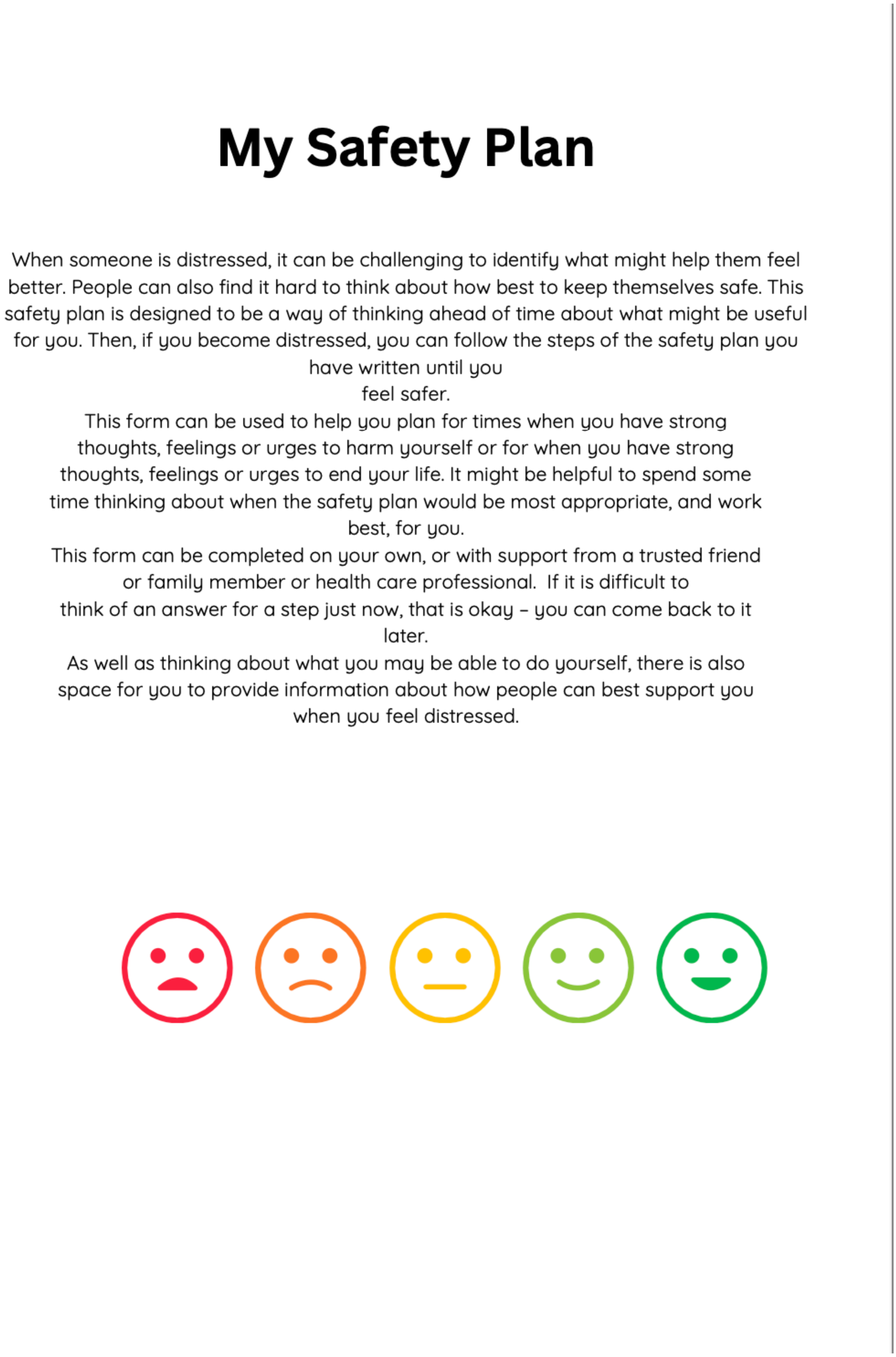
Adverse circumstances
Any adverse circumstances that may arise because of your study/activity must be reported to ethicsadmin@herts.ac.uk as soon as possible.

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

Ethics Administration Team

ethicsadmin@herts.ac.uk

Appendix O: Safety Plan



My Safety Plan

When someone is distressed, it can be challenging to identify what might help them feel better. People can also find it hard to think about how best to keep themselves safe. This safety plan is designed to be a way of thinking ahead of time about what might be useful for you. Then, if you become distressed, you can follow the steps of the safety plan you have written until you feel safer.

This form can be used to help you plan for times when you have strong thoughts, feelings or urges to harm yourself or for when you have strong thoughts, feelings or urges to end your life. It might be helpful to spend some time thinking about when the safety plan would be most appropriate, and work best, for you.

This form can be completed on your own, or with support from a trusted friend or family member or health care professional. If it is difficult to think of an answer for a step just now, that is okay – you can come back to it later.

As well as thinking about what you may be able to do yourself, there is also space for you to provide information about how people can best support you when you feel distressed.

My Safety Plan

What are my warning signs that I may start to have strong thoughts, feelings or urges to hurt myself and/or end my life?

What can I do to help distract myself?

People I can contact to ask for help:

How can other people help support me?

How do I communicate distress?

What stresses me/makes me unhappy?

What can help calm me/makes me happy?

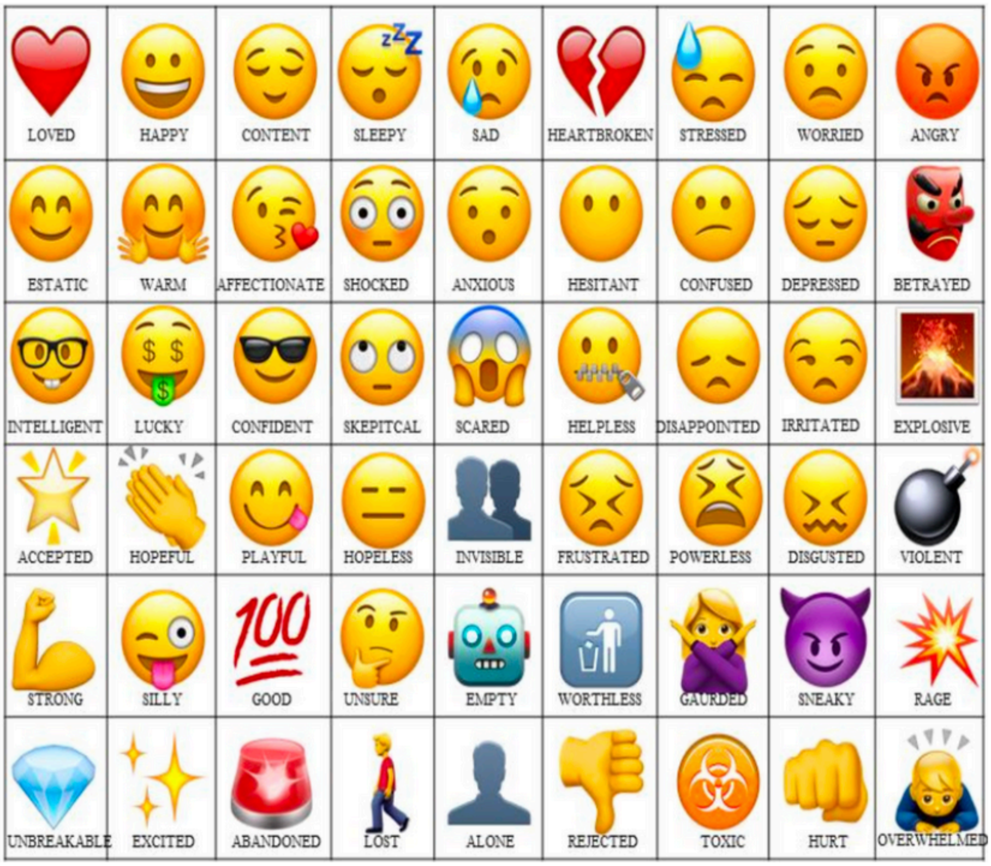
Sharing my safety plan:

Who would you like to share your safety plan with?

How do I Feel?

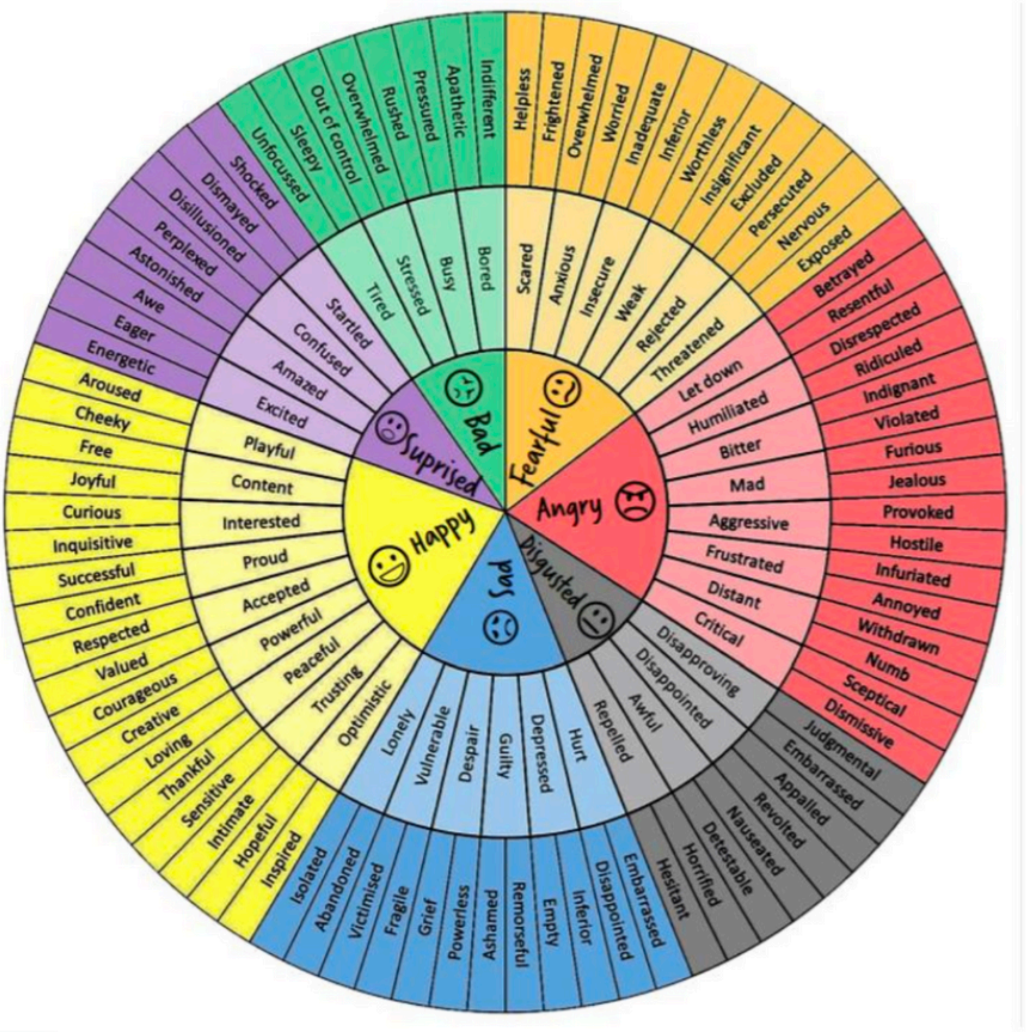
List of emotions

Sometimes it can be difficult to explain feelings. Below are some words and pictures you can use to express yourself.

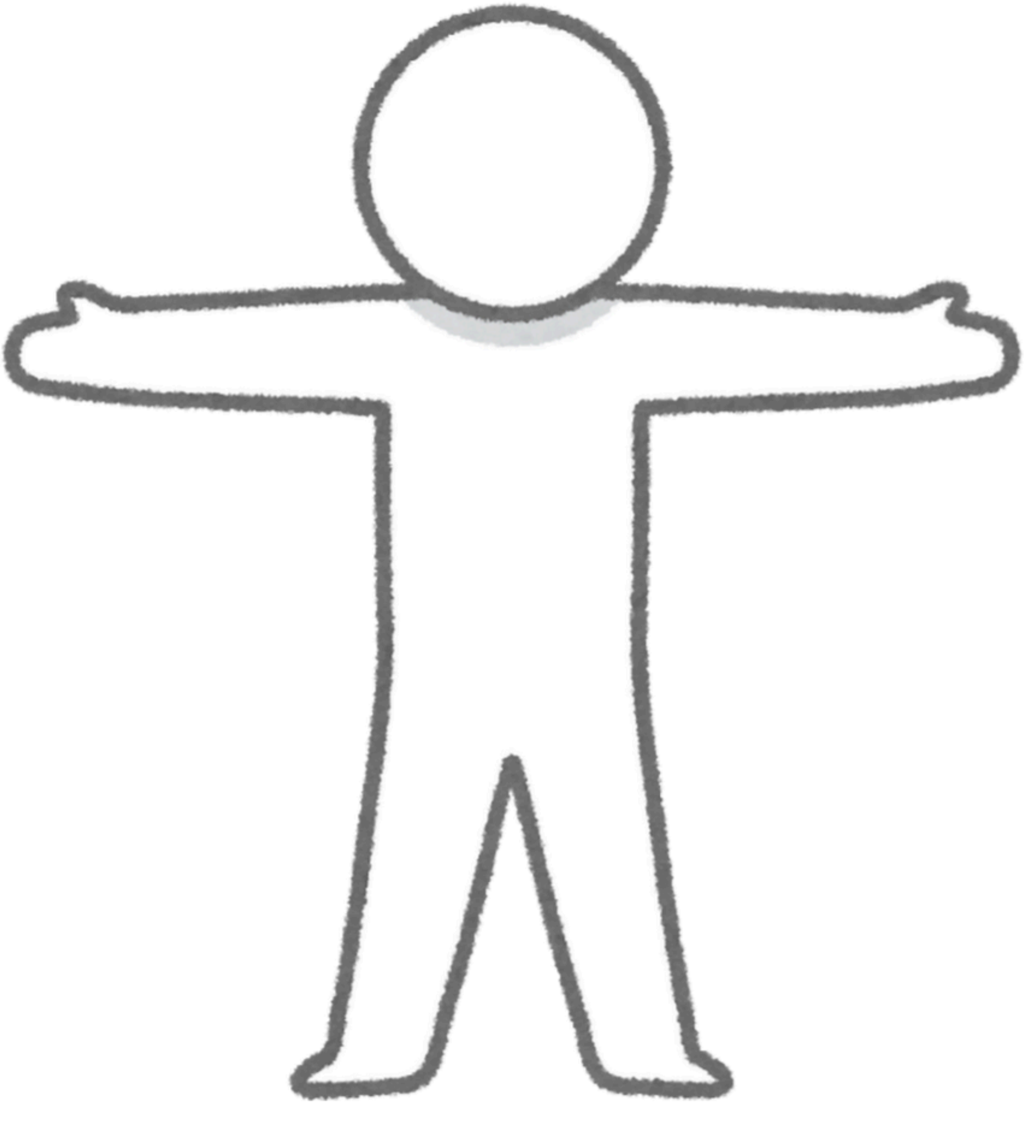


Feelings Wheel

The emotion wheel is a visual aid to help understand our core emotions and give examples of the variations we can feel. This helps build self-awareness and ability to name emotions at their differing levels of intensity.
The wheel is separated into 7 coloured wedges which represent the core emotions found at the centre of the wheel. The outer ring contains examples of lower level intensity feelings while the middle ring contains names for more intense variations of the centre emotion. For example, for the emotion “mad”, the lesser degree is “annoyance”, represented on the outer edge of the slice, and the greater degree is “angry”, situated by the centre of the emotion wheel.



Sometimes you feel emotions in your body. For example, churning in your stomach and an urge to avoid can mean you're feeling anxious. You can use the image below to mark these feelings.



Sources of Support

Taking part in this study might have caused you to feel upset, frustrated, annoyed, or impacted on your mood. This is completely understandable, given what we have talked about. If you continue to feel this way and/or it becomes a problem, you may wish to talk with someone about how you are feeling. Here are some (less urgent) support services.

The Samaritans helpline is open 24 hours a day on 116 123 or 0845 790 9090

ChildLine - a free, private and confidential service where you can talk about anything at anytime. Online and on the phone, Tel: 0800 1111 www.childline.org.uk

The Mix charity provides confidential support for young people 25 and under on 0808 808 4994.

You can send a text to Shout on 85258 for confidential support 24 hours a day.

For confidential suicide prevention advice call HOPELINEUK on 0800 068 4141.

YoungMinds - a leading charity for young people's Mental Health. Parent Helpline: 0808 8025544

Kooth - Free, safe online support & counselling for young people. https://www.kooth.com/

Calm Harm available free of charge to held distract from urges of self-harm) https://calmharm.co.uk

Self-Heal App (Help to avoid self-harm) available on Apple and Google Play; free of charge

GP

if you worry about yourself and how you feel, please contact your GP and arrange an appointment.

If you need urgent support:

NHS 24-hour emergency service 999. Call 999 in a life-threatening medical emergency. This is when you are worried about your immediate safety.

Thank you so much for taking part in this study. Please do contact me if you have any questions.

Zineb Belouadah: Z.belouadah@herts.ac.uk

Appendix P: Risk Assessment

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

FORM EC5 – HARMS, HAZARDS AND RISKS:
ASSESSMENT AND MITIGATION

Name of applicant: Zineb Belouadah
Date of assessment: 12/07/2024

Title of Study/Activity: An exploration of the school experiences of autistic young people using a photovoice methodology

If you are required to complete and submit a School-specific risk assessment (in accordance with the requirements of the originating School), it is acceptable to make a cross-reference from that document to form EC5 in order not to have to repeat the information twice. The purpose of Form EC5 is to consider how a participant might react to the activities in the study and to indicate how you will manage such reactions; the Form also addresses the safety of the investigator and how any risks to the investigator will be managed.

Activity Description					
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED
Activities/tasks and associated hazards Describe the activities involved in the study and any associated risks/ hazards, both physical and emotional, resulting from the study. Consider the risks to participants/the research team/members of the public. In respect of any equipment to be used read manufacturer’s instructions and note any hazards that arise, particularly from incorrect use.)	Who is at risk? e.g. participants, investigators, other people at the location, the owner / manager / workers at the location etc.	How could they be harmed? What sort of accident could occur, eg trips, slips, falls, lifting equipment etc, handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?	Are there any precautions currently in place to prevent the hazard or minimise adverse effects? Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/	Are there any risks that are not controlled or not adequately controlled?	List the action that needs to be taken to reduce/manage the risks arising from your study for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support **must** be made available for participants and/or investigator(s) who require it.

Individual and Group Interviews	Participants	Participants may experience emotional distress from discussing personal experience	Provide a safe and supportive environment for discussions Trainee clinical psychologist will provide grounding techniques. Allow participants to take breaks or withdraw if uncomfortable Follow up call 24 hours after sharing experiences The research passport includes signs of distress and actions to help If a young person abruptly leaves a call, contact their parents. Provide a safety plan and service support numbers for participants and parents		Ensure emotional support is available during and after interviews Continuous monitoring and support throughout the study

			Encourage participants to only discuss comfortable topics Participants may help co-produce questions and methods of sharing experiences If not involved in co-producing questions, send them in advance		
Photography assignment	Participants	Participants could trip, fall, or otherwise injure themselves while taking photos. Participants could violate privacy or ethical guidelines by taking inappropriate photos	Provide guidelines on safe photography practices Ensure participants avoid dangerous or restricted areas Offer support during the assignment Educate on ethical photography Obtain explicit consent for photos Monitor photos and address	Participants might still encounter physical hazards Participants might still take inappropriate photos	Ensure participants understand to avoid dangerous or restricted areas. Offer support if Participants need assistance during the assignment. Provide clear guidelines on appropriate and inappropriate photos. Examples of both will be provided to ensure participants understand expectations. Participants sign a consent

			misuse immediately		form including ethical use of photos, acknowledging they understand and agree to follow the guidelines provided. Provide written rules for taking and sharing photos Address misuse immediately, explaining breaches. This will be explained clearly. Report serious breaches to the university for further guidance on actions. Inform parents/guardians of misuse and actions taken.
Workshop and group discussions	Participants	Participants may feel uncomfortable or anxious in a group setting Might be emotional distress from disagreeme	Send photos of the location beforehand to help manage anxiety Provide detailed steps during the research	Participants might still feel anxious despite precautions	Create a supportive and flexible environments Continuous assessment and adjustment based on participant feedback

		nts or conflicts during group discussions	passport process Ensure participants know they can choose not to share certain experiences or photos Have support staff available to assist (research consultant to support if a child leaves the room) Provide a safety plan and services support numbers for both participants and parents. Establish ground rules for respectful communication Provide a safe space for participants to express concerns privately		Address conflicts immediately and provide support Adjust group dynamics if necessary
Use of audio recording equipment-	Participants	Participants might feel uneasy	Ensure participants understand the purpose	Participants might still feel discomfort	Regularly check in with participants about their

Potential for technical issues or discomfort with being recorded.		about being recorded.	and process of recording Obtain explicit consent for recording Allow participants to request stopping the recording at any time	despite understanding consent	comfort with recording Offer to stop recording at any time if requested
Storage of data- Risk of data breach or unauthorised access to person data	Participants	Participants personal data could be exposed or misused	Store data on password-protected and encrypted devices Use the University of Hertfordshire's secure cloud server. Limit data access to the principal researcher and supervisor Anonymise transcriptions and destroy original recordings after use	Risk of data breach despite precautions	Regularly review data security measures Ensure compliance with data protection regulations
Use of computer / screen time	Participants & Researchers	'Zoom Fatigue' from prolonged screen time	Discuss breaks with participants at the beginning of meetings Offer breaks during meetings if	Participants might still experience fatigue despite precautions	Monitor for signs of fatigue and offer breaks Adjust meeting schedules as necessary

			participants appear fatigued. Space out meetings to allow breaks between participation days Offer to terminate and reschedule meetings if needed Offer face to face meetings as an alternative if needed		
Food	Participants and researchers	Symptoms of food poisoning or issues with allergies	Provide cold food and snacks Ask for dietary requirements. Allergies before meetings Use only approved food vendors Seek medical assistance immediately if participants experience an adverse reaction.	Risk of adverse reactions despite precautions	Ensure food safety standards are strictly followed Have emergency contact information for medical assistance readily available
Covid-19	Participants and researchers	Risk of spreading infectious diseases during in-	Follow current health guidelines	Risk of infection despite precautions	Monitor health guidelines and adjust protocols as needed

		person activities	and protocol Provide masks and hand sanitisers Ensure proper ventilation in meeting spaces Encourage virtual participation if feasible		Provide health screenings if necessary

Signed by applicant:
Zineb Belouadah

Appendix Q: Debrief

DEBRIEF AND SUPPORTIVE SERVICES SHEET

THANK YOU

An Exploration of the School Experiences of Autistic Young Peoples Using a Photovoice Methodology

Thank you

Thank you for allowing your child to participate in this research and share their experiences of mainstream school. There is no denying there are inequalities within mainstream schools that need to change. Unfortunately, there is little research about autistic young people’s experiences of mainstream school. We hope that research will allow this to improve school environments for autistic young people.

Sharing findings

The findings from this study will be shared with organisations that you are happy with us to collaborate with. These may include schools, policymakers, educational bodies, and support organisations, as suggested by participants. Our primary goal is to enhance understanding of autistic young people's experiences in mainstream schools, aiming to result in positive changes within school environments, staff practices, and educational systems. The study will be submitted for publication in a peer-reviewed journal and may be presented at conferences, board meetings of relevant agencies, and through other innovative methods as suggested by participants.

Emotional Impact

We understand that discussing school experiences may have been hard for your child. If taking part in this study has left your child feeling upset, frustrated, confused or distressed or anything else, please let me know before you leave if you want to. We understand that they might not want to share their feelings with us directly, so we are providing information about support services you can contact (please see safety plan).

<u>What happens next?</u>

The results will be written as part of a thesis for the Doctorate of Clinical Psychology at the University of Hertfordshire.

You and your child have the right to withdraw your data until [_/_/_].

Would your child like a call tomorrow [date] to check how they are feeling?

☐ Yes
☐ No

Concerns or Complaints

If you have any concerns or questions about how the project has been conducted, please contact the study's principal supervisor Dr Barbara Rishworth at b.rishworth@herts.ac.uk or the University of Hertfordshire Research Ethics Sub-Committee Chair at hsetecda@herts.ac.uk. The University of Hertfordshire protocol number for this study is (?).

DEBRIEF FORM FOR 116-18 YEAR OLDS

THANK YOU

An Exploration of the School Experiences of Autistic Young Peoples Using a Photovoice Methodology

Thank you

Thank you for helping us co-design this research and for sharing your school experiences. Your contributions are vital in addressing inequalities in schools.

Purpose of the Study

We want to understand what it's like for autistic young people in mainstream schools. Currently there is little research on this topic. We hope this research can help with making things better for autistic young people in schools.

Sharing findings

We will share the findings with schools, policymakers and other organisations that you are happy with us to work with. This study might also be published in a journal or presented at conferences.

Emotional Impact

We understand that discussing your experiences may have been difficult. If you feel upset or need support, please let me know. Alternatively, you can contact support services we have provided (please see safety plan).

What happens next?

The results will then be written as part of a thesis for the Doctorate of Clinical Psychology at the University of Hertfordshire.

You have the right to withdraw your data until [_/_/_].

Would you like a call tomorrow [_/_/_] to check on how you are feeling?

☐ Yes

☐ No

Concerns or Complaints

If you have any concerns about the project, please contact the study's principal supervisor Dr Barbara Rishworth at b.rishworth@herts.ac.uk or the University of Hertfordshire Research Ethics Sub-Committee Chair at hsetecda@herts.ac.uk. The University of Hertfordshire protocol number for this study is (?).

14-15 YEAR OLDS

THANK YOU AND NEXT STEPS

An Exploration of the School Experiences of Autistic Young Peoples Using a Photovoice Methodology

Thank you

Thank you for helping us co-design this research and for sharing your school experiences. Your input is important to help make schools better for autistic young people.

Purpose of the Study

We want to understand what it’s like for autistic young people in mainstream schools. Currently there is little research on this topic. We hope this research can help with making things better for autistic young people in schools.

Sharing findings

We will share what we find with schools, policy makers and other organisations that you are happy with us to work with. This study might also be published in a journal or presented at conferences.

Emotional Impact

Talking about your experiences might have been hard. If you feel upset or need to talk, please let me know. If you prefer, you can talk to someone else. I will share information of support services you can contact (please see safety plan).

What happens next?

The results will then be written as part of a piece of work (known as a thesis), for the Doctorate of Clinical Psychology at the University of Hertfordshire.

You can withdraw your data until [_/_/_].

Would you like a call tomorrow [_/_/_] to check on how you are feeling?

☐ Yes
☐ No

Concerns or Complaints

If you have any concerns about the project, please contact the study’s principal supervisor Dr Barbara Rishworth at b.rishworth@herts.ac.uk or the University of Hertfordshire Research Ethics Sub-Committee Chair at hsetecda@herts.ac.uk. The University of Hertfordshire protocol number for this study is (?).

Appendix R: Recruitment Poster

JOIN OUR RESEARCH STUDY!

Help us Understand School Experiences Of Autistic Young People

Who can join?

- **Autistic young people aged 14-18.**
- Have some experience in mainstream schools.

Why join?

- Share your school experience
- **Help improve schools to autistic students**
- You will be a co-research. Your ideas will shape the study

What will you do?

- Attend workshops to learn photography.
- Take photos that reflect your school life.
- Share your photos and stories in group discussions (face to face) and individual interviews (online).
- **No photography experience needed.**
- **You will be paid for your time.**
- Cameras will be provided

Interested?

Talk to your parents/carers
Contact Zineb Belouadah
Email: z.belouadah@herts.ac.uk

Appendix S: Ethical Photography Guidelines

Ethical Photography Guidelines ☺

Why? These simple rules keep you, and other people, safe and private while you create images that tell your school story.

1 No Photos of People

- Avoid photographing anyone, even in the background.
- If someone appears by accident, crop or retake the photo.
- Never show faces, names, school uniforms, or other identifiers.

2 Avoid Identifiable Settings

- Leave out school logos, street signs, or anything that reveals a location.

3 Before You Click, Ask Yourself…

1. Does this image respect privacy and avoid personal details?
2. How would I feel if someone took this photo of me?

4 Focus on Objects, Spaces, or Symbols

- Desks, clocks, corridors, sensory tools, sunlight on a wall…
- Let everyday things tell your story, people aren't needed.

5 Use Symbolism for Feelings

Feeling overwhelmed by schoolwork?

- Direct: a stack of books on a desk
- Symbolic: tangled headphones or a dark, shadowy room

6 Handle Images with Care

- Some photos may feel personal, share only what you're comfortable with.

7 Stay Safe

- Check your surroundings; no image is worth risking injury.
- Tell a parent/carer if you plan to shoot away from home.

8 Enjoy the Process

- There is no “perfect” photo, focus on what feels meaningful to you.
- Your voice matters; be creative in the way that feels right.

Appendix T: Participant Reflections on the Photovoice Process

This appendix includes selected reflections from participants on their experiences taking part in the Photovoice study. These quotes were collected during the final workshop and through follow up communications.

> “Hearing other people’s experiences and feeling very understood for the first time pretty much ever.”
>
> “Hope.”
>
> “There is no shame in being me, and there’s actually a lot of beauty in the way that we see the world.”
>
> “I care about autism advocacy and that I’m not alone.”
>
> “Just getting to be part of something and help make a change with the people that suffer the same issues.”
>
> “The dissemination is when the action takes place.”
>
> “The most meaningful thing was being able to reflect on growing up autistic and sharing that with people who actually listened. It’s given me a place to channel that and hope.”
>
> “Being able to try something new, which I don’t usually do because it doesn’t fit with my routine.”
>
> “That I like photography, lol.”