# Harnessing the 'well' in being: An exploration of the wellbeing experiences of adolescent autistic girls and how these can be supported within mainstream schools

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This study would not have been possible without the love and support of my family and friends whose belief in me far exceeded my own at times. A massive thank you for everyone who waited patiently and supported me during this process to make sure I got to the finishing line, stayed healthy and got out for fresh air and dog walks. Special and most heartfelt thanks for my husband and children who understood how important this project was to me, kept me feeling positive and helped Team Connolly run smoothly.

# Abstract

Determining how to support autistic wellbeing has become a high priority for research amid calls from within the community and psychology professions (Autistica, 2015; British Psychological Society, 2021; Gowen et al., 2019; Pellicano et al., 2014; Rodogno et al., 2016). The wellbeing experiences of autistic girls throughout their secondary education are influenced by issues of neurodiversity acceptance, power and social justice. Recognising key adolescent developmental tasks and broader eco-systemic factors, this research adopted a positive psychology approach to explore the lived experiences of wellbeing for autistic girls. A clear social justice goal was identified – to develop a shared construct of autistic girls' wellbeing so that mainstream schools can review their wellbeing provision. A transformative paradigm was purposed to create a community-led and participatory research space in which seven teenage autistic girls attending mainstream secondary schools became co-researchers. Their role in co-producing the research design, data collection methodology and analysis was instrumental in ensuring the study's findings were meaningful and impactful. An accessible online forum was created for the co-researcher planning as well as data collection (via semi-structured interviews). Interpretative Phenomenological Analysis was used to honour the voices of the autistic girls at both an individual and group level to emancipate their lived experiences.

Key findings indicated that there are many social, emotional and political factors in the secondary school system which influence the girls' wellbeing. Integral to their wellbeing is an understanding of how they are creating their autistic identity, balancing their emotions throughout the school day, finding where they belong and coping with the pressures of navigating the complex and often unpredictable school system. School support needs to incorporate whole school awareness of how these factors influence autistic girls' wellbeing, the creating of an inclusive community space that recognises and celebrates neurodivergent differences, co-production of personalised wellbeing provision (with the help of relationally attuned adults) and a culture of wellbeing that looks beyond the school gates. Implications for Educational Psychologists' practice in critically challenging school support are discussed and a graduated framework for school leaders is suggested. Recommendation for future research are considered.

# Visual Community Brief

**Harnessing the 'well' in being: An exploration of the school wellbeing experiences of adolescent autistic girls and how these can be supported in mainstream schools**

## Why is this research important?

*Low school wellbeing may lead to non-attendance, isolation and poor mental health.*

- Female autistic voice is often <u>excluded</u> from research.

- <u>Lack</u> of qualitative, pupil-led studies describing autistic girls' experiences of school wellbeing.

- <u>Inconsistent</u> understanding of what school wellbeing is like for autistic girls.

- School staff not confident in <u>how</u> best to support wellbeing.

### Co-researcher aims:

*"I wanted to meet other girls who are having the same experiences as me"*
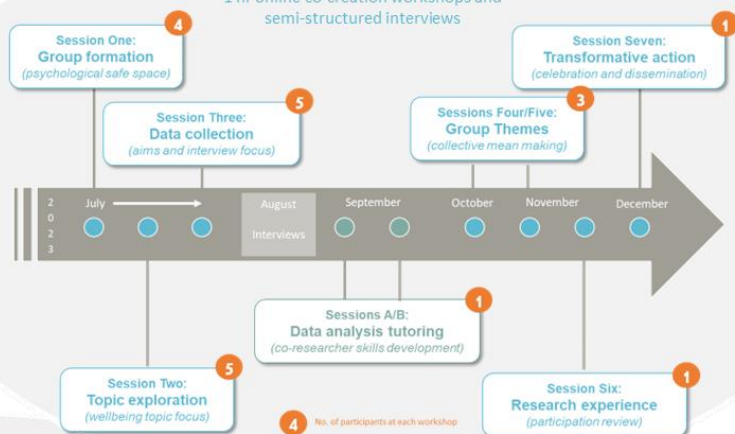
*"A safe space to share my story"*

*"I want school to know how to support our wellbeing"*
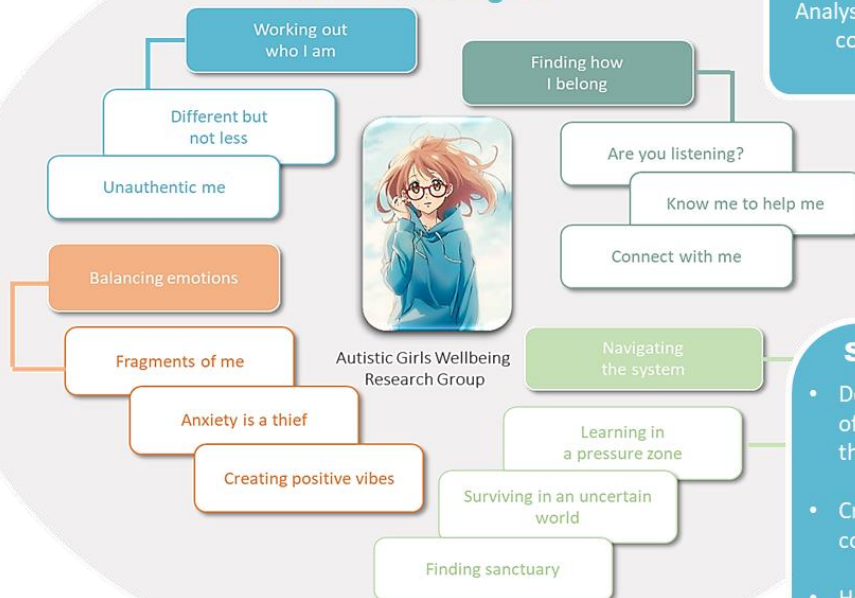
## Who was involved?

Seven autistic girls (aged 12-15 years old) who attended mainstream secondary schools in England.

## Community participatory research

1 hr online co-creation workshops and semi-structured interviews



**Session One:** 4
Group formation
*(psychological safe space)*

**Session Three:** 5
Data collection
*(aims and interview focus)*

**Sessions A/B:** 1
Data analysis tutoring
*(co-researcher skills development)*

**Session Two:** 5
Topic exploration
*(wellbeing topic focus)*

**Session Seven:** 1
Transformative action
*(celebration and dissemination)*

**Sessions Four/Five:** 3
Group Themes
*(collective mean making)*

**Session Six:** 1
Research experience
*(participation review)*

4 No. of participants at each workshop

2023 July — August Interviews — September — October — November — December

## Adolescent autistic girls tell us their wellbeing is:

**Working out who I am**
- Different but not less
- Unauthentic me

**Balancing emotions**
- Fragments of me
- Anxiety is a thief
- Creating positive vibes

**Finding how I belong**
- Are you listening?
- Know me to help me
- Connect with me

**Navigating the system**
- Learning in a pressure zone
- Surviving in an uncertain world
- Finding sanctuary

Autistic Girls Wellbeing Research Group

Interpretative Phenomenological Analysis (IPA) highlighted individual and collective experiences of school wellbeing

*"Being a co-researcher felt really safe. If I didn't feel comfortable with something, I wouldn't have to do it"*

## Support them by:

- Developing whole-school awareness of the supporting factors for their wellbeing

- Creating a neuro-affirming community environment

- Honouring lived experience when co-creating wellbeing provision

- Prioritising reviews of their wellbeing support.

University of East London

*This research study was conducted by a Trainee Educational Psychologist for the Doctorate in Education and Child Psychology at UEL.*
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# List of Acronyms and Abbreviations

| | |
|---|---|
| ASC/D | Autistic Spectrum Condition/Disorder |
| CPD | Continuing professional development |
| CYP | Children and Young People |
| EP | Educational Psychologist |
| LA | Local Authority |
| SEN | Special Educational Needs |
| SENCo | Special Educational Needs Co-ordinator |
| UK | United Kingdom |

*Please note that I do not consistently refer to 'autistic girls/individuals' or 'girls/individuals with autism' within this work. There is considerable debate about which term is preferred in the autistic community. The participants in this study indicated their own preferences which have been honoured throughout and for that reason I have tried to use both variants without preference.*

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*We need to move from a pathological and deficit model to one that respects human diversity and autistic people's strengths and potential. Currently as a society we do not adequately understand what wellbeing and happiness looks like for autistic people and it may well be different to what it is for non-autistic people. We need to go beyond fixing problems to actively help autistic people achieve wellbeing and happiness and fulfil their potential as autistic human beings.*

Wassall & Burke (2022)

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## 1.1   Overview

This research explores how adolescent[1] autistic[2] girls experience wellbeing at school and what factors support this. Firstly, the role of school as a contextual and developmental environment for young people's wellbeing is presented, followed by a broader discussion around theoretical frameworks defining 'wellbeing'. The nature of and influences on female autistic experiences of wellbeing, which continues to be debated within and beyond the autistic, research and education communities, are explored within national and local contexts. This chapter concludes with a brief overview of the role of Educational Psychologists (EP) in supporting young people's wellbeing, leading to the research rationale.

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[1] This research refers to adolescent young people within the context of their secondary education (12-18 years). Adolescence is generally understood to be a time of complex change, characterised by developments in hormones, physical appearance, psychology and behaviour, and socialising (Blakemore, 2012).
[2] Discussion around the social construct of autism is addressed throughout this research. The National Autistic Society describe autism as 'a lifelong developmental disability which affects how people communicate and interact with the world' (National Autistic Society, 2024).

## 1.2   Environment and developmental context

Children and young people's (CYP) development, academic growth and wellbeing is influenced by many inter-related social, cultural and political factors (Bronfenbrenner & Bronfenbrenner, 2009). Secondary school provides a unique setting in which, through their developing motivations, interests and personality, CYP can intentionally shape their environment and learning experiences (Coll et al., 2004). However, adults at school also have a key influence in this process (Paschall & Mastergeorge, 2015). Research shows that differences such as social class and ethnicity affect how teachers interact with their students (Tenenbaum & Ruck, 2007) and CYP's behaviour and characteristics impact how adults respond, which affects how CYP, in turn, behave (Fisher, 2023). As noted by Fisher (op cit), *"diversity within the interactions between CYP and the school environment are the norm and not the exception"* (pg. 24) and therefore should lay a rich pathway towards shaping the adult that a young person will become.

As they transition through adolescence, students experience a significant shift towards peer influence, independent learning and associated self-regulatory behaviours (Chodkiewicz & Boyle, 2017).  For autistic girls, this represents additional developmental challenges around learning new social skills so they can cope with the complexity and demands of new friendships and adult relationships (Tierney et al., 2016). Therefore, the time that adolescent autistic girls spend in school is a key developmental phase that sets the foundations of their future life through social learning opportunities in which they can build and practise skills that might support their wellbeing.

Schools do not, of course, operate within a systemic vacuum. A decade ago, the UK Government advocated that pupil wellbeing was an effective factor in raising academic achievement, supported the Ofsted inspection framework and contributed to the school's reputation in the local community (Public Health England, 2014). Following this, schools began to access early intervention help via their Designated Mental Health Leads (Department of Health & Department for Education, 2017) and 'mental health' and 'emotional wellbeing' were introduced into the compulsory curriculum (Department for Education, 2019).

Arguably, with these broader educational responsibilities, schools nurture children to cope with the economic and societal conditions of their future (Graham et al., 2016; Price & McCallum, 2016). However, it is essential that wellbeing and academic achievement are not pitched as competing priorities in the current educational standards frameworks (T. Clarke, 2020), given reported reductions in children's average happiness[3] - specifically related to school and schoolwork (Children's Society, 2023).

Identifying ways in which schools can help respond to the deterioration[4] in young people's mental health and wellbeing demands urgent attention (Barker et al., 2021), specifically in light of recent statistics showing that persistent attendance difficulties[5] seem to peak in Year 10 (Department for Education, 2023) and particularly impact

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[3] In 2020-21, children's (aged 10 to 15yrs) mean scores for happiness with their life, their friends, appearance, school, and schoolwork were all significantly lower than when the survey began in 2009-10 (Children's Society, 2023). 22 annual online surveys (since 2005) have been conducted within their Wellbeing Research Programme. Stats provide source data for the ONS Wellbeing Measurement Framework and the State of the Nation report from the Department of Education.

[4] 39.2% of 6–16-year-olds had experienced a deterioration in their mental health since 2017 (NHS Digital, 2021).

[5] Persistent attendance difficulties (e.g., missing more than 10% of school) have been rising steadily since the pandemic (Department for Education, 2023).

CYP with SEND. Even prior to Covid-19 parents of autistic children reported 43% persistent absence (Totsika et al., 2020).

Beyond the school gates, there are multiple social, economic and political influences in CYP's wellbeing. In addition to growing up during a cost-of-living crisis, wars in different parts of the world and a global climate emergency, young people and their families are also recovering from the impact of the COVID-19 pandemic. Emerging evidence suggests that whilst changes to social and school routines during the pandemic was detrimental to the mental health and wellbeing of some autistic young people, for others the reduced social demands and adaptations to the learning and physical environments positively influenced their wellbeing (Ashbury & Toseeb, 2022; Crane et al., 2021; Ozsivadijan et al., 2022). Continued scrutiny of the efficacy of adapted support, for all students during the pandemic (T. Clarke, 2020) and the UK Government's current attendance drive (Department for Education & Keegan, 2024), is maintaining pupil wellbeing at the forefront of schools' agendas. Through intervention practice and relationships, schools may be uniquely positioned to influence pupil wellbeing (Noble & McGrath, 2014).

## 1.3  Defining 'wellbeing'

For schools to be successful in operationalising and supporting wellbeing, this abstract construct needs to be clearly defined, (Danker et al., 2016; Seligman, 2018). Despite a growing body of research evidence exploring pupil wellbeing, this value-laden concept is still misunderstood (Graham et al., 2017). Wellbeing is more than an absence of illness or disorder (Magyar & Keyes, 2019). Different paradigms and frameworks of wellbeing are now discussed.

### 1.3.1  Wellbeing paradigms

The first paradigm explored is subjective wellbeing (or *Hedonia*) which measures the emotional affect (positive and negative) and satisfaction with life (Diener et al., 2010). Children's subjective wellbeing represents their self-reported experiences of positive and negative emotions, relationships, flourishing and general satisfaction with life and evidence suggests that pupil's emotional wellbeing is related to feeling satisfied (or happy) with life at school (Deiner, 2009).

Studies from the second paradigm of psychological wellbeing (or *eudemonic)* show that positive functioning, in terms of pupils' personal growth, self-acceptance, life mastery and positive relatedness, may be associated with opportunities to pursue meaningful and purposeful goals at school (Ryff & Keyes, 1995).

A third paradigm, composite wellbeing considers the complementary nature of subjective and psychological wellbeing (Keyes, 2007). In reality, it is likely that there is a series of complex interactions between eudemonic and hedonic wellbeing, coupled with goal-based differences in adult versus child priorities inherent in the education system (Seligman, 2011). For example, adult-led learning which is targeted towards achieving long-term (eudemonic) goals of high academic attainment may conflict with the young persons' short-term hedonic goals of feeling happy studying a particular topic in the moment (T. Clarke, 2020).

### 1.3.2 Multi-dimensional or composite constructs of wellbeing

Alternative discourses in wellbeing suggest that for children to 'be' well in school, their perceived competence (McLellan 2019); sense of belonging[6] (Anderman, 2002) and relationships with peers (Chanfreau et al., 2013) are equally as important as how they feel and function. Social wellbeing (such as the extent to which pupils feel integrated and can contribute to their school) is therefore also an important factor in subjective wellbeing (Keyes, 1998). This might suggest that wellbeing is a broader construct, incorporating social and community facets as well as individual cognitive appraisal of life. An emerging paradigm builds on this idea, presenting a systems-level approach to wellbeing. Centeredness Theory describes the need for individuals to balance their inner self against their self-actualisation goals across four life domains, such as relationships, family, work and community (Bloch-Jorgensen et al., 2018). This paradigm aligns well with the eco-systemic theoretical frameworks used by EPs.

However, a key criticism of many prevailing measures of wellbeing are that they are often developed for adults and so do not acknowledge the power imbalance experienced between CYP and the adults in their systems (Seligman, 2011). Another issue with current understanding of wellbeing is that it is predominantly contextualised within Westernised constructs of what constitutes a good life (Lambert et al., 2020). For example, discussion at the last *International Wellbeing Summit* in Kyoto highlighted broader influences on young people's wellbeing, such as culture, community, nature, society and governance to fully unlock this complex construct – see Lambert et al., (2020) for a fuller debrief.

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[6] A sense of belonging describes the acceptance, inclusion and respect felt by school pupils, according to Prince & Hadwin, 2013)

To this end, it may be useful for educational practitioners to consider multi-domain frameworks of psychological and social wellbeing (Keyes, 1998; Ryff, 2014) which incorporate different eco-systemic, social and cultural influences (Figure 1.1). A critical reflection of the multi-domain approach has been integrated in this visual.

Primarily, it should be noted that these models may seem less relatable to students because they were not formulated with the adolescent development tasks, educational context or an autistic profile in mind.

### 1.3.3 Shifting the dial on positive psychology

The conceptualisations of wellbeing already introduced embrace a positive psychology approach. It is important to understand that the roots of positive psychology lie in its strengths-based outlook on wellbeing, rather than focusing on correcting weaknesses or repairing negatives in the individual (like the medical model of disability). Individual characteristics which enable young people to be successful, manage difficult events and generally thrive are identified and honoured (Duckworth et al., 2005). For example, within the PERMA model, Seligman created an approach that acknowledged the criticism that the abstract nature of wellbeing needs to be re-conceptualised in a tangible and relatable way in order to improve the school wellbeing of students and staff alike (Kern, 2022). This model embraces positive emotions, engagement, relationships, meaning and accomplishment – all five of these pillars are built into positive psychology interventions and models of wellbeing used across classrooms (Seligman, 2011).

However, synonymous with Seligman's ideal of 'flourishing' is tolerant and sustainable environmental conditions. Therefore, integration of these five pillars into schools' wellbeing strategies somewhat depends on whether they align with the school's values and interests, or are relevant for the school community (Kern, 2022).

The theoretical foundations of current (3rd wave) positive psychology invite an even broader look at the socio-cultural factors impacting wellbeing (Lomas et al., 2021), yet the research base mainly focuses on individual wellbeing, and not their wider systems (Kern et al., 2019). This paradigm shift sprang from the global spread of positive psychology methodology. The result of ethnically and contextually diverse studies (Ciarrochi et al., 2016; Lomas, 2018a) is the emergence of the voices of minoritised and divergent communities through qualitative inquiry (Rao & Donaldson, 2015) and the influence of collaborative research processes on new knowledge of wellbeing (Ebersöhn, 2014).

Given the collaborative nature of EP work and the necessity to adopt a curious and inquiring approach to exploring a CYP's eco-systemic influences, the positive psychological approach to wellbeing throughout this study will remain contextually open and rooted within the lived experiences of autistic girls.

**Figure 1.1**

*Critical reflection of multi-dimensional wellbeing frameworks*

| Ryff's dimensions of psychological wellbeing | Keyes's dimensions of social wellbeing | Critical analysis: relevance of domain to developmental and eco-systemic perspectives of adolescent autistic girls' wellbeing |
|---|---|---|
| Autonomy | Social coherence | Heavily influenced by cultural affinity to individualistic or collective priorities. Relies on consistent application of broad school neurodiversity awareness. Dependent on confidence and self-esteem within developing adolescent and autistic identity to resist peer pressure to conform. |
| Personal growth | N/A | Relies on eco-systemic conditions promoting growth and 'flourishing'. Influenced by development of critical and flexible thinking skills to enable and respond to challenges in different circumstances. |
| Self-acceptance | Social integration | Dominated by Western pre-dominance with self although social integration more broadly addresses community cohesion. Influenced by past adaptive experiences of societal, community and peer acceptance. |
| Positive relations | Social contribution | Relies on experiences of acceptance and belonging within different social groups, ability of individual to adapt to different social interactions to maximise shared interests. Wider societal issues of bias towards neuro-typical values, ideals and interests. |
| Purpose in life | Social acceptance | Dependent on accumulation of positive relational experiences in school and exposure to positive role models. Managed through growth mind-set and motivation to change. Influenced by cultural expectations and norms as well as short-term vs longer-term goals. |
| Environmental mastery | Social actualisation | Dependent on attuned adults who operate in a system which embraces critical challenge to the school culture and ethos, adopts a neurodiverse perspective and encourages individual advocacy and agency in change processes |

### 1.3.4 School wellbeing programmes

School wellbeing programmes, which are often anchored in positive psychology, have evolved beyond targeting a pupil's own inner resources and strategies, but without necessarily examining the impact of the school environment (Ciarrochi et al., 2016). It is also important to consider whether school-based positive psychology programmes reflect the broad cultural or linguistic understanding of wellbeing prevalent in the local community. International research shows that whilst school-based positive psychology interventions have been shown to enhance student-teacher relationships (Waters, 2011), wellbeing programmes are not consistently or effectively embedded in the UK school curriculum (Chodkiewicz & Boyle, 2017).

## 1.4 Autistic 'wellbeing'

Cultivating autistic wellbeing, mental health and quality of life has been prioritised as a research area within psychology and autism communities for some time (Autistica, 2015; British Psychological Society, 2021; Gowen et al., 2019; Pellicano et al., 2014; Rodogno et al., 2016). At the heart of discussions around autistic wellbeing are issues of acceptance, power and social justice, in terms of who defines what a 'good life' should look and feel like for young people with autism. Differences in opinion between the neurodiversity[7] lens vs normative agenda, can lead to trade-offs for interventions that are designed to 'normalise' behaviours (Rodogno et al., 2016).

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[7] A term originating in social and political action and collectively defined by autistic scholars in the 1990s (such as Judy Singer), based on their experiences of online communities – see also neurodiversity paradigm (Singer, 1998). Positions autism as a naturally occurring neurological difference to be celebrated and integrated rather than a dysfunction which needs to be 'treated' (Kapp, 2020). Critics of neurodiverse ideology argue that whether autism is regarded as a difference or disorder should be decided by individuals based on their lived experiences and access to services and support (Hunt & Procyshyn, 2024).

The neurodiversity paradigm suggests that naturally occurring variants in brain functioning are all part of human nature and therefore we are all fundamentally neurologically different (Singer, 1998). Consequently, autism (and many other neurological conditions such as attention-deficit/hyperactivity disorder or some learning disorders) can be viewed as a complex difference that needs support to adapt to the neuro-typical[8] world (Kapp et al., 2013). Calls for a new framework to understanding autistic wellbeing; using community-led, neurodiverse epistemological and methodological approaches, and based on the activities, situation and relations that are relevant to the everyday life of autistic young people have been made by Rodogno et al., (2016).

A neuro-affirming lens celebrates an individual's unique strengths as an integral part of their autistic identity (Kapp et al., 2013). Not everyone agrees that the term neurodiversity fully represents a wider cultural understanding and acceptance of autism, given the paradigm can be perceived as a predominantly white and 'high functioning' concept (Jaarsma & Welin, 2012). However, the principle of inclusive social identities inherent within the neurodiversity paradigm aligns with both critical autism studies and intersectionality theories in terms of scrutinising the cultural, geographic, historical and political influences that power social narratives and stereotypes within our society (Crenshaw, 1991; Davidson & Orsini, 2013; Strand, 2017). Consequently autistic community commentators highlight the need to harness individual experiences to empower new research approaches that emancipate the community from dominant negative medical discourses (Davidson & Orsini, 2013).

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[8] As the opposite of neurodivergent, neurotypical individuals are considered neurologically within the average range of human neurology (Walker, 2021).

We could ask why so little is known about adolescent autistic wellbeing. Given the diagnostic characteristics associated with autism such as difficulties with social communication as well as restricted and repetitive behaviours, (American Psychiatric Association, 2013), it's possible that autistic pupils[9] have different school experiences, compared to their neuro-typical peers. Additionally, the differences that autistic young people experience in interacting with non-autistic peers (Crompton et al., 2020), and processing their sensory environment (Gaines at al., 2016), as well as their focused interests and passions (Grove et al., 2018), and self-stimulating or stimming behaviours (Kapp et al., 2019), may also impact the context in which their wellbeing develops.

Yet historically there has been a dearth of literature on how autistic students actually experience wellbeing (Danker et al, 2016). This is worrying considering that a recent survey of 4,000 parents, carers and autistic young people indicated that less than half of autistic children are happy at school (National Autistic Society, 2021). This presents an opportunity to explore their school wellbeing experiences. Calls for children to play an active role in sharing their lived experiences have been previously highlighted (Ben-Arieh, 2005; Tomlinson et al., 2020). Privileging adolescent views on their wellbeing is particularly important as the potential gap between parent's and young person's subjective perspectives widens during adolescence (Sweeting, 2001).

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[9] 206,763 children in England with an EHC or SEN support related to Autism in 2022/23 (Department for Education, 2023).

### 1.4.1  An evolving lens on female autistic wellbeing

The national context for exploring female autistic wellbeing is complicated. Historically, fewer girls have been included in research studies investigating the lived experiences of autistic young people, partly due to researchers finding it more difficult to find and recruit girls with autism (Watkins et al., 2014). However, more recently, a burgeoning interest in the school experiences of autistic girls, and how these may differ from their male peers, has inspired new studies on the impact of bullying (Greenlees et al., 2020), dealing with adolescence (Cridland et al., 2014), masking classroom difficulties (Honeybourne, 2015), school avoidance (O'Hagan et al., 2022) and school exclusion (Sproston et al., 2017). Highlighting female perspectives is important as educational professionals, who may lack confidence in identifying and supporting autistic girls, can be less aware of how these experiences affect wellbeing (Gray et al., 2021).

Lower awareness of autism in girls from supporting professionals is unsurprising as, with an estimated gender ratio of 3:1, the prevailing narrative around autism is more dominant for boys (Loomes et al., 2017). The rationale for this gender disparity has been hypothesised as protective genetic factors for females (Zhang et al., 2020), under-recognition of autism in women (Lai & Baron-Cohen, 2015) and diagnostic measures designed for male characteristics (Lai & Mandy, 2017).

Alongside these historic gender disparities in autism narratives, social construction of gender and the ensuing expectations of girls may also be impeding understanding of how girls with autism experience wellbeing at school (Seers & Hogg, 2021). For example, internalisation of feminine gender norms (such as being shy, sensitive or

emotional) can result in the social sanctioning and alienation of autistic girls who do not conform to these expected behaviours (J. Davidson, 2007) as well as misperceptions by parents and professionals (Bargiela et al., 2016; Cheslack-Postava & Jordan-Young, 2012). This raises an important issue of what is known and understood about an intersectionality of social identities - being female and autistic (Saxe, 2017) – resulting in multiple barriers to school inclusion for autistic girls.

A recent review of clinical stereotypes of expected female social behaviour revealed that gender differences in autistic characteristics became more noticeable during adolescence, suggesting that secondary school-aged girls are more vulnerable to misdiagnosis or late diagnosis than boys (Jamison et al., 2017). Consequently, autistic girls are more likely to begin their diagnostic pathway once they are in secondary school (Rutherford & Johnston, 2022) – data from the largest recent cohort study shows increasing rates of female diagnosis across adolescence with 14.9 years the mean age for adolescent girls to receive their diagnosis (Russell et al., 2021). Late diagnosis may have been triggered by experiences of mental health issues, such as eating disorders (Westwood et al., 2017) and anxiety (Jackson et al., 2022). Further adding to the delay in receiving a diagnosis for girls is the lack of specialist knowledge in health clinics (Jackson et al., 2022; Young et al., 2018) and difficulty accessing services for their mental health needs (Tint & Weiss, 2018).

In mainstream schools, autistic girls without an intellectual disability have been described as at risk of 'flying under the radar' (Carpenter et al., 2019) and so frequently having their wellbeing needs overlooked (Zener, 2019). For teachers focused on creating an orderly learning environment, girls with autism typically exhibit fewer

externalised behaviourial problems, compared to boys (Giarelli et al., 2010), and therefore staff are more likely to associate outward behaviourial difficulties as signs of autism in boys (Jarman & Rayner, 2015). As a result of their efforts in masking differences at school, autistic girls can internalise difficulties, leading to disparities between parental and teacher report (Mandy et al., 2012). Sproston et al's. (2017) summary of teachers' awareness of autism in girls revealed that social communication difficulties were less visible in female students because of both a tendency to camouflage[10] differences to try and blend in with their peers, and their positive classroom demeanour.  Difficulties detecting autism in girls has also been attributed to their social-formatting skills such as pretend play (Solomon et al., 2012) and social imitation (Hsiao et al., 2013).

Continuing to expand our understanding of the intersectionality of different identities is also important because there is little research available on the experiences of autistic girls from minoritised backgrounds (Tromans et al., 2021) or those who identify as lesbian, gay or bisexual (Driver & Chester, 2021).  Without a diversity of autistic perspectives, a limited understanding of female autism could continue to impact the sensitivity of autism-related interventions (West et al., 2016), limit research participation (Watkins et al., 2014) and affect the way in which female autism is culturally interpreted (O'Dell et al., 2016; Saxe, 2017). Therefore, these gaps in the evidence base leave school leaders unsure how to support the wellbeing of the autistic girls in their schools (Morewood, 2019). There is an urgent need for professionals to

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[10] Often experienced as stigmatized social differences, camouflaging is a strategy used by neurodivergent people that discriminates between how they appear and what they feel (Lai et al., 2017).

engage with the wider political, social-cultural and environmental conditions that shape autistic girls' experiences of wellbeing (Seers & Hogg, 2021).

### 1.4.2 Risks of poor school wellbeing

A general difficulty in building a picture of the risk factors in autistic girls' wellbeing at secondary schools is the lack of qualitative studies exploring female lived experiences. However, recent research exploring experiences of school wellbeing report the following impacts on female students. Sproston et al's (2017) study utilised parent-child dyads to reveal: pressures of mainstream classrooms, associated sensory problems and difficulties with peers; lack of tailored support; and perhaps most importantly, relational issues with both staff and peers. Not being able to talk about wellbeing issues within the increasingly pressured secondary school environment is challenging for autistic girls, who tend to internalise their anxiety, leading to emotional based school non-attendance (Higgins, 2022; Munkhaugen et al., 2017; O'Hagan, Bond and Hebron, 2022). A current study exploring reasons for school non-attendance, including experiences of school distress, revealed that 83.4% of pupils experiencing school distress were described as autistic and displayed significant emotional stress around school at a younger age and for longer than their neuro-typical peers (Mullally & Connolly, 2023). The authors boldly challenged a seemingly systemic failure by the UK government to uphold its responsibility to provide an education for all CYP, in line with the United Nations Convention on the Rights of the Child (1989).

## 1.5 The EP's role in supporting school wellbeing

Educational Psychologists (EP) complete a three-year doctoral training programme in which wellbeing features across the curriculum, including young people's social and emotional mental health, therapeutic interventions, systemic influences on individual, group and community wellbeing, supervision of supporting adults, and consultation, amongst others. As applied psychologists working in schools with young people, EPs are obliged, through their professional standards (Health and Care Professions Council, 2015), to maintain the health and wellbeing of service users by being aware of individual differences on psychological wellbeing. EPs also use their skills to raise educational standards and remove barriers to progress by promoting psychological wellbeing and through statutory advice for EHC plans and at a whole school level.

As agents of change, a focus on wellbeing can be implicitly woven throughout EPs' work (Roffey, 2015), however a lack of awareness from school SENCos and other professionals of EPs' capacity for therapeutic work (Andrews, 2017), may be limiting their influence. Other barriers that have been identified to this sort of work include a professional atrophy of therapeutic skills and time limitations for longer therapeutic or organisational change work (MacKay, 2007), due to the changing nature of service delivery and under-staffing in EP services.

Even so, with under-funding of mental health services[11] (since the Covid-19 pandemic) and the current cost of living crisis driving a mental health crisis[12] in our communities, it could also be argued that EPs are well-placed to provide whole school, relational approaches to wellbeing. Their work can develop the skills and narratives of school staff so that the wellbeing of autistic pupils can be viewed through an alternative lens that promotes protective factors and avoids negative school experiences becoming a 'double whammy' for vulnerable young people (Roffey, 2016).

As exemplified by the social model of disability[13], espoused by Oliver (2013), it can also be posited that a key task for EPs is critically challenging the environmental constraints for wellbeing.  This is important where the dominant and normative culture around mainstream 'ability' creates physical, social and attitudinal barriers that 'others' those who do not quite fit in (Schulze et al., 2019). By emancipating the experiences of young people through participatory and collaborative processes, EPs facilitate opportunities for marginalised CYP to use their lived experiences to challenge 'typical' narratives, and in the process, become actors for social justice[14] (Groundwater-Smith et al., 2015). EPs also act as change agents within their local authority (LA) system (Sheridan & Gutkin, 2000), ensuring that the wellbeing experiences of different communities (such as autistic girls') are understood and supported at a strategic level. Ultimately in advocating for the voices of autistic girls to be heard, EPs themselves

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[11] A report by the Children's Commissioner states that a lack of ambition in improving children's mental health services, even before the pandemic, may affect children's recovery and wellbeing (2021)

[12] Over a quarter of parents surveyed by YouGov said their children's mental health had worsened because of the cost-of-living crisis (Barnardo's, 2022).

[13] As a divergence from the medical model of disability, the Social Model of Disability advocates that the challenges faced by disabled individuals are the result of systemic barriers to accessing a world created predominantly for an able-bodied population (Woods, 2017).

[14] A socially just system enables all social identity groups to fully and equally participate because their needs have helped shape the system (Bell, 2007).

may elicit a dissenting voice within the very systems, structures and discourses designed to deliver social justice (Mercieca & Mercieca, 2022).

### 1.5.1 Local context for supporting autistic girls' wellbeing

This research originated in a Child and Educational Psychology Service in an authority in the South-East of England. With exclusion rates above the national average, the LA recently released its *Inclusion, Behaviour and Wellbeing Strategy* (Local Authority Council, 2022) which sets out new principles to ensure a consistent, equitable approach to supporting pupils with Social, Emotional and Mental Health needs. Top of the strategy's agenda are pledges to challenge negative language and practices which marginalise children in school, training support using trauma-informed and relationship-based approaches to support behaviour, and the development of student voice to inform intervention.

To bring the strategy to life, multi-professional working groups have been established to explore the holistic and systemic factors which influence young people's wellbeing. It is hoped this will result in improved wellbeing outcomes, targeted provision incorporated within schools' graduated approaches and identification of broader systemic school issues. The researcher hopes this study will contribute to local understanding of and support for adolescent autistic girls' school wellbeing.

## 1.6  Rationale and aim for this research

As discussed, there are many ways to conceptualise wellbeing, however calls from within the autistic community and on behalf of young researchers highlights a lack of confidence as to the application or relevance of a specific

wellbeing framework for adolescent girls in schools. Further to this, it has been suggested that understanding of 'psychological wellbeing' is constantly evolving, especially in the field of education (Fee, 2011). This research intends to emancipate student voice to explore the current social, environmental and developmental contexts for a shared understanding of how adolescent girls experience autistic wellbeing and their school supports.

The researcher's interest in exploring this topic initially developed from early professional experience working with autistic young people (Section 3.3.4). An interest in autistic wellbeing and how to support this progressed further within placement and training experiences on the doctoral programme. To support future EP practice, it has become apparent there is an overarching need to drive social justice by empowering autistic girls to share their lived experiences of wellbeing so that professionals can tailor their support. Further aims of this research were co-developed with study participants and are described in sections 3.3, 3.94 and 5.11.

## 1.7  Summary

This chapter introduced key theoretical concepts around wellbeing and posed questions around a seeming lack of knowledge regarding the school wellbeing experiences of female autistic students. The local and national contexts for the research were briefly discussed, alongside the role of the EP in bringing a broader perspective around the educational, cultural and social systems in which wellbeing is experienced.

*The wellbeing of pupils is the most important priority for any school; however, the wellbeing of autistic pupils is profoundly less likely to be met in the education system. This can result in academic struggles and disengagement with school life, as well as lifelong mental health concerns.*

Bonnello (2022)

## 2.1  Overview

This chapter systematically and critically reviews what the existing research tells us about how autistic girls experience wellbeing at school and what factors support this.  Included are details of the search methodology, followed by a critical appraisal of the relevant evidence base for this study. Key themes from the literature review are discussed and the chapter concludes by continuing to develop the rationale for the current study.

## 2.2   Search methodology

### 2.2.1  Literature review question

What does the literature tell us about how adolescent autistic girls experience wellbeing at school and the supporting factors?

### 2.2.2 Search strategy

A previous scoping review (to support the initial research proposal) identified a body of relevant literature representing autistic girls' wellbeing. To identify studies which met the inclusion criteria for this study, a systematic search strategy was used, following the four stages of the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) approach (Page, McKenzie & Bossuyt, 2020) (Figure 2.1). Since the concept of 'wellbeing' is a ubiquitous term, the subject index terms for key databases were utilised and in April 2023, systematic searches of the following three databases were completed: EBSCO hosted Psych INFO, Education Resources Information Centre (ERIC) and Academic Search Ultimate. Additional hand searches were made through Google Scholar, ETHOS, the grey literature as well as reference harvesting of eligible studies. Table 2.1 highlights the search terms and rationale for choosing them.

Initial filters applied were: 'peer-reviewed', 'English', 'open access', 'academic journal/dissertation' and '1994-2023'. After removing duplicates, screening titles for relevance and applying the inclusion and exclusion criteria (Table 2.2), 69 papers remained.

However, after detailed reading of the abstract, methods and some results sections, it became evident that many of these studies combined the views of autistic girls with professionals, parents or teachers and it was difficult to unpick participant's contribution to the final themes. This may be contributing to the flawed and unreliable knowledge base about autistic experiences of wellbeing, described by Milton & Sims (2016). There was also little research with secondary aged pupils (Ben-Arieh, 2005; G. Clarke et al., 2011), despite acknowledgement of the unique developmental

challenges already described for adolescent autistic girls (Tierney et al., 2016). This realisation of the paucity of community views within the available literature was disappointing, given the emancipatory aims of this author's research (Mertens, 2007).

**Table 2.1**

*Search terms used in the search strategy*

| Subject mapping area: | Subject Index terms and Key Word search terms: | Rationale: |
| --- | --- | --- |
| "Wellbeing" | OR Subjective well-being OR Psychological well-being OR Well-being | There are many ways to conceptualise wellbeing. |
| **AND**<br><br>"Autism Spectrum Condition" | OR Autism Spectrum Disorders OR Asperger's Syndrome OR Autism OR Autism in adolescence OR Autistic traits OR Neurodiv* | There are many ways to refer to Autism. |
| **AND**<br><br>"School experience" | | |

Lam et al., (2021) recommend applying a critical psychology lens to challenge the basis of prevailing psychological knowledge. This approach examines how research methods reflect the axiology (e.g., what are the purposes and values of autistic participants' data) and teleology (e.g., whose perspective is being marginalised) in a study. Congruent with this approach, this literature search focused on studies that privileged the voices of autistic girls. Consequently, where the autistic girls' views could not be clearly distinguished from other stakeholders' perspectives, a further 63 studies were excluded.

**Figure 2.1**

*PRISMA analysis of literature search*



**Identification of studies via databases and registers**

**Identification of studies via other methods**

Papers identified from:
Databases (n= 684)

Records removed *before screening:*
Duplicate records removed (n= 284)
Records removed for other reasons[1] (n=29)

Records identified from:
Websites (n= 0)
Organisations (n=0)
Reference harvesting (n = 2)
Ethos (n= 2)

Records screened[2]
(n= 371)

Records excluded[3]
(n= 297)

Papers sought for retrieval
(n= 74)

Papers not retrieved[4]
(n= 5)

Papers sought for retrieval
(n= 4)

Papers not retrieved[4]
(n= 0)

Papers assessed for eligibility[5]
(n= 69)

Papers excluded[6]
(n= 63)

Papers assessed for eligibility[5]
(n= 4)

Papers excluded[6]
(n= 0)

Studies included in review
(n= 10)

Identification — Screening — Included

[1] Records removed if not in English (n=11) or format other than peer reviewed article (n=18)

[2] Records screened by reading title and abstract

[3] Screening exclusion criteria – Voice of other stakeholders than female (n=91), participants not attending secondary mainstream education setting in the UK (n=98), not autistic or related diagnosis (n=5), study not related to wellbeing (n=100), participants boys only (n=3)

[4] Retrieval exclusion criteria – papers not available as full text

[5] Eligibility assessment criteria - Detailed read of abstracts, methods and results sections of papers

[6] Eligibility exclusion criteria – Participants not female (or mixed with undefinable results attributable to female participants) (n=14), not aged 12-15 years old (n=7), not attending secondary mainstream education setting in the UK (n=14), study not related to wellbeing (n=15), not the voice of adolescent females (n=13)

**Table 2.2**

*Inclusion and exclusion criteria for the literature search*

| Studies included if: | Studies excluded if: | Rationale: |
|---|---|---|
| a. **Publication date** Published - 1994-2023 | Published prior to 1994. | Due to the promotion of inclusive education for all children via the Salamanca Statement (UNESCO, 1994). |
| b. **Location and Setting** Conducted in the UK or Ireland, with mainstream secondary school pupils. | Conducted outside of the UK and/or with pupils attending Special Educational Need settings, Alternative provision or Home Educated. | Research relates to the UK educational context in which the author works. Recognition that non-mainstream settings may adapt their provision to meet the specific needs of their pupils. Schools with autism base included as long as the participants spend the majority of their school day in the mainstream environment. |
| c. **Participants** Forefront the views of autistic girls (aged 11-18 years). Female gender assigned at birth. | Promotes other perspectives (e.g., parents, teachers, primary age pupils or professionals). Views of girls within mixed gender studies not easily identifiable. No autism diagnosis. Male gender assigned at birth. | Author's research focus is forefronting the views of autistic girls as they navigate their secondary school experiences. Professional context of author's work relating to promoting the views of young people and their school experiences, in line with the SEN Code of Practice. |
| d. **Study type** Peer reviewed journals or doctoral theses. **Qualitative studies only**. | Books and magazines. | Ensures that papers are published with academic and professional rigour, providing full findings to research questions, to reduce selective reporting of outcomes. Qualitative studies provide meaningful answers, based on lived experiences. |

Following a detailed reference harvesting process and search of grey literature and theses (via EThOS), four additional papers were found. In total, ten studies were critically analysed using the Specialist Unit for Reviewing Evidence (SURE, 2018) – see Appendix 1.1 for detailed analysis and Table 2.3 for an overview. Interestingly, all the reviewed papers were published in the past decade, indicating a burgeoning interest in exploring the experiences of autistic girls.

### 2.2.3   Critical appraisal

The transformative aim of this study is to develop a shared construct of wellbeing through making sense of the lived experiences of autistic girls. Therefore, in line with the critical psychology approach recommended by Lam et al., (2021), wellbeing is positioned as unfixed and situated because we have not yet explored how autistic adolescent girls make sense of their wellbeing.  Whilst quantitative research methods may enable participants to give their views, the reductive and realist nature of numeric measures do not enable contextualised narrative recounts which are required to fully explore a 'lived experience', according to Braun & Clarke (p.6, 2022). Consequently, this literature search sought studies that employed primarily qualitative methods.

Throughout the ten studies identified, a range of data collection methods were utilised, including focus groups, semi-structured interviews, case studies and an online survey. Aside from the online survey by Ozsivadjian and colleagues (2022), which was part of a larger longitudinal study conducted during the national pandemic, all other qualitative methods were specifically chosen by the authors after careful consideration of their appropriateness for data collection when working with the autistic community.

**Table 2.3**

*Mapping overview of included studies (using the Specialist Unit for Reviewing Evidence, SURE, 2018)*

| Study name, authors and year *(see Appendices for summary of each study)* | Analysis criteria *(see Appendices for detailed descriptors of criteria)* | | | | | |
|---|---|---|---|---|---|---|
| | SPICE achieved | Sampling strategy and participants | Data collection methods | Data analysis methods | Ethical and power issues discussed | Credibility and limitations |
| **The mainstream school experiences of autistic girls and adolescents.**. Tomlinson, C., Bond, C., & Hebron, J. 2022 | Yes | Three female Year 10/11 pupils recruited via SENCo. | Qualitative – multiple case study design Semi-structured interview at school following week-long self-selected data collection. | Inductive thematic analysis | Yes | Yes Accessibility - researcher prompts needed. |
| **Perceptions of friendship among girls with Autism Spectrum Disorders.** Ryan, C., Coughlan, M., Maher, J., Vicario, P., & Garvey, A. 2021 | Yes | 10 girls recruited from a community service for children with ASD. Aged 12-15 years old | Qualitative design. Two parallel, semi-structured focus groups with four key themes explored | Guided by principles of thematic analysis | Yes | Yes Perspective vs. reality. Participation in focus group setting. |
| **Exploring how a sense of belonging is constructed in the accounts of autistic girls who attend mainstream school in England.** Brennan de Vine, N. 2022. | Yes | Purposive sampling - 18 female participants, aged 12-18 years old | Qualitative design with background quantitative measures. Semi-structured interviews (over 2 sessions) following a participatory research approach | Thematic analysis | Yes | Yes Diversity of participants, US measures used. |

| Study name, authors and year (see Appendices for summary of each study) | Analysis criteria (see Appendices for detailed descriptors of criteria) | | | | | |
|---|---|---|---|---|---|---|
| | S.P.I.C.E achieved | Sampling strategy and participants | Data collection methods | Data analysis methods | Ethical and power issues discussed | Credibility and limitations |
| **The social experiences and sense of belonging in adolescent females with autism in mainstream school.** Myles, O., Boyle, C., & Richards, A. 2019 | Yes | Purposive sampling – 8 female participants aged 12-17 years old | Qualitative design. Semi-structured interviews across 2 sessions | Thematic analysis | No | Yes Small sample size |
| **Autism and the U.K. secondary school experience.** Dillon, G. V., Underwood, J. D. M., & Freemantle, L. J. 2016 | Yes | Purposive sampling methods to recruit 14 autistic participants (3 girls, 11 boys) and chronologically and gender matched control group of non-autistic peers. Mean age around 13 yrs. | Mixed method study. Self-report questionnaire and semi-structured interviews. | Not specified – qualitative analysis | No | Yes 3 female participants – data extracted of use were direct quotes. |
| **Autistic and non-autistic young people's and caregivers' perspectives on COVID-19 related schooling changes and their impact on emotional wellbeing: An opportunity for change?** Ozsivadjian, A., Milner, V., Pickard, H., Hollocks, M. J., Happé, F., & Magiati, I. 2022 | Yes | Voluntary sampling. 4 female participants – mean age 15:!2 years. | Qualitative online survey. | Thematic analysis | Yes including community consultation during measure development | Yes Small sample. |

| Study name, authors and year (see Appendices for summary of each study) | Analysis criteria (see Appendices for detailed descriptors of criteria) | | | | | |
|---|---|---|---|---|---|---|
| | SPICE achieved | Sampling strategy and participants | Data collection methods | Data analysis methods | Ethical and power issues discussed | Credibility and limitations |
| **Looking behind the mask: Social coping strategies of girls on the autistic spectrum.** Tierney, S., Burns, J., & Kilbey, E. 2016. | Yes | 10 female participants. | Qualitative design. Face-to-face semi-structured interviews. | IPA | Yes | Yes High functioning individuals, lack of generalisation from IPA. |
| **Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings.** Cook, A., Ogden, J., & Winstone, N. 2018. | Yes | Purposive sampling. 11 female participants (aged 7-12 years) + parents. Only 6 girls attended mainstream settings. | Qualitative design. Semi-structured interviews. | Thematic analysis | Yes. | Yes. Difficulty attributing data between parents and girls. Used direct quotes. |
| **"Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators.** Halsall, J., Clarke, C., & Crane, L. 2021. | Yes | Purposive sampling to recruit eight triads of pupil, parent and educator. | Qualitative design. Semi-structured interviews. | Thematic analysis BUT combined views from all participants | Yes | Yes Camouflaging techniques used in interview? |
| **Missing: the autistic girls absent from mainstream secondary schools.** Moyse, R. 2021. | Yes | Purposive and snowball sampling. 10 female participants | Qualitative, structured data collection sessions – 3 per participant | Thematic analysis | Yes with participatory approach | Yes Participants self-selecting. |

Interestingly, only three of the papers sought direct autistic community involvement, either through member checking initial coding during data analysis (Tomlinson et al., 2022) or using participatory approaches to inform research design and data analysis via Autism Advisory Groups (Brennan da Vine, 2022; Moyse, 2021).

## 2.3 Thematic synthesis of literature

Application of thematic synthesis (J. Thomas & Harden, 2008) allowed themes from the literature to be analysed within the contextual frameworks of adolescent development and systemic factors that are important to this study. Firstly, the themes raise questions related to key developmental tasks of adolescence, such as developing a clear sense of who you are, feeling in control and establishing a place for yourself in society (Crocetti, 2017). These tasks are particularly important during transitional phases when young people may be feeling less stable or certain (Erikson, 1968), especially about their social attachments which are in a complex state of flux throughout secondary school (Tierney et al., 2016).

Secondly, studies from the field of neuroscience and social psychology point to adolescence as a critical period of brain growth related to social development (Blakemore, 2012), therefore it felt important to review the existing wellbeing literature within an eco-systemic model of relevant social environmental contexts. Further to this, the recent Geneva Charter for Wellbeing calls for a whole-society approach to actioning wellbeing (World Health Organization, 2021) with collaboration across all levels and stakeholders (see page 153 for a definition). Context and social cognitive influences are also important to the work of EPs therefore, the unique environment and support that constitutes the mainstream secondary school system was included

in an eco-systemic mapping of themes (Bronfenbrenner & Bronfenbrenner, 2009) –
see Figure 2.2.  The impact of each theme on female autistic wellbeing is described
throughout.

**Figure 2.2**

*Eco-systemic thematic template for analysis of literature*
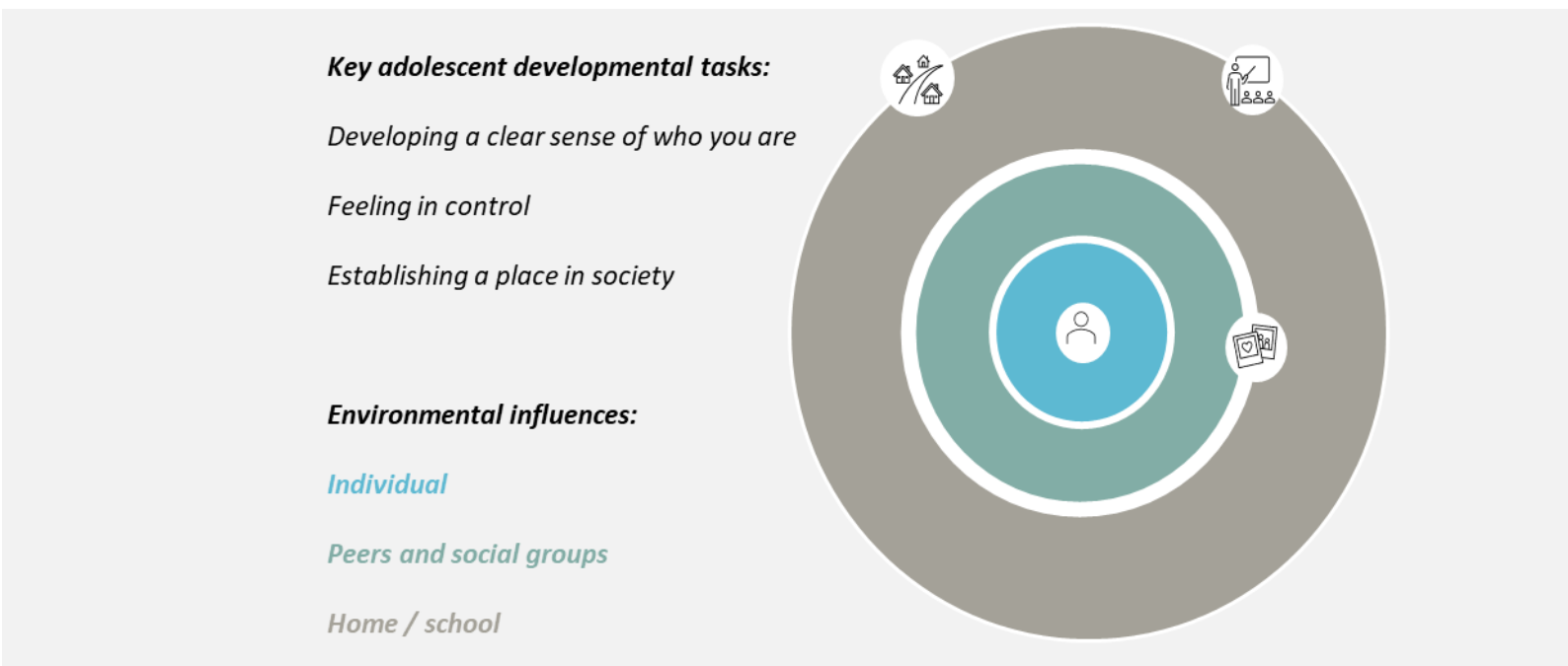


Key themes derived from the ten relevant papers are now discussed (Appendices 1.2-
1.4 for detailed methodology, examples of theme development and researcher
reflection).

### 2.3.1  Who am I really?

#### 2.3.1.1  A new 'label'

For some girls the move to secondary school, and associated emotional
and social challenges following this transition, leads to a late diagnosis of
autism (Moyse, 2021). The negative impact on wellbeing of assimilating a new
diagnostic label into their developing identity was discussed by Tomlinson et

al., (2022) who interviewed three autistic girls attending mainstream secondary school. Whilst experiences of receiving a diagnosis helped their female participants gain insight into their underlying individual needs, ongoing awareness of difference from their peers including associated mental health difficulties (e.g., self-injurious behaviours, depression, anxiety, suicidal ideation and disordered patterns of eating) were described as clear indicators of poor wellbeing (Tomlinson et al., 2022).

### 2.3.1.2 Camouflaging social differences

A sense of not wanting to feel different and a protective and social need to hide their differences was a common theme emerging across this literature review with four studies commenting on the impact of masking[15] on the girls' wellbeing. Brennan de Vine (2022), who explored the sense of belonging of autistic girls attending secondary schools in England described the detrimental effects of masking (e.g., to avoid social isolation) on girls' wellbeing and identity. This builds on earlier research into the purpose of masking for autistic girls to hide their differences and fit in with their peers (Halsall et al., 2021; Tierney et al., 2016).

### 2.3.1.3 Masking learning differences

Masking is a common protective mechanism across all areas of school life. Research shows that masking difficulties helps minimise the likelihood that mainstream peers would think autistic girls are 'stupid' (Halsall et al., 2021). The

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[15] The National Autistic Society define 'masking' or 'camouflaging' as an unconscious strategy, used to hide aspects of yourself so that you can socially connect with peers (Belcher, 2022).

eight female participants in this study described being trapped in a negative cycle of increasing camouflaging of their learning needs but the associated anxiety then reduced their capacity to learn (Halsall et al., 2021). It is possible that one of the reasons for delayed diagnosis of girls is that various adaptive strategies, including camouflaging in the classroom, hides the true extent of their wellbeing difficulties.

It is unclear whether the strategy of camouflaging across academic and social contexts is experienced by all autistic girls. In Halsall et al's., (2021) study, the autistic girls attended a mainstream school and accessed some of their learning in a specialist resource base. For these girls, there was less reported need to camouflage their difficulties when learning in their peer-group lessons in the resource base, compared to when learning with their neuro-typical peers in the mainstream lessons. This might indicate that camouflaging serves a distinct, contextually and peer-dependent purpose for autistic girls and therefore may have a variable impact on wellbeing.

### 2.3.1.4  Hidden but needing to be seen

As long as autistic girls are perceived as academically able by school staff, barriers to learning resulting from anxiety or stress may remain un-noticed. In research conducted by Moyse (2021), natural tensions felt by the girls were revealed - between feeling undeserving of teacher support or not wanting to stand out from their peers - despite clear learning needs requiring support. Not wanting to 'feel like a burden' (Moyse, 2021, p. 143) reduced their likelihood of asking for help and supported teachers' assumptions about their academic

ability, leading to less assistance in class. Moyse (2021) also reported on a secondary tension experienced by autistic girls who didn't want to be treated differently from their peers and requested support from teachers that was subtle and discreet. However, in contrast to research highlighting the prevalence of masking strategies (Cook et al., 2018; Halsall et al., 2021), participants also wanted to feel their individual contributions and achievements were recognised and valued. The complexity of these tensions undoubtedly impacted the girls' wellbeing as well as their developing identity as a learner in the school community.

Halsall et al., (2021) also reported that for female participants in their study, inconsistent camouflaging across different learning contexts resulted in feeling like they didn't fit in with either their neuro-typical or autistic peers, indicating a dual invisibility.

### 2.3.1.5 Emotional cost of masking

For many participants, the cost of masking was described as emotionally draining. Halsall and colleagues (2021) emphasized how exhausting continuous camouflaging (to avoid being bullied or socially isolated) was for their female participants. Furthermore, not knowing if their camouflaging attempts were successful led to frustration and anger which needed to be masked whilst at school, but then over spilled into home life. Uncertainty over masking success was also described as contributing to high levels of anxiety at school, signalling a further detrimental impact on the girls' wellbeing, according to Halsall et al. (2021). In addition to the immediate effects on emotional

wellbeing, the longer-term consequences of camouflaging were reported to be loneliness and low self-esteem (Halsall et al., 2021).

Despite the emotional cost, autistic girls struggled to stop masking at school because this required even more energy to return to their authentic self (Brennan de Vine, 2022). Consequently, this increased the likelihood of school staff missing signs of psychological or emotional distress such as depression or anxiety (Cook et al, 2017; Tierney et al., 2016). Halsall and colleagues (2021) commented that autistic girls often rely on support staff, who know them well, to see through the camouflaging and recognise the subtle indications that they were feeling anxious or over-whelmed. Accounts that teachers sometimes expressed disbelief when they learned of the autistic girls' struggles to cope have been reported (Tierney et al., 2016). Similarly, when autistic girls don't feel listened to, they report that their experiences were devalued (Myles, 2019). Arguably, this may reduce their sense of safety and belonging at school.

### 2.3.1.6   Supporting factors

There were some suggestions from the studies on how autistic girls can be supported to feel comfortable being their authentic selves. Albeit from a clinical perspective, Tierney and colleagues (2016) suggested that it might be helpful for professionals to find out about the girls' masking or imitation coping methods by asking parents or peers what they had observed.

Another suggested provision that could easily be developed in the secondary school environment is the use of a drama club to help develop wider acceptance of neurodiversity[16] and differences in social communication and interaction (Tierney et al., 2016). However, Tierney and colleagues (2016) also reflected that it would be important to consider how to make this a safe space for autistic students so that there was less need for girls with autism to mask their behaviours and feelings. A need for safety was highlighted by participants in other studies, who appreciated being able to access particular areas of the school where they felt secure and able to check-in with staff or peers, like a lunchtime club (Myles et al., 2019).

## 2.3.2 Am I in control?

### 2.3.2.1 Distortion of autonomy[17]

A challenge for autistic students is being treated differently and thus losing their sense of autonomy after sharing their diagnosis of autism (Moyse, 2021; Myles et al., 2019). In a small-scale study into the social belonging experiences of secondary aged autistic girls, Myles and colleagues (2019) noted that participants felt they were 'being treated like babies' by teachers once their diagnosis was shared in school (p.16). In the case studies explored by Moyse (2021), differences in autonomy were noted through the way that teachers and professionals used problematic and judgemental language to

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[16] Neurodiversity is defined by the National Autistic Society as an acknowledgement of the different ways that humans think, learn and relate to each other, with around 20% of the population estimated to be neurodivergent or not neuro-typical, in some way (Honeybourne, 2018).

[17] According to Deci & Ryan (2012), feeling autonomous means that when others validate your feelings, you have choices and feel in control of your own behaviour, and you are more likely to independently make decisions.

describe the girls' needs or behaviours. The girls described feeling insulted and discriminated against when the label and characteristics of their autism were used in deficit terms. Moyse (2021) suggests that the deficit-based language used by adults may be common practice, reflecting low acceptance of the neurodiversity paradigm in wider society. The repeated experiences of hearing one's needs and behaviours invalidated in this negative way would likely reduce the girls' sense of autonomy and belonging, and overall wellbeing.

### 2.3.2.2 Owning the agenda

On a positive note, for the female participants in a different study, sharing their diagnosis was viewed as an opportunity to educate people about neurodivergence and thus improve their sense of belonging (Brennan de Vine, 2022). Being able to make choices and take responsibility for the messages shared with others was reported to build a sense of agency[18], which is closely related to positive wellbeing, according to Brennan de Vine (2022).

A developing sense of agency in selecting meaningful coping strategies, which allowed some autistic girls to manage their own wellbeing, was reported by Tomlinson and colleagues (2022). Examples from their case studies included participants choosing to take extra time to find a quiet place when they needed to regulate their emotions or reducing their use of social media to self-monitor frustration resulting from social interaction challenges. Other strategies

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[18] When able to influence one's own actions and life circumstances, an individual is described as having personal agency (Bandura, 2006)

included proactively using headphones or ear defenders (Tomlinson et al., 2022). According to Ozsivadjian et al. (2022), this sense of agency may have been honed during Covid-19 when learning at home enabled autistic students to experience more freedom to access coping mechanisms such as stimming and listening to music, without fear of judgement from others. Results from their longitudinal study on schooling changes showed greater agency increased pupils' ability to focus on their learning and improved emotional wellbeing (Ozsivadjian et al., 2022).

### 2.3.2.3  Supporting factors

Research from Dillon et al., (2016) highlighted the value of autonomy for autistic learners in the classroom. This qualitative study, presenting first-hand perceptions of autistic students at secondary school, reported that female participants valued the autonomy of peer learning and engagement rather than being told what to do by the teachers. These findings have consequences for how schools promote choice for autistic girls across different areas of school life and the positive impact this has on their wellbeing.

## 2.3.3  Where do I belong?

### 2.3.3.1  Friends who understand me

Research suggests that having friends supports autistic girls' wellbeing (Brennan de Vine, 2022; Myles, 2019). Participants in the study by Myles et al., (2019) attributed having a friendship to supporting their overall happiness and emotional wellbeing in school. Contributing factors included feeling their autism

was well understood and accepted as well as being comfortable to interact with friends on their own terms, sometimes without pressures of verbal communication. The study concluded that a sense of belonging can be a protective factor for mental health (Myles et al., 2019).

This closely relates to the work conducted by Brennan Da Vine (2022) who explored how autistic girls construct a sense of belonging and the impact of this on their wellbeing. This was a particularly robust study in which all 18 autistic girls contributed their views on belonging through individual activities and across multiple interview sessions. A unique contribution to the knowledge base from this research highlighted how overt peer acceptance enabled the girls to express and assert their individuality.

The participants perceived their friendships as facilitating the removal of barriers to difficult experiences because their friends inherently understood their difficulties and what support they needed. The study described causal links between external validation (i.e., experiences of non-judgement from peers) and internal acceptance of their autistic identity (i.e., unveiling their true selves), leading to improved mood and reduced anxiety. Furthermore, with an enhanced sense of belonging, confidence and happiness in social relationships participants were more motivated to attend school (Brennan de Vine, 2022; Moyse, 2021).

### 2.3.3.2 Shared interests

Intrinsic to membership of social groups where autistic girls could meet others and form friendships (Brennan de Vine, 2022), was being able to share activities at school (Cook et al., 2018; Moyse, 2021). However, despite being highly motivated to make friends, as reported by Tierney and colleagues (2016), autistic girls may also experience difficulties fitting into friendship groups (Cook et al., 2018).  Research suggests that it is not uncommon for social interaction difficulties to arise when autistic girls transition to secondary school. An amalgamation of dealing with their emerging sexual identity, encountering new, covert social norms as well as deteriorating friendships (based on diverging interests) present significant challenges for some autistic girls (Cook et al., 2018; Tierney et al., 2016).  Additionally, difficulties translating the social nuances of communication via social media can create conflict in peer relations (Tomlinson et al., 2022). The challenges that new social expectations present often result in secondary mental health difficulties which may create the catalyst for referral to professional support or a diagnostic pathway (Moyse, 2021: Tierney et al., 2016).

### 2.3.3.3 Outside looking in

Three studies highlighted the negative impact on wellbeing from a lack of belonging. Myles and colleagues (2019) stated that being on the periphery of a social group had resulted in their female participants feeling either ignored or unable to join in because of a lack of shared interests. Tierney and colleagues (2016) also observed that when the group dynamic and foci of interest was dominated by neuro-typical adolescent girls, this also posed a

problem for autistic girls who didn't always want to follow the same social agenda. Both these studies concluded that autistic girls often give an outward impression of being part of a social group but still lacked self-esteem and social confidence.

Additionally, girls felt lonely and isolated especially when they perceived the constant effort they put into social relationships was not reciprocated by non-autistic peers (Tierney et al., 2016). The extended impact on the girls' wellbeing of engaging in negative cycles of making new friends and being rejected - low self-esteem - was discussed in connection to future adult relationships (Brennan de Vine, 2022).

### 2.3.3.4  Supporting factors

To overcome obstacles related to mutual bonding, which often created discomfort and distress (Tierney et al., 2016), research suggested that autistic girls need structured support and safe opportunities related to their interests and hobbies (Myles et al., 2019). Identifying the activities the girls would like and adapting the group environment so that it feels safe to join was considered fundamental to inclusive school practice and supporting wellbeing (Brennan de Vine, 2022).

In addition, autistic girls in a study by C. Ryan and colleagues, (2021) valued friendships which began in school but thrived by expanding across other social contexts, where interests can continue to develop. Therefore, for optimal

wellbeing, friendships must organically merge across contexts. It is also worthy to note that successful experiences of friendships for autistic girls may also permeate different social groups. For example, girls in the study by Halsall and colleagues (2021) shared that school staff were perceived as friends because the consistency of adult interactions helped girls feel safe and less inclined to camouflage social interaction differences. The study also reported a similar finding to Tomlinson et al., (2022) that autistic girls liked playing with younger peers because they experienced a sense of control or felt more comfortable with the lower maturity level. These findings converge with that of Cook and colleagues (2018) who identified that one of the reasons why friendships break down during secondary school may be due to autistic girls enjoying different interests than those pursued by their peers.

Together these studies highlight the importance of and difficulties within friendships experienced by autistic girls. Successful experiences building on shared interests can create a sense of belonging which is a protective factor for mental health. Conversely, autistic girls who struggle with their friendships can feel marginalised and experience isolation, resulting in accumulative negative effects on their wellbeing.

### 2.3.4 How do I navigate the secondary school system?

A major theme emerging from this literature review was the effect on the girls' wellbeing of the academic, relational and sensory demands aligned with mainstream secondary school.

### 2.3.4.1  It's not all about the grades

Moyse's research into why autistic girls were missing from education asked participants to draw their ideal school. Girls prioritised wellbeing over academic achievement (2021), citing this as a protective factor enabling them to engage in their learning. Exam pressure was consistently referred to by Tomlinson et al., (2022) with two case studies describing intense stress experienced by the girls in accessing school work, revision and tests.

### 2.3.4.2  Building new relationships

Across all the studies reviewed, autistic girls experienced significant changes in their peer and adult relationships, as they progressed through secondary school. This was a marked contrast to their early experiences of transition from primary schools, where autistic girls reported feeling safe and confident, especially if with close friends (Myles et al., 2019). Integral to feeling like they belonged in their new school was being acknowledged and valued by their peers (Myles et al., 2019). However, relationships with support staff were also important, especially if the girls had any concerns (Dillon, 2016). Research by Brennan da Vine (2022) concluded that participants felt heard, validated and trusted when school staff sought the girls' views to adapt the teaching or environment for them. This created a greater sense of connection to their new teachers and provided validation for their experiences.

### 2.3.4.3  Collaborative learning

Secondary school brings changes to the way that young people are asked to learn. Collaborative learning approaches are a key and recommended feature of the secondary curriculum in English schools (Education Endowment Foundation, 2023). Whilst female participants in a study by Dillon and colleagues (2016) reported valuing the autonomy of peer learning, group dynamics needed to be managed carefully by teachers to ensure that autistic students felt comfortable and productive working with peers whom they know well.  However, because Dillon and colleagues (2016) focused on the social interaction benefits of inclusive education, the findings did not delineate the interactional benefits of working within neuro-type versus cross-neurotype groups. It is therefore unclear whether autistic girls would have found significantly more autonomy and engagement had they been working solely with autistic peers.   Moyse (2021) suggests that schools should focus on teaching students how to work in partnership. This approach would firmly locate potential difficulties in social interacting as a group-wide, bi-directional issue, as per Milton's (2012) double empathy problem.

Disengagement from group learning tasks and social repercussions from peers and teachers were reported in other studies (Moyse, 2021; Tierney et al., 2016). For example, autistic girls felt ill-equipped to cope with the social demands of group work and were often left out by their peers (Tierney et al., (2016). For other participants, group work was their least favourite way of working because their peers' behaviour negatively impacted their concentration on the task, negating the point of social learning (Moyse, 2021). It can be hypothesised that

repeated negative experiences of feeling unable to integrate and contribute within group situations may increase the sense of objectification and vulnerability experienced by autistic girls in mainstream secondary school (Brennan de Vine, 2022).

### 2.3.4.4 Supporting factors

In Tomlinson et al's., (2022) study, individual case studies identified the personalised accommodations which supported autistic girls' wellbeing at school. However, it should be noted that the participants in this study attended a school which had been recognised by Ofsted for its inclusive and flexible approaches. Personalised accommodations available to autistic students included flexibility in exam arrangements, a pass to leave lessons and a designated space to support learning. However, Moyse also acknowledged that these types of accommodations often displaced rather than resolved the underlying reason for discomfort (2021). Further, accumulative experiences of leaving the learning environment generated a lack of belonging and an understanding that absence or avoidance was an acceptable coping strategy (Moyse, 2021). This became problematic when girls were subsequently denied informal, short absences from class, resulting in an overwhelming sense of feeling unable to cope with the environment, leading to difficulties attending school and overall negative wellbeing.

Whilst autistic girls appreciate specialist support (e.g., time out cards, calm spaces etc) provided by schools (Tomlinson et al., (2022), research shows that

this provision is often designed by teachers - based on a broad understanding of special educational need (SEN) or neurodivergent[19] needs, rather than individual needs (Brennan de Vine, 2022).  For example, to help students advocate for their requirements, the use of pupil passports was deemed a useful tool in highlighting the girls' needs but only if teachers read them (Tomlinson et al., 2022). A lack of staff understanding about autistic girls' needs may lead to girls feeling marginalised and poorly connected to their secondary school community.

However, on a positive note, being in a school where staff take time to understand what support is needed can offset the accumulative frustration from missed educational or social experiences, resulting from late diagnosis (Halsall et al., 2021). Attuned relationships with adults also featured in Brennan de Vine's (2022) research in which the girls explained that a 'good pupil-teacher relationship improved their interest in the lesson and motivated them to pay attention and want to do well' (p120).  Appropriate relational support, especially at unstructured times of the school day, was valuable to all three participants in Tomlinson et al., (2022) study. Through the adults' enhanced understanding of how to support autistic students, the participants felt successful in seeking help to problem solve together as well as learning new social skills. According to the UK Government, feeling successful at school is associated with high life satisfaction, which is an important indicator of higher levels of wellbeing in adulthood, (Public Health England, 2014).

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[19] Considered the opposite of neuro-typical, a neurodivergent person has neurological differences that are atypical (Walker, 2021).

School-wide initiatives which supported the girls' wellbeing included staff training that promoted autism awareness amongst adults and peers (Tomlinson et al., 2022). The authors report that broader understanding of the differences between neurodiverse and neurotypical students in school reduced misunderstandings around social interactions and negated the personal conflict experienced by autistic individuals because they felt different to their peers. The link between neurodiversity informed school practices and sense of belonging was also highlighted by Brennan de Vine (2022).

A unique finding of this research was that autistic girls wanted to contribute to the training, to place their views at the heart of new resources (Brennan de Vine, 2022). However, despite attempts by schools to foster greater autism-awareness throughout their body of staff, the lower efficacy of supply staff's support and understanding was acknowledged by all three participants featured in the research by Tomlinson and colleagues, as a reality of staffing in secondary schools (2022). This often resulted in participants experiencing high anxiety from having to justify self-regulatory behaviours to unfamiliar adults (Tomlinson et al., 2022). Overall, feeling supported by well-informed staff and peers who comply with school-wide neurodiverse policies has important ramifications for autistic wellbeing.

### 2.3.5 How can I manage sensory challenges?

#### 2.3.5.1 Regulating sensory overload

A key theme emerging from this literature search is that mainstream school environments are not designed to respond to the girls' sensory needs (Brennan de Vine, 2022; Myles et al., 2019; Tierney et al., 2016). The resulting sensory overload (e.g., textures from uniform, noise and smell from communal areas) had a significant negative impact on the girls' wellbeing (Brennan de Vine, 2022; Tierney et al., 2016). Sensory challenges in the environment often contributed to stress and anxiety. For example, navigating noise and over-crowding in social areas, such as the canteen, corridors or learning environments, was found to be particularly challenging (Tomlinson et al., 2022). Other emotional impacts from sensory differences reported by Tomlinson and colleagues (2022) were intense and overwhelming feelings of distress and anger, often resulting in self-injurious behaviours. According to Ozsivadjian and colleagues, there appears to be little respite from these sensory challenges (2022). A participant in their study described feeling exhausted because she constantly felt over or under-stimulated, with little opportunity to self-regulate.

#### 2.3.5.2 Supporting factors

According to Brennan de Vine (2020), coping strategies described by the girls include removing themselves from the overwhelming sensory space or creating a barrier to processing the sensory information by 'shutting down'. The associated impact on their wellbeing is often missed learning or social experiences, as well as internalised anxiety and exhaustion.

Conversely, in the case studies presented by Tomlinson et al., (2022), the importance of the school environment was flagged as providing respite from sensory challenges. One participant commented that access to an abundance of green spaces in the school environment, as well as designated social and creative spaces for SEN pupils, had a calming effect. Another participant described how petting the school's animals helped regulate her emotions and so improved her wellbeing.

## 2.4  Conclusions

The literature review question invited a critical exploration of existing research into the lived experiences of school wellbeing for autistic adolescent girls and the supporting factors. It should be noted that none of the studies in this literature review focused exclusively on the school wellbeing of autistic adolescent girls – emotional, psychological or social wellbeing was often mentioned as a secondary impact. The lived experiences of autistic girls, as heard through their individual voices, were sometimes difficult to isolate, and this perhaps reflects the general difficulties finding literature representing female autistic voice. A thematic synthesis of the available evidence base highlights that for autistic girls attending mainstream secondary school, there is a myriad of challenges to their wellbeing, ranging from social, environmental, political, relational and those factors related more specifically to their individual experiences of autism (Appendices 1.2-1.4).  The combined developmental, eco-systemic and wellbeing theoretical overlay on the thematic synthesis provided insights into five pillars of understanding around the girls' wellbeing (see figure 2.3 for visual summary).

**Figure 2.3**

*Visual summary of thematic literature review*



Figure 2.3 depicts a circular diagram. The outer ring poses questions in each quadrant: "Where do I belong?", "Who am I really?", "Am I in control?", "How do I navigate the secondary system?", and "How do I manage sensory challenges?". The outer ring contains: Neurodivergent acceptance; Co-production of personalised support; Treated with respect and understanding; Extended social experiences; Adapted activities; Triangulated approach; Sensory safe spaces; Isolation; Attuned adult relationships; Collaborative or group working; Accommodation of individual needs; Value of pupil passport; Whole school autism awareness training; Pupil choice in learning; Owning the agenda; Social clubs. The middle ring contains: Camouflage true self or differences to fit in; Shared interests & activities; Failed friendships; Camouflage social differences; New label; Masking learning differences; Emotional cost; Distorted autonomy; Agency to choose coping strategies; Stress from academic and learning pressures; Views validated and trusted. The inner ring contains: Hidden but needing to be seen; Understanding friends; Social confidence; Regulating sensory overload; Emotional wellbeing and stress; Coping mechanisms.

## 2.4.1 Identity

To fulfil the developmental task of creating a clear sense of identity, it seemed necessary to overcome the often-stigmatising attitudes towards autism in their schools and wider society, in order to reach a state of self-acceptance. Given the environmental and relational transition to secondary school, as well as potential late diagnostic journey, this presents a significant responsibility for adolescent girls to burden. Unspoken in the literature base was the need for schools to re-examine their

wellbeing practice and policies through a neuro-diverse lens in addition to retaining a flexible, intersectional approach to individual needs.

### 2.4.2 Belonging

Another development task explored was establishing a place in society. Social integration to both school and peer communities seemed key to individuals having a sense of belonging but was often compromised when their authentic self and interests were not aligned with others' views and priorities. Masking behaviours met short term integration goals and environmental mastery of social context but with longer term detrimental effects on personal growth and friendship retention. Consistency of positive relations with staff and collaborative approaches with individuals to create inclusive support, environments and opportunities is key but also relies on social interaction and communication skills which some autistic girls find tricky to navigate.

### 2.4.3 Control

To help autistic girls build their independence towards adulthood through experiences of autonomy, the literature base revealed an inherent lack of control over the attitudes and judgements of others. This was flagged alongside a desire to own the neurodivergent agendas in their schools by actively contributing to support and training. However central to these experiences was an invisible thread linking the school as a key facilitator in helping individuals build their confidence and self-advocacy skills as well as providing a culture of acceptance. Absent from the literature was acknowledgment of the importance of re-balancing power relations between

students and staff so that a sense of control and choice could be realised by autistic students.

### 2.4.4  Navigating the system

Evidence cited numerous examples of how the academic and cultural ethos of the school helped or hindered individuals' navigation of the school system.  Beyond the control of individuals were unpredictable and political influences of the environment. This draws attention to the importance of considering wider eco-systemic influences on individual wellbeing. However, this was also reliant on whole school approaches that emphasized neuro-affirming and holistic development of wellbeing support.

### 2.4.5  Sensory environment

The final wellbeing challenge was mastery of the sensory environment, again mostly requiring individual responsibility to find alternative comfortable and safe spaces in which to regulate. Not discussed in the literature was the responsibility of the school in creating neuro-affirming sensory spaces to support social inclusion, regulatory states or the architectural challenges of newly-built schools designed for capacity and efficiency rather than students feeling safe and comfortable. Also absent was comment around the flexibility of student choice in policies related to engagement, attendance and behaviour which may well restrict an individuals' capacity to find alternative sensory spaces.

### 2.4.6  School support

Woven throughout the studies was the need for consistent, attuned adults who could work collaboratively with individuals to help them understand and advocate for their needs.  However, beyond this relational support, many other supporting factors rely on responsive neuro-affirming systems, culture and ethos in the school system.

## 2.5  Rationale for current research

The current literature search generated an overview of how adolescent autistic girls may experience wellbeing at school and identifies some supporting factors. Together these findings highlight the significant differences within challenges to wellbeing faced by autistic girls during secondary school. However, the evidence base is limited and even within this literature search, the direct views of female participants were difficult to extract from triangulated data collection methods. This makes it difficult for school leaders to truly understand how autistic girls construct wellbeing and what constitutes effective support. This research aims to extend existing knowledge by explicitly exploring and promoting individual views from autistic girls about their lived experiences of school wellbeing, in recognition of the universally recognised heterogeneity within autism (Masi, et al., 2017).

Autistic girls will be invited to work in a research partnership; harnessing their agency and autonomy to co-construct an understanding of what 'wellbeing' means to them and the school factors they find most supportive. By using participatory approaches, this study also hopes to build further awareness of how to effectively collaboratively with the autistic community '*to ensure that the research is translational'* and relevant

(Pellicano & den Houting, 2022, p390). This study will also generate real world, contextual implications for improving the inclusivity of school wellbeing for autistic young people (Horgan et al., 2023). The research question and aims of the study will be finalised with the participants.

*It's important that the girls can identify how they feel and what they want, so that they can begin self-advocating. We don't believe in suffering in silence at Limpsfield Grange. If the girls can ask for the support and guidance that they need, then it is the responsibility of the neurotypical world to provide it, so that they can be the best brilliant versions of themselves.*

Wild (2019)

## 3.1 Overview

This chapter details the research methodology, beginning with the study's orientation and underpinning epistemological position. Following this, the research design and methodology are described, including the procedures to recruit participants. The participatory approach used to generate the research design, data collection and analysis methods is explained. The chapter concludes by exploring the reflexibility and trustworthiness of the research, including ethical considerations and implications for working effectively and safely with vulnerable young people and within the autistic community.

## 3.2 Methodological orientation

The concept of a 'research paradigm' is often accredited to Kuhn (1962) and encapsulates 'a loose collection of logically related assumptions, concepts or propositions that orient thinking and research' (Bogdan & Biklin, 1998, p.22). The designated paradigm to a piece of research describes the motivation, focus and

expectation of the study's design, according to Mackenzie & Knipe (2006). In plain terms, the research paradigm provides a lens to help the researcher make sense of the world they are exploring. In line with post-modernist views that the 'truth' may often serve particular local, cultural or political struggles, research that incorporates this lens moves away from an epistemological belief that there is one fundamental truth about reality towards an ontological understanding about the complexity of the world (Smith et al., 2009).

### 3.2.1  Embracing the alignment of EPs' research and practice ethics

As applied practitioners of psychology, in an increasingly complex and ambiguous moral, social and political landscape, EPs recognise and respond to the ontological and epistemological differences revealed within their stakeholder relationships. According to Moore (2007), this balances practice between active challenge that promotes change versus a restorative or therapeutic stance. Arguably as researchers. EPs can adopt both roles.

When applying this post-modernist focus, it is important that EP researchers consider their own intellectual, emotional and moral relationship with the power, cultural complexity and social justice that may be implicitly and explicitly embedded within the phenomenon they are researching (Mertens, 2007). Consequently, EPs harness their reflexive practice within working partnerships to acknowledge and legitimise different ways of understanding, when researching within diverse and marginalised communities.

### 3.2.2   Exploring a transformative paradigm

As Hurtado (2022) explains, to resolve enduring inequity, to retrieve voices from marginalised communities and defy enduring bias, innovative and collective ways of defining new standards of research are required. Independent of the prevailing constructionist or realist ontological positions represented through other research paradigms, the transformative paradigm creates a framework with marginalised communities that challenges contemporary societal understanding and addresses issues of social injustice (Mertens, 2007).  This research aims to take an exploratory and emancipatory approach to creating social justice outcomes related to the school wellbeing of adolescent autistic girls. The theoretical and practical implications for the transformative paradigm are now explained.

#### 3.2.2.1   Ontology

A researcher's ontological position describes their beliefs about the nature of being and existence (Crotty, 2020). A transformative researcher is aware of the societal values and privileges that determine the reality affecting the most social transformation (Mertens, 2007). By embracing and valuing the lived experiences of members of the autistic community, this research situated the participants' perspectives on wellbeing within their school system, in line with the environmental principles underpinning the social model of disability (Oliver, 2013). It is hoped that societal transformation will occur when secondary schools critically review their wellbeing intervention ethos and practice using this new and inclusive conceptualisation of female autistic school wellbeing.

### 3.2.2.2 Epistemology

Epistemology explains how new knowledge about a phenomenon is socially constructed (Tuli, 2010). In the transformative paradigm, researchers value and contextualise the trust, culture and power differences inherent in the interactions between researchers and participants. By using the culturally informed transformative paradigm in their research and combining this with their consultation skills, psychological knowledge and professional experience of the secondary education system, EPs are uniquely placed to intentionally challenge the inequalities in schools' wellbeing provision. As outlined in the professional competency framework (Health and Care Professions Council, 2018), EPs are skilled in respecting a participant's active agency despite prevailing cultural, social or economic adversities.

Therefore, a key epistemological goal of this research was establishing partnerships that empower the voices of autistic adolescent girls to transform the current neuro-typical, social construction of autistic wellbeing. This goal also aligns with the conceptual framework of the neurodiversity movement[20] (den Houting, 2019) which celebrates the individuality and heterogeneity of neurological differences.

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[20] This is a social justice movement that advocates for equality, respect, civil rights and inclusion for neurodivergent individuals (Walker, 2021).

### 3.2.2.3 Methodology

Research methods used within a transformative paradigm must flexibly accommodate cultural complexity, power and discriminatory issues experienced by the community involved in the study (Mertens, 2007). This project consciously embraced the benefits of and ways to work effectively with young members of the autistic community, ultimately connecting the research to social action. Throughout the research process, methodological consideration was given to maximising the participation of the autistic community by continuously reviewing and adapting the design, data collection and analysis and dissemination to meet their needs. The reflexive practice of this researcher in maintaining an awareness of the cultural values of the autistic, female population in this study is monitored throughout.

### 3.2.2.4 Axiology

Derived from the Greek meaning for the study of what is valuable and meaningful, it is important that a researcher considers how their own values could impact the aims and methods of a study (Killam, 2013). Therefore, the assumptions around axiology within the transformative paradigm focus on the ethical considerations of social justice-based research within culturally complex communities (Mertens, 2007). This researcher's values are beneficence, respect and justice. In line with rights-based theories, the transformative researcher must also seek to recompense inequalities by forefronting the voices of disadvantaged groups and empowering them to be actively involved in social change (Mertens, 2007). As every participant in this

research has the right to be treated with dignity and respect, the cultural norms of interacting and researching with the young autistic community are rigorously explored throughout. The avoidance of harm will be a guiding principle throughout the research process, especially considering the emotive topic of wellbeing being investigated. Finally, social justice will be promoted through explicit ethical connectivity between the research process and desired outcomes of improving school wellbeing practice.

### 3.2.3   Practical considerations within the transformative paradigm

To maximise social change through transformative research, it is recommended that mixed methods data gathering, and a cyclical programme of decision making are utilised (Mertens, 2007). A mix of data sources, such as insights in qualitative dialogue and quantitative assessments (e.g., demographic, attendance, attainment or ability assessments), help underpin the reality of the lived experiences of a culturally complex community, according to Mertens (2007).

However, given the scarcity of adapted wellbeing measures and the paucity of research into autistic wellbeing for this specific population of adolescent girls, quantitative data beyond participant demographics would not add significant value in developing an actionable understanding of wellbeing experiences at school. It was useful to hold the 'action agenda' described by Creswell (2003, p.9) in mind during the initial stages of gaining ethical approval to ensure that the proposed methodology and timeframe adequately supported educational change.

## 3.3  Research purpose

### 3.3.1  Transformative aims

Regardless of calls for enhanced research engagement with the autistic community (Lai & Mandy, 2017; Pellicano, Dinsmore & Charman, 2014), the evidence base indicates that participatory autism research is rarely explored (Jivraj et al., 2014). Abiding by the principles of the transformative research paradigm previously described, a key tenet of this research process was developing trusted relationships with participants - autistic girls who are attending mainstream secondary school. It was hoped that combining their 'experience-based expertise' (Collins & Evans, 2002) with this researcher's 'methodological expertise' would generate a research process that would be beneficial for them and their schools, be scientifically sound (Cargo & Mercer, 2008) and achieve the social justice goal of liberating the voices within this vulnerable community.

In addition to the emancipatory aims of this transformative research, the study also adopted an exploratory design. For the research to be meaningful it needed to move beyond tokenistic delivery and became congruent with autistic girls' values (Fletcher-Watson et al., 2019). Therefore, it felt critical that autistic participants should lead the research process of co-constructing new knowledge about their wellbeing experiences, without being constrained by prior hypotheses.  Consequently, the exploratory function of this research was the inductive, individual and collective understanding of participants' perceptions about their school wellbeing. It is hoped that the outcome of these emancipatory and exploratory aims will inspire schools to co-develop effective wellbeing practices for autistic girls.

### 3.3.2 Qualitative mean making

To fulfil the transformative aims of this study and honour the research goals of the autistic community, a qualitative methodology was selected because it enables the systematic collection, organisation and interpretation of verbal, visual and textual data (Flick, 2007) and is therefore appropriate for exploring the meaning and perspectives within individuals' lived experiences (Hammarberg et al., 2016).

A range of different qualitative methodologies have been used successfully with autistic young girls to forefront their views on wellbeing. For example, semi-structured interviews (Brennan De Vine, 2022; Cook et al., 2018; Halsall et al., 2021; Moyse, 2021; Myles et al., 2019; Tierney et al., 2016; Tomlinson, et al., 2022); focus groups (C. Ryan et al., 2021) and self-report questionnaires (Dillon et al., 2016; Ozsivadjian et al., 2022). It is hoped that this research study will add to the knowledge base of effective qualitative methodology used with autistic young people.

### 3.3.3 Participatory knowledge-production

Participatory research, which broadly speaking means working together with community members to make decisions about all stages of the research process, is still relatively rare in autism research (den Houting et al., 2021). Yet involving autistic young people in the research process has already been reported to increase the potential for provision to be adapted to meet their strengths and needs (Bolic Baric et al., 2016; Crane et al., 2019) and provide potential to transform the experiences of autistic pupils (Fletcher-Watson et al., 2019).

The theoretical underpinnings for the participatory approach used in this study were rooted in child-centered scholarship (Kehily, 2009) which views young people as meaning makers, social actors and rights-bearing citizens (Woodhead, 2009). Working in this way embraces paradigmatic shifts towards child-centered practice and the acknowledgment of children's rights to social inclusion and agency (James, 2007). However, a recent systematic review by Fayette and Bond (2018) criticised methods of eliciting autistic young people's views as research that was 'conducted to and not with participants' (p.359).

There is no agreement amongst scholars as to the benefits for young research participants on the rebalancing of perceived power differentials related to privileging their voice (Gallacher & Gallagher, 2008). Traditional models of community participation (e.g., Arnstein, 1969) focus on the hierarchy of power and control which can be passed between academic researchers and community participants, and in the case of adults working with child co-researchers would focus on the correct positioning of the adult to rebalance generational and agentic power (Skelton, 2013). This fails to consider the 'multiple layers and influences behind an authentic voice', according to E. Davidson, (2017, p. 230). For example, critiques of childhood studies research point to young people's rights to <u>not</u> participate and considers the marginalisation of groups of children and young people whose agency is impacted by their real and perceived independence and autonomy (L. C. Hill, 2012; Plows, 2012).

Equally, the authenticity of a child's response may be influenced by their perception of the social processes used to gain their view (Komulainen, 2007) as well as autistic

children's tendency to think there may only be one right answer to questions researchers ask (Winstone et al., 2014).

It was hoped that this research study enabled autistic girls to co-develop a research design that empowered their experiences of school wellbeing to advocate for the support they most desire, in ways they felt most comfortable to do so. A secondary participatory aim of this research was to add to the knowledge base of effective participatory research methodology with autistic young people.

### 3.3.4 Aligning with own values

Finally, this researcher's own values and contribution to the research purpose were considered. The transformative methodology focuses on empowering the voices of a marginalised community to promote meaningful social change (Mertens, 2007). This paradigm closely aligns with the researcher's personal and professional values of respect, beneficence and social justice.

Respecting the cultural norms of communication within a community is critical when collaborating on research projects and has been considered throughout this study. Empowering the views of autistic girls on their experiences of school wellbeing necessitated a high degree of effective community participation which closely aligned with the researcher's professional experiences of fostering and maintaining young peoples' trust and co-operation.  Forefronting young people's views through person-centered practice is a core principle within EP practice, reinforcing the legal and human

rights of children to 'have their views heard on matters concerning them', (UNICEF, 2023). Alongside this, promoting active participation to collaboratively generate outcomes, is another key pillar of EP work, as outlined in the Special Educational Needs and Disability Code of Practice (Department for Education & Department of Health and Social Care, 2014).

In terms of beneficence, which is concerned with the promotion of human rights and social justice, the researcher has  professional experiences of critically challenging school wellbeing support which can be founded in a societal and systemic understanding of non-autistic pupil needs. Harnessing EP skills (e.g., attunement and anti-oppressive practice) to sensitively promote alternative views that can undoubtedly challenge dominant neuro-typical norms is an increasing aspect of daily practice. The fact that these conversations are happening in schools is hopeful and indicative of a wider societal awakening to understanding the neurodiverse paradigm.

A social justice agenda can only be achieved with the oversight of the community in the end goal. Continuous reflexivity ensured that explicit connections were made between the research process, the researcher's personal values, bias, language and interpretation of meaning and the community's intended outcomes of the study. Consequently, to reduce mutual misunderstanding, described in Milton's double empathy problem (2012), a co-designed research process that embraced intersubjectivity was essential – so that a bi-directional approach to new perspectives on autistic wellbeing was considered. Essentially this meant that not only was participatory sense-making informed and co-created by interactions between all

researchers (De Jaegher & De Paolo, 2007) but the interactions between co-researchers throughout the research process were also recognised as an influencing and transformative power, as per De Jaegher (2015).

## 3.4 Research design

This section describes how the research was conducted, including participant recruitment, rationale for chosen methods and facilitation of the participatory co-research process. Data collection and analysis methods are also detailed.

### 3.4.1 Recruitment and participants

#### 3.4.1.1 Sampling

To achieve this study's transformative goal of creating new knowledge it was important that all participants belonged to the same community. As previously discussed, data shows that it is within their secondary education that many girls with autism receive a diagnosis and may experience associated mental health difficulties, resulting in high levels of school non-attendance (O'Hagan et al., 2022; Russell et al., 2021). As this study seeks to identify the wellbeing constructs and supporting factors for wellbeing, participants will be aged 12-15 years, encompassing Years 7-9, leading up to the end of Year 10. Further inclusion and exclusion parameters for selection, participation and withdrawal are outlined in Table 3.1. Participation in the study was voluntary. The sample size achieved for this research was 15 young people.

**Table 3.1**

*Inclusion and exclusion criteria for the research sample*

| Must… | Must not… |
|---|---|
| Have a primary diagnosis of autism | Have a different primary diagnosis (even if this is a neurodivergent diagnosis). Parental judgement is acceptable. Experience to date suggests that the manifestation of features of other diagnosis could be quite different. |
| Be aged between 12-15 years old | |
| Identify as female at birth. | |
| Be on roll at a mainstream secondary school in England. This can be within a resource base attached to a mainstream school as long as the student is also accessing a proportion of their lessons within the mainstream classroom. | Be accessing their education solely within a specialist setting such as a resource base or specialist school, or from home or another setting. |
| Have sufficiently good wellbeing or positive mental health to be happy to engage in the study topic of wellbeing (as assessed by the pupils themselves and their parents/carers) | Must not be at obvious risk of being adversely affected by inclusion in the study either as a co-researcher or data participant, and engagement with the study topic of wellbeing (as assessed by the pupils themselves of their parents/carers). |
| Be willing and happy to participate in the study, sharing their views either individually (as data participants) or in a group forum (as co-researchers), through any means of appropriate communication they wish. | |
| Be capable of understanding and following the study rules on confidentiality and not sharing experiences of participating in the research study with those not involved. | Not having Gillick competency. |

### 3.4.1.2 Recruitment process

An initial driver for this research study was to inform the school practice of secondary settings in the local authority in which this researcher is on placement. In April 2023, a recruitment poster was emailed to nominated Inclusion Managers and Special Educational Needs Co-ordinators within link secondary schools of colleagues in the Educational Psychology Service (Appendix 2.6 for recruitment flyer).

Despite initial enthusiastic support for the research project from these school staff, the on-flow of recruitment communication to parents and young people was slow, resulting in only two parents and participants signing consent forms. Ethical approval was granted for sampling methods to be purposive, voluntary and snowballing, across a range of referral pathways. Subsequently, a broader recruitment process was initiated, fully utilising colleagues within the SEN and Educational Psychology professions and harnessing the power of relevant social media platforms. Parents were asked to email the researcher directly so that information sheets could be shared with interested families. Further details of informed consent in Section 3.8.1.1.

In line with research guidance (British Psychological Society, 2010), participants were reminded of the availability of this researcher for follow-up conversations about their participation to ensure ongoing consent. A visual account of the recruitment process can be found in Figure 3.1.

**Figure 3.1**

*Visual flowchart of recruitment process*



Recruitment gateways:

Referrals from EP colleagues in local authority services

SENCO at local schools

Expressions of interest from Twitter/EPNet

Referrals from other local authority professionals (e.g., Autism Advisors)

Recruitment material:

EP referral N=5

Schools N=2

Other referral N=4

Social media N=4

Volunteers from sampling N=15

Discontinued interest N= 3 (after reading Information Sheets)

Discontinued interest N= 2 (after initial selection via telephone call)

Participants and parents signing consent and data forms N=10

Rejected by Researcher N=2 (didn't meet inclusion criteria – ADHD diagnosis)

Active co-researchers N=7 (attending workshops and interviews)

Non-active co-researchers N=1 (not able to attend due to social anxiety)

### 3.4.1.3  Participants

Interpretative phenomenological analysis was the chosen data analysis method for this research and guided the ideal sample base. Smith et al., (2022) recommend that because participants 'represent a perspective rather than a population' (p 43) and inductive analytical methods are used to explore phenomena, smaller sample sizes of between 6-10 participants are expected for professional doctorate research projects. Papers located within this study's literature search had a small participant base of between 3-18 participants.

Within this study, a total of eight participants were recruited, all of which shared an ethnicity of White British. Characteristics and break down of roles of the seven active participants are shown in Table 3.2. Flexibility was maintained throughout the research process to enable participants to select whichever roles they felt most comfortable with.

Whilst a comprehensive neurodevelopmental profile was not requested, many participants had been diagnosed within the previous five years and two shared co-occurring learning or communication differences related to social anxiety. Parents also qualified whether their daughters had sufficiently stable wellbeing to engage in the study and ongoing wellbeing was confirmed by participants at the end of each contact point in the research. Other accessibility factors included checking whether the girls understood and could follow the study's rules on confidentiality and had digital access.  All the participants attended mainstream secondary schools in England, with three also partially accessing

an attached autism base[21] for specialist intervention support.    Participants were invited to create a research identity including a pseudonym to protect their identity and they also shared their preferred autistic identify (Table 3.2).

**Table 3.2**

*Characteristics of active participants*

| Research identity *and role* | Age | Diagnostic profile | Preferred autistic identity | School setting |
|---|---|---|---|---|
| Hermione *Co-researcher & data participant* | 13 yrs | *Autism diagnosis:* 2020 <br><br> *No needs:* | I am autistic | Mainstream secondary school with an autism base |
| Lizzy *Co-researcher & data participant* | 14 yrs | *Autism diagnosis:* 2012 <br><br> *No needs:* | I am autistic | Mainstream secondary |
| Ivy *Co-researcher & data participant* | 14 yrs | *Autism diagnosis:* 2018 <br><br> *Related learning or communication needs:* Anxiety & Dyspraxia | I am autistic | Mainstream secondary |
| Katniss *Co-researcher & data participant* | 12 yrs | *Autism diagnosis:* 2022 <br><br> *No needs:* | I am autistic | Mainstream secondary |
| Ron *Data participant* | 15 yrs | *Autism diagnosis:* 2023 <br><br> *No needs:* | I have autism | Mainstream secondary school with an autism base |
| "E" *Co-researcher* | 15 yrs | *Autism diagnosis:* 2018 <br><br> *Related learning or communication needs:* Social anxiety | I am autistic | Mainstream secondary |
| "M" *Co-researcher* | 12 yrs | *Autism diagnosis:* 2023 <br><br> *No needs:* | Unknown | Mainstream secondary with an autism base |

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[21] To provide equitable opportunity for any autistic girl that attends a mainstream secondary school to participate in this research, schools with autism resource bases were included in this study. The Department for Education (2019) reports that 640 secondary mainstream schools have autism bases in England.

### 3.4.2 Co-constructing the research design

Participatory research processes that democratise knowledge production are dependent on the social relationships between the lead researcher(s) and participants, how research methods are practised and the personalised and adapted responses to each individual's capacity (E. Davidson, 2017). In effect, participatory research is based on a 'social contract', according to Groundwater-Smith et al., (2015, p21).

Additionally, in research with autistic girls there are multiple layers of intersecting power differentials to unpick, related to belonging to a 'twice excluded' and therefore highly marginalised group (Shefcyk, 2015, p132). Gaventa & Cornwall (2008) advocate that good quality participatory research should expose, rather than ameliorate, inequalities and invite reflexivity so that researchers can bring about social change and emancipation.

Groundwater-Smith et al., (2015) discuss how tokenistic forms of engagement with young people (e.g., scoping their interests at the beginning or measuring their reaction to research findings) can be avoided using a holistic framework covering all elements of the research process, whilst incorporating principles of working together, knowledge production and ethics. Their tool was used as a planning aid and as an 'in-action' reflective framework throughout this project (Figure 3.2).

**Figure 3.2**

*Map of participatory options across the research process* (Visual representation of information from Groundwater-Smith et al., 2015 to be participant friendly)

| Type of participation | Consultee | Collaborator | Owner |
|---|---|---|---|
| **Research design, development and planning** | Adults seek perspectives from young people and may reflect on these during decision making. | Young people have opportunities to be involved in and influence adult-led research decisions and outcomes. | Adults facilitate the development of young people's research skills, enable them to identify research topics and support them to undertake the research. |
| **Timing of participation** | Consultation at key decision points. | Throughout the research. | From the beginning to end. |
| **Generating the data** | Young people provide advice on data generation (how information is generated, who participates and when). | Data is co-produced by young people and adults. This means data collection methods are designed together. | Young people determine what data is generated, how, when and by whom. |
| **Analysing the data** | Adults may provide advice about data analysis and interpretation. | Adults and young people collaborate on data analysis. | Young people guide data analysis. |
| **Reporting and sharing** | Young people may be consulted about the final report or plans to share it. | Young people may be involved in planning strategies for reporting and sharing the results of the research and for creating the final report. | Young people are considered to be the owners of the research and take the lead in reporting and sharing it. |

Researchers investigating issues related to autistic young people's experiences have previously sited that barriers to participation in verbal methods (such as interviews) include:

- Individuals being unable to retain attention on the topic being discussed

- Difficulties remembering their past experiences or talking about their emotions

- Delays or short answers when responding to open-ended questions

(Harrington et al., 2014; Preece & Jordan, 2010).

To address this, Williams and colleagues (2020) recommended adjusting questioning techniques to meet the needs of autistic participants by removing potential bias inherent in closed (e.g., 'yes/no') or leading questions. There is growing recognition that it is the researcher's responsibility to find a way to enable autistic children to participate and share their views using methods that are appropriate for their maturity, ability and age (Cunningham, 2022) and so remove barriers to meaningful engagement around exploring their social worlds. Analysis of the evidence from the autistic research base on eliciting the views of autistic young people inspired the planned adaptations for this research study (Appendix 2.5). The participatory approaches used in this study are now discussed.

### 3.4.2.1 Co-researcher workshops

Part of the social contract of working with children as co-researchers (Groundwater-Smith et al., 2015), is creating accessible spaces that meet logistical demands within the busy lives of young people. As participants in this

study were geographically situated across England, an online research forum was the most accessible and inclusive setting for participation. In consultation with families, workshop sessions were arranged for Sunday evenings between 6-7pm.

Working with autistic young people during the Covid-19 pandemic, when many pupils were learning remotely, has undoubtedly extended researchers' understanding of the flexibility and accessibility of using virtual online meeting spaces (Newman et al., 2021). For example, in their study which engaged autistic adolescents in direct participatory research via an online forum, Vine Foggo et al., (2020) concluded that one of the benefits of the virtual environment was it reduced the anxiety that in-person meetings might create. This study utilised the Microsoft Teams platform for all interactions with co-researchers. Adult supervision was required to facilitate technical set-up and monitor wellbeing.

As recommended by Nicolaidis et al. (2015), factors supporting a consistent approach to meeting others online were evaluated. The following arrangements were made:

- Consistent format was used for every online workshop
- Predictability of the online sessions was created via a flyer detailing the purpose of the session which was emailed a week before to co-

researchers' parents. See Appendix 2.7 for examples of pre-session materials.

- Consistency of the online space was ensured by using the same visual backdrop for the researcher's screen display throughout
- Familiar format of welcome, check-in, reminder of the rules, recap of session purpose and check-out were followed each time.

To help create an environment of emotional and psychological safety, ground rules to promote positive engagement and behaviour were democratically agreed in the first workshop session by co-researchers (Hennessey et al., 2022). Emotional check-ins at the beginning and end of each workshop ensured co-researchers had opportunities to discuss their wellbeing throughout the study

In total, seven co-researcher workshops were scheduled between July and December 2023. Each workshop lasted 60 minutes and was recorded to aid reflective practice. Co-researchers were invited to attend via email, sent to their parent's nominated addresses. Participation varied each time with between 1-5 co-researchers attending. Figure 3.3 illustrates the timeline, purpose, outcome and attendance of each workshop. An additional two workshops were arranged for training the co-analyst in the data analysis methods.

**Figure 3.3**

*Programme of co-researcher workshops*
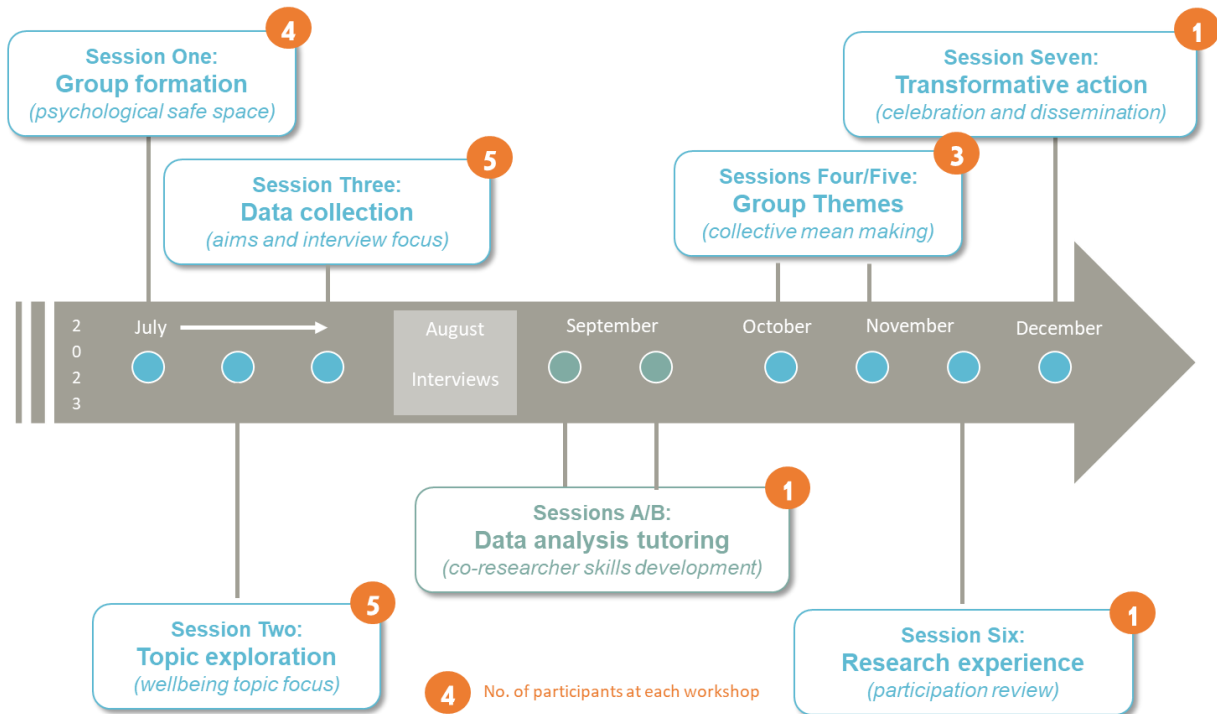


### 3.4.2.2 Co-planning 'in-action'

In addition to the participatory framework and planned adaptations identified from the literature base, further co-planning initiatives were taken throughout the research design stage. Sequential outputs further influenced the research design (Figure 3.4). This researcher's reflexive diary was also an invaluable tool for recording and analysing which adaptations worked well for the girls (Appendix 3.2).

**Figure 3.4**

*Influencing outputs from co-researcher workshops*

Session plan -------------------- Outputs    (C) Co-researcher-led
                                            (R) Researcher-led

**Session One:**
**Group formation**
*(psychological safe space)*

- Ground rules and hopes for participation (C)
- Early exploration of wellbeing experiences (R)
- Review of accessibility – chat function, emoticons, slower pace, helpful questioning (R)

**Session Two:**
**Topic exploration**
*(wellbeing focus + aims)*

- Contextualised understanding of school wellbeing experiences – good/bad (R)
- List of potential school wellbeing issues to explore + aims (C)

**Session Three:**
**Data collection**
*(interview schedule + prompts)*

- Scaling and language of primary research questions (C)
- Flexible range of interview prompts (R)
- Represent key words associated with good/bad wellbeing in a Word Cloud (C)

### 3.4.2.3  Agreeing aims of research and research question

During Session 3 the aims of the research were discussed (Appendix 2.8). Previously, co-researchers had listed all the areas of wellbeing that they were individually interested in (Appendix 2.8).  The group agreed to retain a broad exploratory lens rather than choose a specific topic area so that their individual interests could be honoured.

As the research question was not explicitly discussed with the co-researchers (due to spending more time spent thinking about their hopes and aims for the research), this researcher suggested (in consultation with Research Tutor during supervision) that the overarching research question should be:

**What are the lived experiences of adolescent autistic girls' wellbeing at school and what factors support this?**

### 3.4.3  Valuing participation

To demonstrate the value of the participatory processing (Hennessey et al., 2022) and fulfil ethical requirements of the research process, a debrief sheet was emailed to all participants, a certificate of participation (Appendix 2.7) and the Visual Communication Brief were sent to all participants, after the final workshop session,

## 3.5  Research resources

### 3.5.1. Creative resources

According to Clark (2010), person-centered research methods aim to match the interests and communication needs of young people engaged in participatory research. Creative methodologies such as writing, photography, drawing and games help autistic children organise reflective discussion (Warren et al., 2021) and engage in research (Scott-Barrett et al., 2022), so their views can be meaningfully elicited. For example,  Goodall & MacKenzie used a flexible qualitative approach including visual and practical activities within semi-structured interviews to support autistic girls in their

reflections of experiences in mainstream school (2019). Cunningham's (2022) research asked primary school pupils to explore their perceptions of school using the 'Three Houses' drawing technique during individual or group interviews. Photo elicitation has also successfully stimulated discussion about autistic individuals' school experiences (Danker et al., 2019; L. Hill, 2014). Photo elicitation was modelled in Workshop One when broadly exploring the phenomena of wellbeing - co-researchers were asked to find and talk about a photo from their phone's camera roll that represented their wellbeing.

Following on from this, a key feature of Workshops Two and Three was a discussion of different data collection tools with the co-researchers, with the aim of presenting opportunities for different visual prompts to accompany their reflections during interview. During these discussions, co-researchers also agreed they wanted to share their experiences of wellbeing on an individual basis, rather than via a focus group.

### 3.5.2. Language as a resource

One critique of autism research is that it holds the potential to exacerbate stereotypes about the autistic community (Gernsbacher, 2007) because of the ableist language used to objectify (Botha, 2022), stigmatise (Bottema-Beutel et al., 2020) or 'other' participants and their views (Botha & Cage, 2022).

To ensure that the language used throughout the research materials was accessible and appropriate for the autism community, co-researchers were invited to create and

review written resources. This included the questions used in the semi-structured interview schedule, summaries of individual case studies as well as dissemination resources (see examples in the Appendices – 2.7, 2.11 and Visual Community Brief).

### 3.5.3. Interview schedule

During workshop three, co-researchers were invited to consider what questions they would like to ask interviewees. Having already considered what a good and bad day at school for wellbeing felt like, during workshop two, the co-researcher team held a brainstorm to consider different interview questions, to explore whether the language was accessible and meaningful and subsequently creating a semi-structured interview guide. It was agreed that it would be useful to email the interview questions to interviewees in advance (Appendix 2.7).

### 3.6  Data collection

The data collection process began in August 2023. After obtaining written consent from parents or carers and the participants, the researcher arranged interview times with parents and emailed an MS Teams link and joining instructions, and a copy of the interview schedule (Appendix 2.7). Interviewees were invited to email any visual prompts that had aided their reflective process. Two participants offered visual prompts which included paintings and a mind-map.

At the beginning of the virtual interview, the researcher reviewed with the participant key features within the information sheet and their right to withdraw. Participants were

asked for their preferences in terms of muting the video function and whether they would like a parent or carer to attend. Two participants requested adult attendance. The researcher reminded parents that only the young persons' views would be accounted for. Only one participant was new to the research study (i.e., wasn't a co-researcher) so to create a welcoming environment for this young person, the researcher spent time building rapport by asking about their interests and answering any questions about the interview.

The purpose of the qualitative approach was to collect 'thick-descriptive research data'. In effect, the in-depth interview process is a constantly evolving, interactional process in which initial questions can be modified depending on the interviewee's responses, according to Smith et al., (2009) - like having a 'conversation with a purpose' (p57). During the interview process, the researcher used an interview schedule (Appendix 2.9) as a prompt but also included exploratory questions to deepen discussion and remain curious about how the young person was constructing their lived experiences of wellbeing.

The five interviews, which lasted an average of 77 minutes were recorded, then later transcribed, using MS Word (Appendix 2.10 for an example transcription). At the end of the interviews, the researcher thanked the participants for their time and views, answered any outstanding questions and described the debrief process. The debrief process entailed a follow-up phone call to parents to check on the participant's wellbeing, emailing of the debrief sheet to parents as well as explaining the next steps

in the research process (e.g., transcribing of recorded material, analysis and written summary of analysis process for member checking).

## 3.7 Data analysis

Interpretative Phenomenological Analysis (IPA) was the qualitative analysis approach used to explore autistic girls' experiences of school wellbeing in this study. Under the transformative paradigm, the need to emancipate participants' voices is fulfilled with an IPA approach because the method creates detailed analysis of the innermost deliberations of the lived experiences of participants (Alase, 2017), before generating a collective meaning to their subjective experiences of a particular phenomenon (Smith et al., 2022). The inductive nature of the individual case study approach used in IPA serves to validate and celebrate the heterogeneity of ability and experience commonly found in the autistic community (Georgiades et al., 2013).

The pre-selection of IPA methodology by the researcher was useful so that a thorough understanding of 'what the research job is' (p39) could be established early on and thus influence preliminary thinking about data collection methods (Smith et al., 2022).

### 3.7.1. IPA procedures

As this was the researcher's first-time using IPA methodology, and although there is no correct way to conduct IPA analysis, the stages suggested by Smith et al., (2009) for novice researchers were closely adhered to. To maximise focus on 'sustained engagement with the text and the process of interpretation' (Smith, 2009,

p66), data analysis was completed across a 5-week period in the school summer holidays where distractions from university and placement could be minimised.

Figure 3.5. provides a visual representation of the data collection and analysis procedures used in this study.

### 3.7.1.1 Participatory data analysis

Co-production approaches to analysing data help reduce inequities and misrepresentations when members of a research team do not belong to the same community or where there are power or privilege differentials in relationships (e.g., professional adults working with young people), according to Williams et al., (2020). It has been argued that the autistic advantages of hyperfocus, autistic 'flow' and creative thinking are assets to a research team, enabling attention to detail and concentration during short timescales and when searching for connecting patterns of data (Grant & Kara, 2021). In this project, one autistic participant kindly provided 60 hours of time to co-analyse the data, during the school summer holidays.

*Visual representation of data collection and data analysis process*
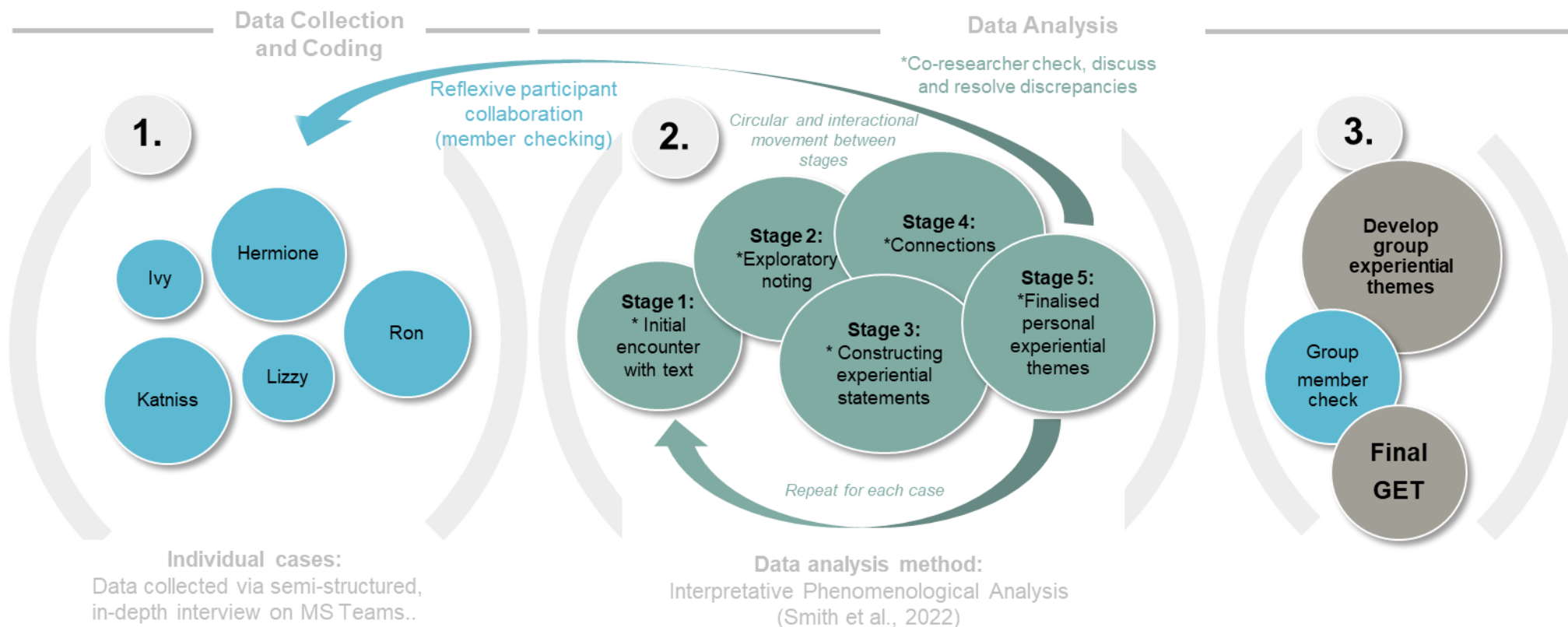
Following a 2-hr tutoring on the IPA process, using Figures 3.5 and 3.11 to explain the process, a step-by-step co-analysis of all stages for case study 1 was completed to identify both surface and latent-level features of the data. The remaining four case studies were also co-analysed, with differences of opinion discussed and resolved. Inter-coder reliability is usually used within qualitative research studies to agree a coding frame which can then be applied across data sets (O'Connor & Joffe, 2020). However, within IPA methodology, each case study represents a unique data set and given the project's time constraints and brevity of training provided to the autistic co-analyst, informal comparisons of code patterns across each interview were deemed appropriate for this study.

A brief explanation for each phase of the data analysis follows. See Smith et al., (2022) for more detailed descriptors of this technique.

### 3.7.1.2 Stage 1 – Initial encounter with text

To become fully immersed in the data and actively engage with the interviewee's experiences (Smith et al, 2022), the transcribed recordings of interviews were read 2-3 times whilst watching the video recording. Feelings evoked whilst re-reading were recorded in the research diary and considered within post-encounter analysis (Table 3.4 and section 3.7.2.3).

### 3.7.1.3 Stage 2 – Exploratory noting

Holding in mind the importance of describing what matters to the interviewee (e.g., places, people or events), the meaning of these for the interviewee (e.g., what these are like), and initial interpretation (e.g., how and why) was helpful when making exploratory notes (Appendix 2.10 for example extracts). A colour code system was used to delineate these different phenomenological foci. A second complete read through and cross reference to the researcher's significant statements (section 3.7.2.1) identified potential interpretative bias.

### 3.7.1.4 Stage 3 – Constructing experiential statements

In reducing the data set from the transcript and exploratory notes, this stage focused on identifying the most prominent aspects of the exploratory notes and consolidating these into experiential statements (Smith et al., 2022). It was important to maintain the connection between relevant quotations from the interviewee and the resulting experiential statement. These were organised in a table (Appendix 2.10 for an extract).

### 3.7.1.5 Stage 4 – Searching for connections

Emerging themes in an individual's data set were presented individually on a large surface area. First level coding created a chronological order for experiential statements, as they emerged during Stage 3 (Figure 3.6 (a) for a coding map).

Second level coding involved mapping the experiential statements into contextually related, categorical clusters of subordinate themes to enable the analysts to make meaningful connections (Figure 3.6 (b) for thematic coding). Using the abstraction technique described by Smith et al., a higher order superordinate theme was then attributed to each cluster (2009) - see blue post-it notes.

**Figure 3.6 (a**)

*First level coding*
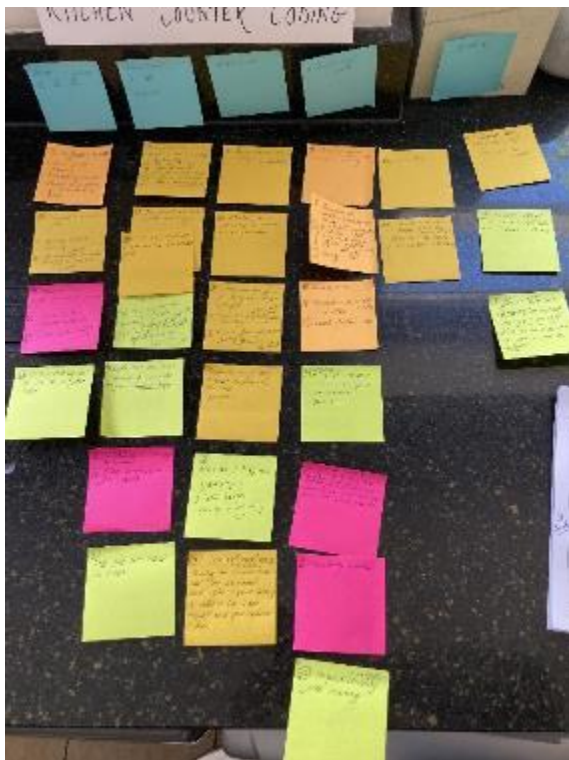
**Figure 3.6 (b)**

*Second level coding*
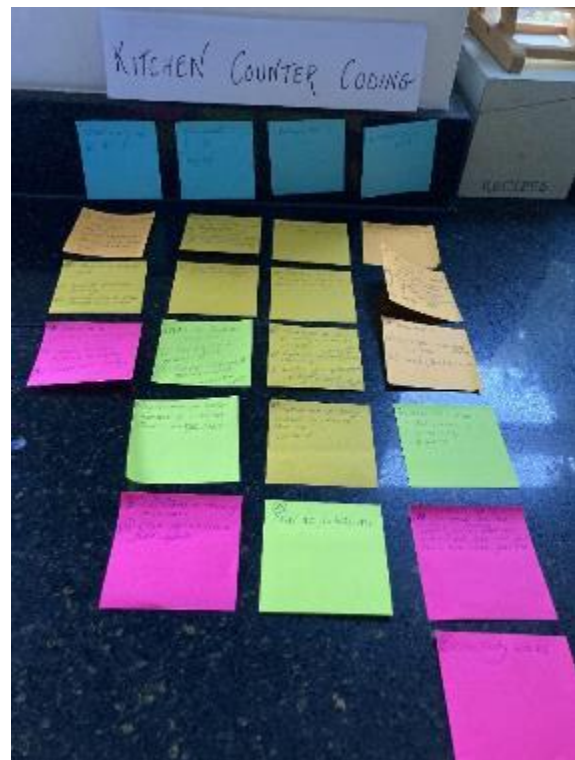


### 3.7.1.6 Stage 5 – Finalised personal experiential themes

Each superordinate 'label' was reviewed against the underpinning experiential theme (i.e., the subordinate themes) as well as re-reading the

contextualised quotations (from exploratory noting) before a formal Personal Experiential Theme was agreed (Smith et al., 2022). These were organised into a table for ease of review by participants. Under each PET, a relevant exploratory note was included to maintain an auditable evidence base as well as contextualise meaning alongside extracted quotations.

### 3.7.1.7 Individual reflexive participant collaboration

Accurate representation of participants' lived experiences was critical to ensuring the credibility and validity of this study (D. Thomas, 2017).To reduce the potential for misinterpretations of meaning (Milton, 2012) between autistic interviewees (e.g., an autistic analyst and a neuro-typical analyst), case summaries of the data analysis were emailed to the parents of all interviewees for review with the girls.

To help contextualise the case summary and goals of participant reflexivity, brief instructions were also provided (Appendix 2.11 for an example of a case summary). Parents confirmed via return email that their children had read and discussed the document. There were no revisions, perhaps indicating a lack of response from participants (particularly during the school summer holidays) which is acknowledged as a common issue when member checking in qualitative studies (D. Thomas, 2017).

### 3.7.1.8 Develop group experiential themes

Following the advice of Smith et al., (2022), after each interview transcript had been analysed using this process, all PETs were laid out together to explore patterns of similarities and differences (Figure 3.7). With the co-analyst, new group names were allocated and re-allocated throughout this inductive process, resulting in the identification of 12 GETs (Figures 3.8 and 3.9). Following supervision in which the indiscriminate nature of the 12 GETs was discussed, the researcher began a second round of pattern analysis, culminating in four GETs and sub-themes (Figure 3.10).

**Figure 3.7**
*Pattern mapping of PETs*
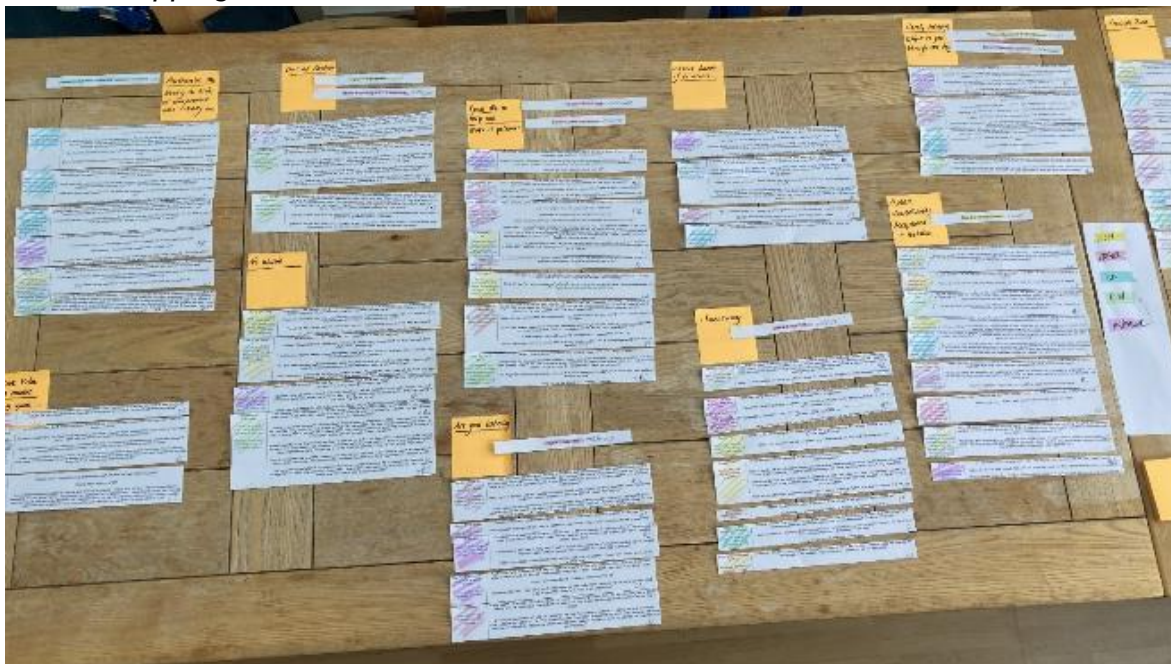
**Figure 3.8**

*Emerging GETs with exploratory notes and extracted quotes*
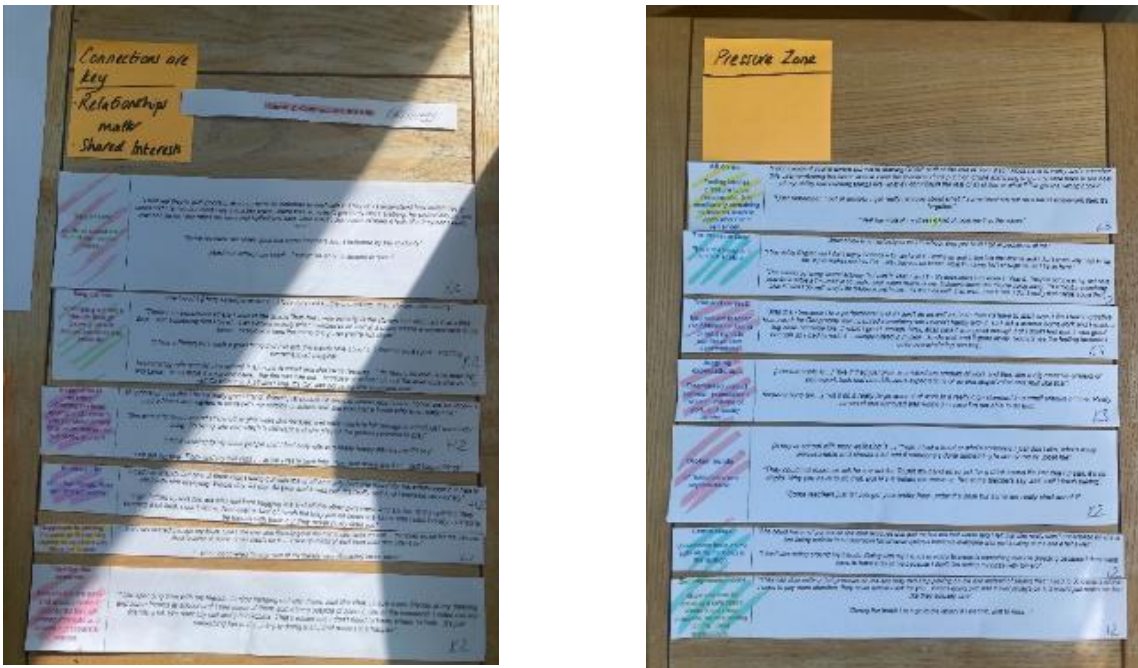


**Figure 3.9**

*Visual representation of initial (unchecked) Group Experiential Themes*

Group Experiential Themes – Round One *(before supervision and member check)*

| | | | |
|---|---|---|---|
| Unauthentic me | Are you listening? | Know me to help me | Barely surviving |
| Autism key | Intense battle of emotions | Connections are key | Out of control |
| Pressure zone | Finding your positive vibe | No words | Sanctuary |
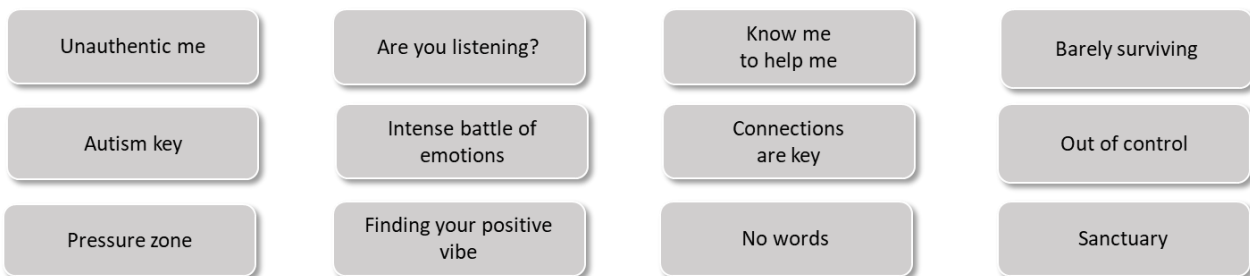
### 3.7.1.9 Finalising the Group Experiential Themes through reflexive participant collaboration

As with individual case studies, it was important to the feasibility, validity and collaborative nature of this study to review draft GETs with co-researchers. Therefore, at Workshop Sessions 4 and 5, following a brief recap of the research process to date, the 4 draft GETs were discussed (Appendix 2.12 for briefing presentations). Co-researchers engaged well with the review and made amendments related to language and perspective (Figure 3.10).

**Figure 3.10**

*Visual representation of Final Group Experiential Themes*

Group Experiential Themes – Round Two *(after categorising into adolescent framework + member check\*)*

| Working out who I am | Balancing emotions | Finding how I belong | Navigating the system |
|---|---|---|---|
| Different but not less | Fragments of me | Are you listening? | Learning in a pressure zone |
| Unauthentic me | Anxiety is a thief | Know me to help me | Surviving in an uncertain world |
| | Creating positive vibes | Connect with me | Finding sanctuary |

*Workshop 4 (29th October 2023)*      *Workshop 5 (12th November 2023)*

### 3.7.2 Hermeneutic analysis

According to Smith et al. (2022) the purpose of this part of the analysis is to examine the role of the researcher's own lived experiences on <u>how</u> they make sense

of the reported lived experiences of the participants (i.e., exploring the double hermeneutic).

### 3.7.2.1 Theoretical background

Critically examining the theoretical and philosophical foundations of IPA was useful in understanding why it is important to consider the influence of the researcher's lived experiences in data analysis procedures. For example,

- Understanding the fore-conception – gaining an enhanced awareness of the researcher's latent bias and interactional relationship towards a specific phenomenon, in line with the Heideggerian concept of an individualistic and contextual approach to phenomenology (Smith et al., 2022).

- Being aware of how the researcher's pre-conceptions of the phenomena might be transformed by an open analysis of the emerging phenomena, according to Gadamer's concept of a developing dialogue between old and new understanding (Gadamer, 1977: 9, as cited Gyollai, 2019).

- Acknowledge the holistic relationship between the researcher and the author of the experience and how value is added within the interpretation process, as described in Schleiermacher's (1998: 266, as cited in Smith et al., 2022) work on hermeneutics.

- Acknowledge the interactional nature of allowing the text to 'talk to us' as the researcher immerses and transposes themselves into it (Gyollai, 2019)

- Understand the idiographic nature of IPA and how to move flexibly between depth of analysis in single case studies towards cautious claims at a group level (Smith et al., 2022).

Developing a visual understanding of the hermeneutic processes within IPA reminded the researchers of their unique role in making sense of the wellbeing phenomena experiences by the co-researcher team (Figure 3.11).

**Figure 3.11**

*Hermeneutic Circles*
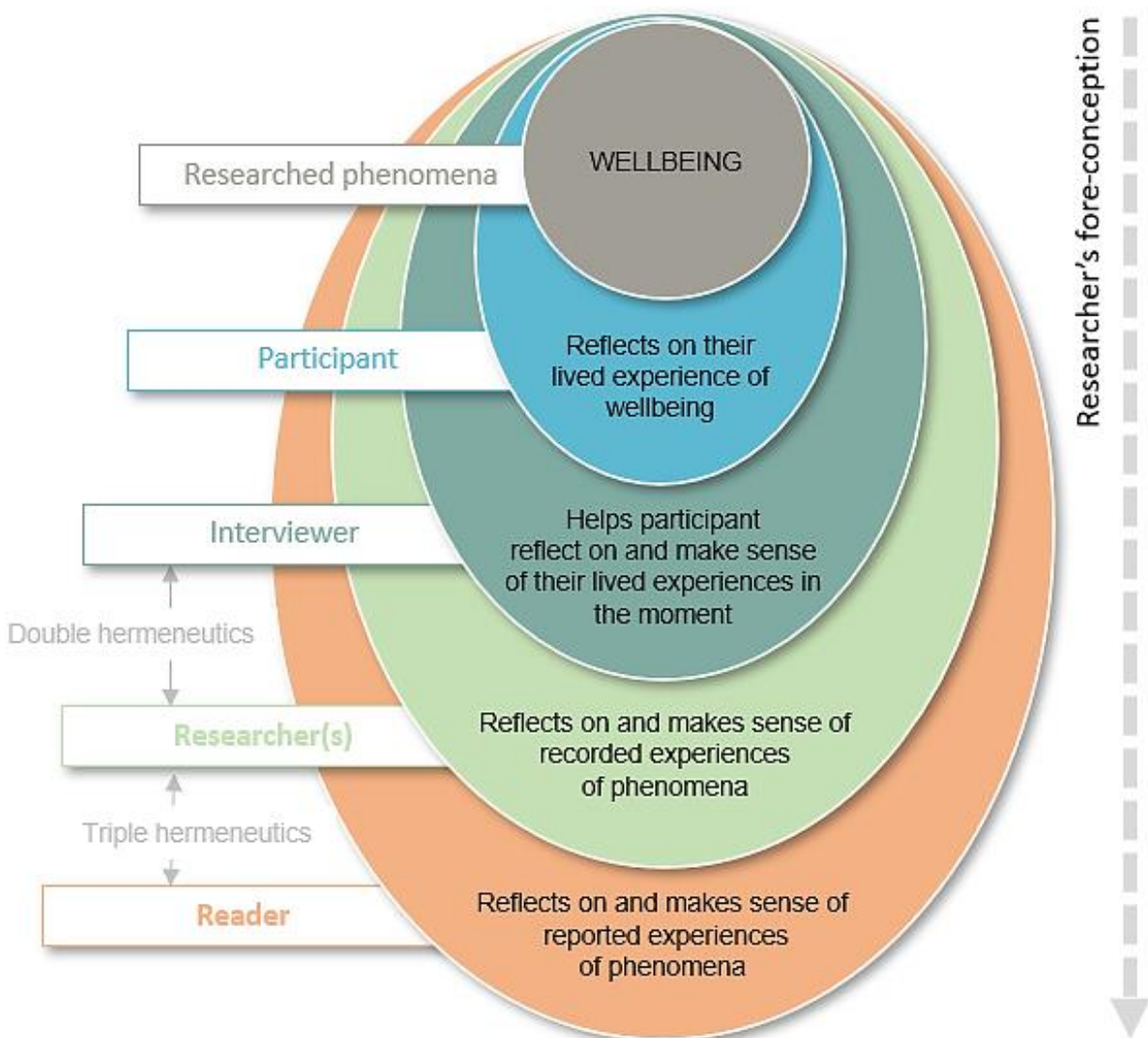
### 3.7.2.2 Developing the fore-conception[22]

The purpose of developing a fore-conception was to understand how the researcher's prior experiences of the phenomena could potentially influence their interpretations of other people's experiences of the same phenomena (Gyollai, 2019). By micro-analysing their own experiences, the researcher becomes aware of pre-existing knowledge that could influence their interpretative work (Cresswell, 2003). In this study, fore-conception was contextualised as the start of the interpretative process (Gyollai, 2019), rather than as a tool for removing or bracketing bias at the early interpretative phases, as recommended by Smith et al., (2022). This researcher wrote a self-reflection statement of own experiences of wellbeing at school, including perspectives as a child, a parent and psychology professional, then created a list of significant statements (Table 3.3).

### 3.7.2 3 Interpreting the interviewer's encounter (double hermeneutics)

Key words noted during the interview were compared to post-encounter reflections of the interviewer's experience of the interview (Table 3.4). The purpose of this was to unveil the potential impact on interpretation of experiences related to own fore-conception versus new and emerging participant-led responses**.**

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[22] NB: As the co-analyst did not wish to complete a personal statement, it was not possible to include analysis of her own fore-conception within the process.

**Table 3.3**

*Researcher's significant statements from personal experience*

| | |
|---|---|
| **Social anxiety is real, frightening and disabling. Sometimes it's easier and safer to stay hidden.**<br><br>*"I distinctly remember feeling anxious when invited to a party or trip to town, where I would feel extremely exposed and vulnerable. The impact on my wellbeing of this social anxiety has been that I definitely missed many experiences, making me feel equally sad and frustrated with myself across the years".* | **It can feel difficult to know where one belongs at school, resulting in a sense of isolation, loss and loneliness but also sometimes freedom.**<br><br>*"Playtime necessitated a constant effort of seeking out a secure group. Whilst sometimes I would feel lonely, I also felt lucky to have choice and freedom to not be confined to one 'tribe'.* |
| **Bouncing back from the negative wellbeing experiences depends on having a safe space or person. Important to find what works for you.**<br><br>*"Many hours were spent nestled in the quiet stillness of the school library, reading alone or beside others. These were comfortable, safe times where I could lose myself in a good book with minimal interaction and social effort".* | **Being academically able doesn't equate to coping.**<br><br>*"In pursuit of the perfect essay, the most beautiful visual illustration or a neatly presented workbook, I spent hours creating and then re-creating work until it was 100% aligned to my highest standard. Only then could I submit the work with peace of mind and pride. The consequence of this relentless effort was complete burnout by the holidays."* |

**Table 3.4**

*Exploring own emergent influences[23]*

| Within encounter:<br>*Key words from reflective diary* | Post-encounter reflection on experience of interview:<br><br>*Related to personal experiences – 'known and understood'* | Researcher's emergent influences |
|---|---|---|
| Being aware of and noticing<br>Girls being fake.<br>School – rope around lungs – can't breathe.<br>Zoning out/zoning in<br>Sanctions – Control - Fear<br>Tranquillity - Predictable<br>Pressure - Time limits – Noise - Detention<br>Art & lunch & friend happy exciting<br>Difficulty focusing | Helpless<br>Anger at school staff for not doing more to help.<br>Big words and big emotions used – sincere and heartfelt.<br>Desperate to get it all out – sped up talking at times – breathe<br>Watched…judged.<br>Lonely - No-one to help.<br>Captive – feelings of being too scared to talk/move - a prison<br>Hyper alert to other people and own feelings<br>Lack of autonomy and advocacy | At times difficult to listen to – so much pain and distress in experiences.<br>Living in fear<br>Too much to deal with – impossible.<br>School is a write-off – to be forgotten.<br>New school = new hope |

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[23] This researcher noted own emotive responses to participant's experience – possible re-triggering of own experiences of wellbeing at school

### 3.7.2 4 Interpreting the researchers' encounters (triple hermeneutics)

Both researchers reviewed the emergent influences outlined above against the exploratory notes and emerging experiential statements (Appendix 2.14). The relative autonomy of the participant's recounts of their experiences of wellbeing against this researcher's emergent bias were considered.

### 3.7.3  Visual analysis

IPA's primary purpose is using mean making approaches to understand individual and group experiences, however the hermeneutic philosopher, Heidegger, describes language as 'the house of being' (p140) indicating that language also has a prominent role in shaping (and limiting) our interpretations throughout the process (Heidegger, 1962: 140, as cited in Smith et al., 2022). See also section 3.5.2. Language as a resource.

Interviewees requested that their words (indicating feelings or emotions associated with school wellbeing) were also analysed and represented in a visual way.  Relevant individual words were identified from the interview transcripts and typed into a free Word Cloud generator app from the internet. This created two different word clouds – positive and negative experiences of school wellbeing. The size of words in the visual were commensurate with the frequency of the word being used in the interview ( Figure 3.12).

**Figure 3.12**

*Examples of word clouds – positive and negative experiences of wellbeing*

love_learning   like_the_same_thing
release   doing_my_work
doing_what_i_want_to_do                    relax
less_people          peaceful     understand_me
everyone_the_same                              able_to_learn
less_stressed   quiet_place        excited
not_alone   be_focused   with_a_friend        able_to_cope
being_supported   less_anxious                              less_angry
with_family                                    not_having_people_around_me
be_free   talking   happy        away_from_school
calm     being_listened_to                take_me_out
something_i_loved   not_worry   love_reading
chatty                    in_the_stories

brain's_not_working   less_chatty   quiet
fidgety   not_controlling_class
anxiety   headaches   busy   annoyed   noise
hard_to_think   dark   defeated   troubles   I'm_not_right
can't_stay   angry   mad   struggle
poor_communication   jumbled_up   sad   uncontrolled   anxious
crying   can't_talk   triggered   confusion   masking   don't_ask_me_questions
migraines   hard_to_learn   shaking   stomach_aches
stressed   students'_bad_behaviour
they_don't_care   confusing   less_able_to_cope
fidgeting   stressful   less_focused   feeling_different
struggling_with_peers

## 3.8  Ethical considerations

Research with autistic participants highlights that it is good practice to ensure that participants have a good awareness of their rights within the research process (den Houting et al., 2021; Jivraj et al., 2014). Especially when working with marginalised and vulnerable communities, ethical considerations range beyond

approval and consent, addressing extended issues of respect, empowerment and inclusion (Cascio et al., 2020). By considering procedural, situational and person-centered ethical issues, this researcher aimed to safeguard the participants' wellbeing, autonomy and confidentiality, and protect them from harm.

### 3.8.1 Procedural ethics

The formal governance of ethics procedures including pre-established approval processes and research guidance is sometimes referred to as procedural ethics (Ethical Research Involving Children, 2020).

Throughout this study, the researcher complied with ethical guidelines including the BPS Code of Human Research Ethics (British Psychological Society, 2010), Best Practice Guidance for Psychologists Working with Autism (British Psychological Society, 2021) and the HCPC standards (Health and Care Professions Council, 2018). Further ethical issues were explored using Barnado's framework for working with vulnerable young people (Harper & Scott, 2005) and reviews of ethical practice frameworks for autism research (Cascio et al., 2020; Chown et al., 2017) and education (British Educational Research Association, 2018). Ethical approval was granted from the University of East London School of Psychology Ethics Committee (Appendix 2.2) and a Letter of Approval was received from the Principal Educational Psychologist of the Local Authority in which the researcher works (Appendix 2.1).

### 3.8.1.1. Consent, assent and withdrawal

This study used an individualised approach to gaining informed consent, as recommended by Lloyd, (2013) to ensure that participants who may have been nominated by contacts at school or their parents or carers didn't feel obliged or coerced into attending. This approach entailed offering an exploratory  telephone consultation with families to respond to any questions about the study, after they had reviewed the study's Information Sheets. This provided an opportunity for families to find out more about the nature, purpose and participatory processes of the study as well as share their learning and communication preferences. Following this, consent and data forms were emailed to parents (Appendices 2.3 and 2.4 for the Young Person's Information Sheet and Consent Forms). Written consent was given by the parent or carer and written assent gained from participants prior to data collection. Participants were informed, before their formal involvement began, that they had the right to withdraw from the research up to three weeks after data collection.

A continuous approach to reviewing consent and withdrawal was also used to address the power imbalance inherent in parental advocacy for attendance at co-researcher workshops or interviews (Harrington, 2014). At the beginning of each contact point, participants were reminded of the purpose of that session and their right to withdraw or not fully participate at key decision points (Lloyd, 2013).

### 3.8.1.2. Confidentiality, safeguarding and privacy

Confidentiality is especially important in small-scale autism studies where cases may be easily identified thus potentially increasing the vulnerability of participants within their communities (Kossyvaki, 2018). Pseudonyms were used at data collection stage to protect the anonymity of interviewees. Co-researchers suggested a ground rule about not naming schools or individuals. Participants were made explicitly aware of the limits of confidentiality should a safeguarding disclosure be made. The researcher also adhered to Local Authority safeguarding policies.

Privacy was maintained via the use of parental email for accessing MS Teams meetings (and therefore young people's full names were not disclosed) during virtual workshop sessions. During co-researcher workshop sessions, participants could choose to disconnect their video feed and mute their microphone for further privacy. During data collection, pseudonyms were nominated by participants and used throughout all written materials pertaining to this study.

### 3.8.1.3. Data management

This research complies with the GDPR data guidance outlined within the Data Protection Act and the university-approved Data Management Plan.

### 3.8.2 Situated and person-oriented ethics

Situational ethics are described as 'ethics in practice' and sometimes referred to as the day-to-day issues arising in research work (Guillemin & Gillam, 2004). This micro-ethical approach looks beyond the ethics committee and responds to unexpected dilemmas arising from working with participants and how the researcher responds. The interactional nature of this ethical lens is particularly appropriate given the complex participatory nature of this research study. Further, the use of a reflexive research diary aided the researcher in talking about and validating ethically important decisions (Guillemin & Gillam, 2004) and enhanced understanding of ways of working with different communities.

Person-oriented ethics utilizes community-engagement to determine ethical guideposts that are important to participants from the researched community (Cascio et al., 2020). The adaptability of this ethical lens is well suited to addressing power dynamics between the researcher and co-researcher and facilitating close attention to emotions and empathy. Table 3.5 provides an overview of situational and person-oriented ethical factors that influenced this research study

**Table 3.5**

*Reflexive adaptations to ethical factors*

| Ethical factors | Reflexive adaptations *(Notes from research diary)* |
|---|---|
| **Individualisation:**<br><br>*Unique needs of participants* | • Consistent monitoring and adaptation of procedures and accessibility throughout workshops and data collection phase. |
| **Empowerment in decision making**<br><br>*Strategies to maximise participant's decision-making abilities* | • Facilitate slower pace for 'chat' function<br>• Initiate questions with examples or choices<br>• Use of ranking, scaling and emoticon (thumbs up/down) in decision making<br>• Reflexive participant collaboration (e.g., member checking) at all decision points and during data analysis. |
| **Respect for holistic personhood:**<br><br>*Respect and recognition of the value of all potential research participants, even those whose capacity to consent is limited* | • Open recruitment advert to any autistic girl attending mainstream secondary school in England<br>• Flexible co-researcher roles offered dependent on personal preference and capacity |
| **Acknowledgment of lived world:**<br><br>*Social context and significant others* | • Exploration of wellbeing in school and personal contexts<br>• Exploration of the role of others and self in improving or maintaining wellbeing (interview question) |
| **Focus on researcher-participant relationships**<br><br>*Relational aspects of research, including power dynamics* | • Reflection and reflexive practice throughout using research diary, tutor and peer supervision sessions<br>• Opt in/out mechanisms including 'pass' option<br>• Co-researcher-led ground rules of participatory engagement |

## 3.9 Trustworthiness

In qualitative studies, trustworthiness is often understood in the context of whether the findings are reliable and will benefit their intended community (Angen, 2000). This study had improved participation during the research design, data collection and analysis processes, by ensuring that the research originated from the autism and participant community, met their needs and was meaningful to them (Walmsley et al., 2018). Careful recording of and reflection on their participatory

contribution throughout indicated more accessible design, enhanced feasibility and ethical integrity (Chown et al., 2017).

### 3.9.1 Sensitivity to context

Ground rules were established by participants for the virtual co-researcher workshops. These were designed to create a safe psychological space for participants to engage with co-production activities (Appendix 2.7). The virtual interaction space used via MS Teams in this study was consistently scrutinised to increase accessibility and engagement. Personal and school wellbeing experiences were explored as well as the role of self and others in supporting wellbeing practice.

### 3.9.2  Commitment and rigour

Closely linked to this coherent and transparent approach acknowledged throughout this chapter, reflective spaces (e.g., in-action, diary and supervision) were used to continuously adapt research practice for power differentials and ethical considerations. Reflexive participant collaboration (e.g., member checking processes) were used throughout the research design, data collection and data analysis phases of the study to improve validity, accurate representation and reduce inequality between researcher and participants, as recommended by D. Thomas (2017).

### 3.9.3 Coherence and transparency

During the first co-researcher workshop session, the researcher shared their own rationale and journey towards establishing this community-led project, discussing personal and professional interests in the school wellbeing experiences of autistic girls (Figure 3.13).

**Figure 3.13**

*Graphic visualisation of early inspiration*



Co-researchers were also invited to share their hopes for participating in the project. Hermione shared that: *"I'd like my high school to understand how to support me in class"*. Lizzy also hoped that: *"I just want teachers to understand I'm not going to be*

*the same as every other student in class".* These were incorporated into the aims of the research (Appendix 2.8).

Participants were also reminded of the reflexive purpose of recording and note taking activities by the researcher to ensure research rigour as well as a highly detailed and transparent audit trail. Sense checking and mean making processes with participants were used throughout the study to ensure that this researcher paid attention to the fine line described between making decisions for participants and supporting them throughout the research (Puyalto et al., 2016). See also sections 3.4.2.2 (Co-planning 'in-action') and 3.8.2 (Situated and person-oriented ethics).

A visual community briefing is included at the beginning of this thesis to increase accessibility and transparency of research findings.

### 3.9.4 Summary and impact

This transformative research project has real-world relevance with participatory validity and community origins. As qualitative research with autistic young people is still an 'emerging field', according to Harrington et al., (2014, p.154), this study used participatory methods that researchers and EPs may find useful when working collaboratively with young autistic researchers. The 'nothing about us without us' research ethos, influenced by the social model of disability movement (Oliver, 2013), can  feel empowering for autistic participants, who may previously have felt their views

were unheard or marginalised. In following this approach of 'naming the world together' and not 'on behalf of another', epitomised by Freire, 1970: 69-70, as cited in Nind & Vinha (2012), it is hoped that this participatory approach answers calls from the autistic community to explore autistic wellbeing through revealing examples of the lived experiences of school wellbeing which will, in turn, empower schools to reflect on and adapt their wellbeing support.

Finally, but perhaps most importantly, participating in this study creates opportunities for adolescent autistic girls to meaningfully connect with and share their stories with peers, perhaps validating their experiences. Potentially sharing their constructs of wellbeing with others creates an advocacy platform for challenging school support.

*Language matters because…*

*Each different construction also brings with it, or invites, a different kind of action from human beings. Our constructions of the world are therefore bound up with power relations because they have implications for what it is permissible for different people to do, and how they may treat others.*

Burr (2005, pg. 5)

## 4.1  Overview

Leading on from the methodology chapter, in which the IPA data analysis process was described in detail, this chapter presents the research findings.  In honouring and validating individual experiences, the superordinate themes are presented for each of the five participants, generating a cohesive overview of their lived experiences of wellbeing[24]. An example of a summary of themes for each participant, with extracted quotes, is included in Appendix 2.11, as a reminder of how the findings originated. Co-researchers requested that the visual analysis of language precede the summary of emerging themes because they deemed this an impactful way to present the findings, therefore this is reflected in the organisation of this chapter. The chapter will continue by exploring common themes across all

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[24] Direct quotes from interviewees were not given in this section, to protect word count.

participants, including direct extracts from interviews to promote and prioritise the voices of the autistic girls in this study. A conclusion of key findings completes this presentation of findings.

## 4.2    Individual experiences of wellbeing

### 4.2.1  Introducing 'Ivy'

Ivy is a 14-year-old autistic girl who participated in this research as a co-researcher and data participant. Figure 4.1 synthesises her positive and negative emotions related to experiences of school wellbeing into a visual summary, organised by frequency of language use. Figure 4.2 illustrates emerging themes from her interview.

**Figure 4.1**

*Visual analysis of Ivy's experiences positive and negative wellbeing*



#### 4.2.1.1   Superordinate Theme 1:  'This does not feel OK'

The first superordinate theme highlighted Ivy's anxiety around the intrusion on her core values (e.g., obeying rules, pleasing people and 'doing the right thing'). The consistent use of first person suggested Ivy felt a strong sense of responsibility and vulnerability when her identity as a *'ruley'* person

was compromised and she felt obliged to behave in an unethical way that was not congruent with her principles.

**Figure 4.2**

*Themes identified from Ivy's interview[25]*
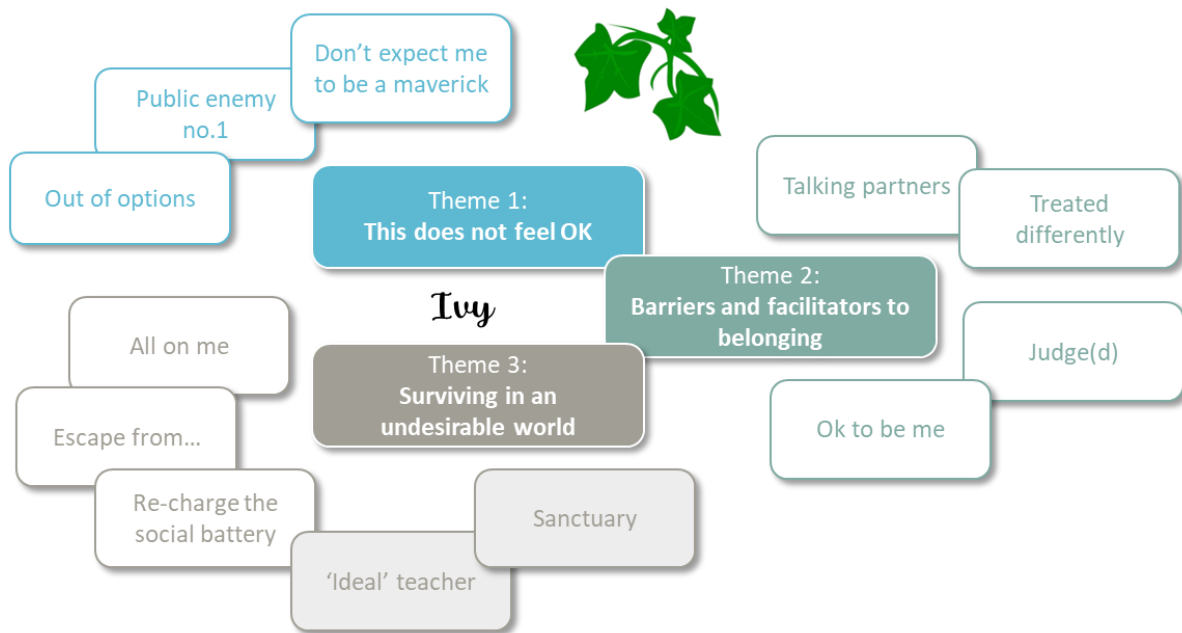


Related to this was the social consequence of not being able to always please others. She spoke fearfully about weighing up the emotional risk of whose displeasure she might incur when '*breaking the rules*'. Using words such as '*hated*' and '*truce*' highlighted the extent to which Ivy felt emotionally isolated and overwhelmed by this daily battle. A further sense of hopelessness and anxiety was also revealed when Ivy anticipated that others may make negative comments – the perceived threat of this happening generated intense feelings of being paranoid and scared.

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[25] Light grey shaded subordinate themes indicate school factors that support positive or negative wellbeing.

Ivy also indicated feeling trapped through a perceived lack of tenable options, when supporting herself. Even with temporary escape strategies such as a Time Out card, her anxiety and lack of experience using the card restricted her decision-making ability (i.e. the fear of perceived reputational consequences of using the Time Out card was almost as bad as not using it). Her reflections further revealed the emotional toll of feeling powerless and dependant on adult support. It was clear Ivy felt frustrated by the daily tension between loss of autonomy versus her desire to 'do the right thing', which would affect her wellbeing, especially her ability to think and act positively.

In summary, Ivy's reflections indicated that when her core values were violated, this had a long-lasting and devastating effect on her emotional capacity to deal with other pressures and worries. This appeared to compromise her wellbeing in the immediate and longer term, creating stress and anxiety as she battled to devise coping strategies.

### 4.2.1.2  Superordinate Theme 2:  Barriers and facilitators to belonging

The second theme collectively represented factors that influenced how successful Ivy felt when connecting with her peers. Ivy shared her sadness about being unable to fulfil the everyday, social obligation of talking to others. The self-awareness and incompetence Ivy felt around her situational silence was a barrier to her sense of belonging within her peer group. Throughout the interview, I'd also noted the self-conscious way that Ivy repeatedly apologised for struggling to find the right words.

Ivy reflected on how her anxiety around language affected the social responses of others towards her. She reported how others thought her stupid and younger than her years, evidenced in how they talked to her like a primary school pupil. The attribution of this to her developing autistic identity was evident. She seemed frustrated about having to challenge the assumption she was less capable and mature. The constant effort of struggling to express herself, and being treated differently as a result, negatively impacted Ivy's sense of belonging, and associated school wellbeing.

Another barrier to belonging, raised by Ivy, was a sense of feeling like there was no escape from the emotional fall out of being watched and evaluated by her peers, especially when communication differences arose. A secondary, longer-term effect was revealed when Ivy hypothesised that her 'over-sensitivity' to feeling judged resulted in an intense emotional burden and daily uphill struggle from fighting to fit-in at school. However, a supporting factor for her sense of belonging was revealed in her experiences of acceptance by her close friendship group who provided emotional support and opportunities for her to engage in 'listening' rather than talking mode.

### 4.2.1.3   Superordinate Theme 3:  Surviving in an undesirable world

Ivy's final theme highlighted the role of stress and uncertainty on Ivy's school wellbeing. She reflected on internal and external survival mechanisms (combinations of people, places and spaces) that were helpful in alleviating the cumulative pressures of school life.

Within her narrative, Ivy constantly internalised her thoughts and emotions through a cycle of anxiety, stress and responsibility. She detailed the multi-faceted pressures of school life such as retrieving homework briefs, rising to academic challenges and remembering resources. The vulnerability of the unpredictable nature of school life fuelled her worries and vulnerability around having to stay organised.

Conversely to these pressures, Ivy attributed one of her survival mechanisms to escaping into dystopian realities. She recalled the emotional freedom from social obligation and judgment she felt when engaging in a fantasy world. Contrary to feeling vulnerable in rule-bound, real-world scenarios, such as conversing with peers, she welcomed becoming metaphorically abandoned in an alternative realm, citing a sense of control in how she could act, be and feel. It's possible that her sense of competency and autonomy felt greater in worlds that she could control and perhaps provided opportunities to navigate and edit complex relationships, environments and emotions.

As already alluded in previous themes, the effort of interacting with others and the associated emotional fallout of feeling judged and different, required an easily accessible restorative mechanism. The act of reading and writing was equally as important to Ivy as the protective space in which this could be accessed. Ivy spoke fondly of lunchtime and breaks spent in the solitude and sanctuary of the school library, in which she could re-charge her emotional and social battery.

Whilst Ivy seemed keen to be as autonomous in problem solving as possible, she acknowledged that she was dependent on support from highly attuned support staff at school, with whom she could have problem solving conversations. In addition, the feeling of safety she described when staff were familiar to her, predictable in their approach and warm in their welcome appeared a stark contrast to other situations in which she'd previously recalled feeling marginalised by teachers and made to feel unwelcome in their classroom.  She felt most vulnerable when substitute staff adopted a 'person-first' approach to her autistic identity, demonstrating their lack of connection and understanding towards her individual needs.

### 4.2.2 Introducing 'Katniss'

Katniss is a 12-year-old autistic girl who participated in this research as our youngest co-researcher and data participant. Figure 4.3 synthesises her positive and negative emotions related to experiences of school wellbeing, organised by frequency of language use. Figure 4.4 illustrates emerging themes from her interview.

**Figure 4.3**

*Visual analysis of Katniss' experiences positive and negative wellbeing*

**Figure 4.4**

*Themes identified from Katniss' interview*
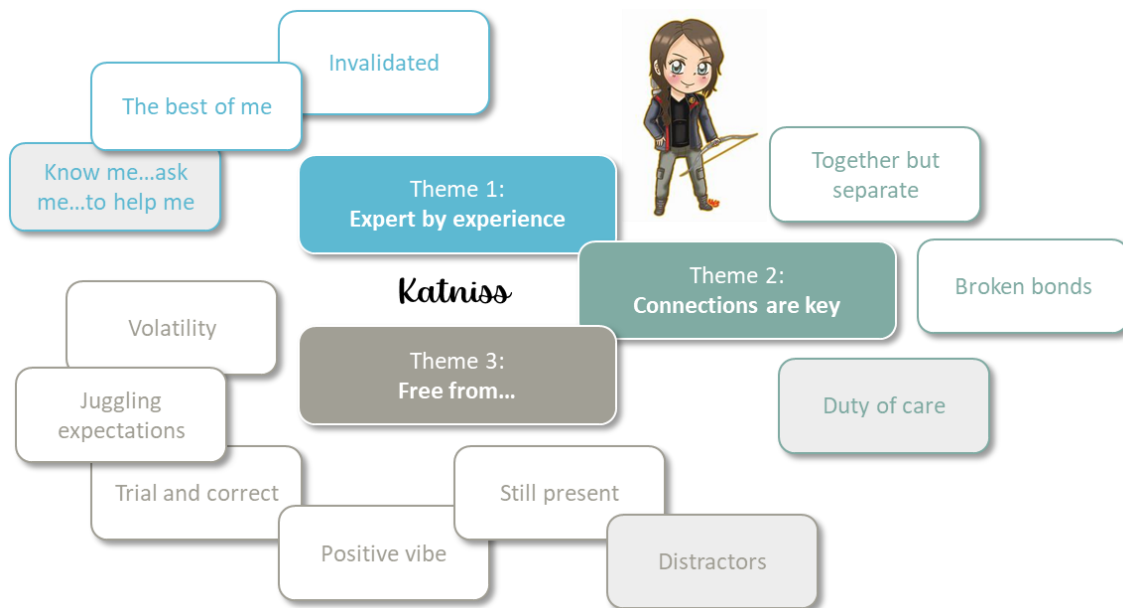


## 4.2.2.1 Superordinate theme 1: Expert by experience

This theme represented the injustice felt by Katniss when her experiences of school wellbeing, as an autistic young person, were not validated and her emotional states remained unsupported by adults. She reported how teachers seemed oblivious to her sensory needs and unresponsive to her pro-active requests for help. This left her feeling 'othered' which was in stark contrast to the inclusion and success she experienced when performing with her peers in her school production.

Drawing comparisons between the difference that positive and negative feedback made to her wellbeing was helpful in formulating desired support from the school system. She summarised this as adults needing to know her, to help her, by incorporating her opinion and experience in relevant support strategies

- beyond the basics, developed for all students.  In particular, she suggested that staff could benefit from advanced training in supporting autistic students, resulting in more attuned and individualised responses to pupil's needs.

### 4.2.2.2  Superordinate theme 2:  Connections are key

Katniss valued predictable and stable connections, perhaps as an antidote to other pressures at school. She appreciated the uncomplicated nature of her friendships in which she could share interests and activities in person or online.

In contrast, she described 'broken bonds' with school staff due to the inconsistency of their responses, irregularity of school rules (such as having drinks on the table) and a resulting lack of emotional containment. Further reflection signalled a need for a more defined duty of care from supporting school adults. She summarised this duty of care as being beyond the academic teaching roles – and incorporating more pastoral and wellbeing support. This included empathy and acceptance for differences in how autistic pupils process emotions.

### 4.2.2.3  Superordinate theme 3:  Free from…

Katniss' final theme reflected her desire to escape from the incessant reconciliation of internal and external spheres of influence which impacted her stress and emotional wellbeing at school. Alongside the unpredictability of social responses from adults at school, Katniss also reflected on the unpredictable nature of her own emotional responses to stress, considering a

cycle of volatility that occurred regularly. She detailed, in a highly mature and self-aware way, how feeling stressed at school stopped her concentrating on her work. She found this upsetting because she prided herself on her high academic standards and failure to meet this created additional stress. This had a subsequent effect of decreasing her preparedness for tests which were the key benchmarks for her success.

On top of this, she noted that her perfectionist tendencies accelerated feelings of disappointment which added to the volatile emotional responses she experienced, and at times became too overwhelming to cope with. Blaming herself for failing to consistently achieve her desired standards often generated more work, as she adopted a 'trial and correct' approach to work. Conflicting thoughts around the effort of this versus the school's expectations for volume and quality of work produced a pressure cooker of stress which she longed to feel free from.

Coping mechanisms such as music and acting helped alleviate some of these internal and external pressures, providing brief respite through controllable influences. Katniss described how listening to a favourite playlist initiated a positive vibe that felt immersive and uplifting – an antidote to the negative wellbeing generally felt at school. Singing relieved her stress and drama activities, in which she could be creative, established editable opportunities to express and perhaps release her feelings.

Katniss was keen to promote the 'distractor' approach to supporting her stress at school, via talking, listening to music or time out from the classroom. These were strategies that had been developed for her, with her and had proved successful.

### 4.2.3 Introducing 'Lizzy'

Lizzy is a 14-year-old autistic girl who participated in this research as a co-researcher and data participant. She has known about her autism since she was three years old. She is a self-confessed Taylor Swift super-fan which informed many of the theme titles emerging from IPA analysis. Figure 4.5 synthesises her positive and negative emotions related to experiences of school wellbeing, organised by frequency of language use. Figure 4.6 showcases Lizzy's mind-map of wellbeing experiences that she utilised as an interview prompt. Figure 4.7 illustrates emerging themes from her interview.

**Figure 4.5**

*Visual analysis of Lizzy's experiences positive and negative wellbeing*

**Figure 4.6**

*Visual prompt to support Lizzy's interview experience*
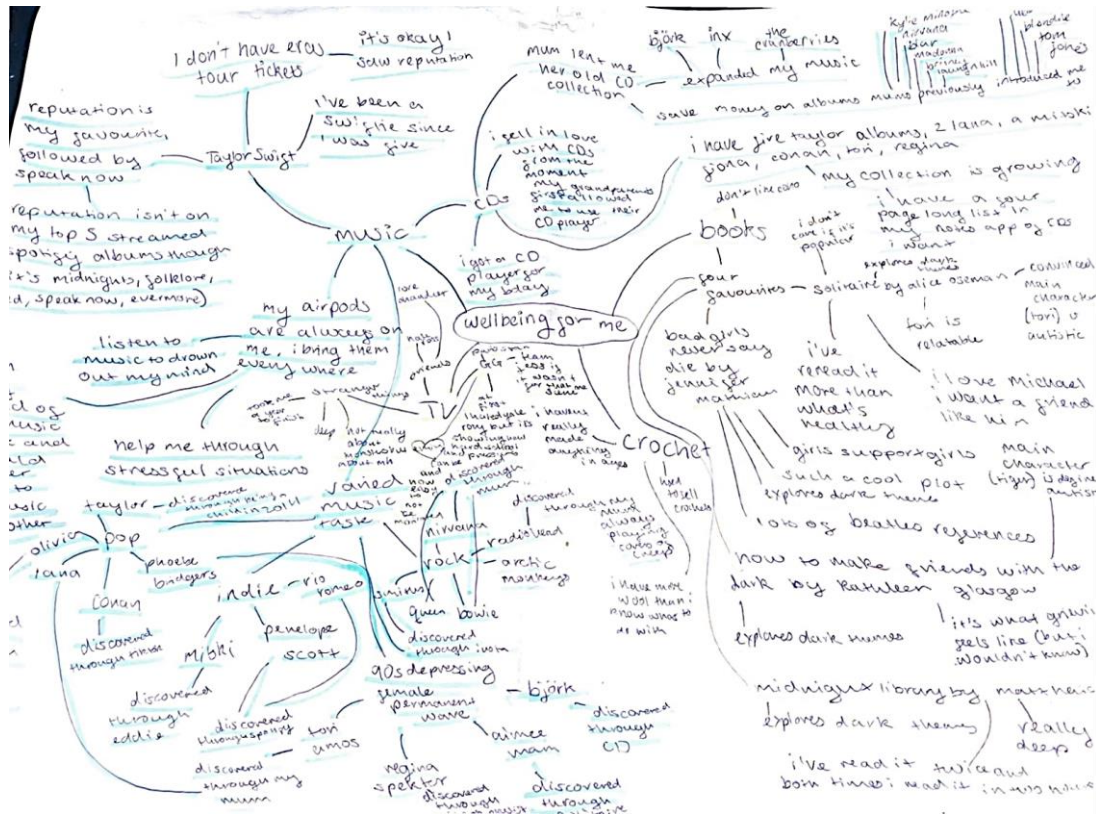


**Figure 4.7**

*Themes identified from Lizzy's interview*
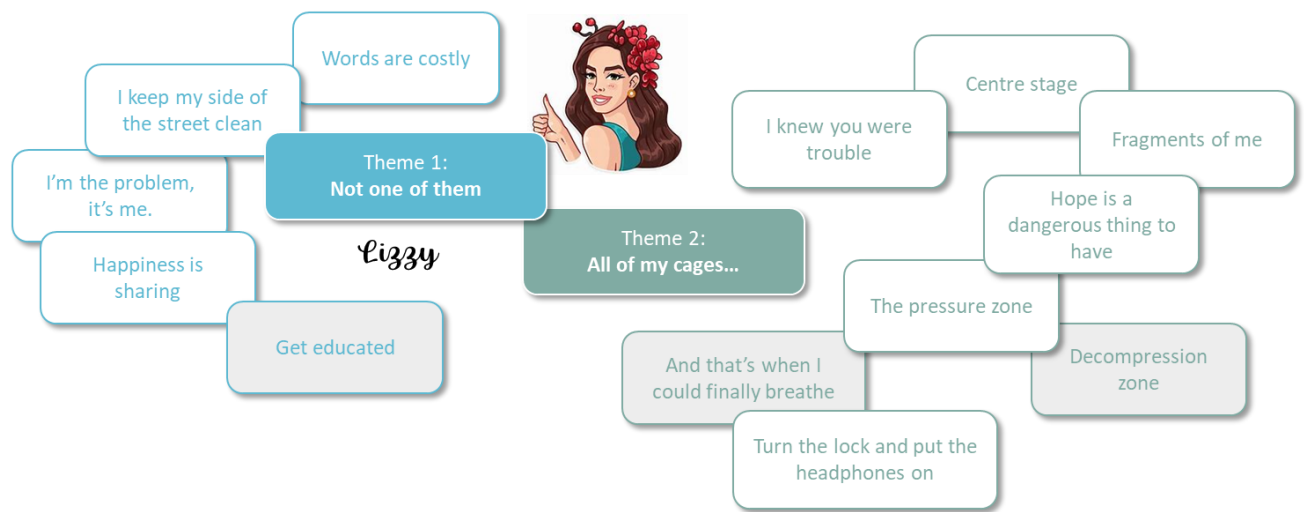
### 4.2.3.1  Superordinate theme 1:  Not one of them

This theme spoke powerfully of a sense of 'othering' experienced by Lizzy. Clear influencing factors emerged through sub-themes, revealing her vulnerability and isolation as well as intense anxiety and internal retrospection. She described the social and emotional costs associated with unchecked language – with difficulties in both finding the right words in conflict situations and inhibiting her own responses. Her overriding protective mechanism was often to say nothing at all rather than risk harming herself or rejecting others. However, this meant that she often 'bottled her feelings up' and ruminated about whether she had been at fault. This led to paranoia and a watchfulness in social scenarios, especially around adults whom she felt showed less understanding than her peers.

Dealing with feeling socially alienated, scrutinised and targeted was exhausting and necessitated 'zoning out' to recalibrate but this became difficult in lessons when teachers misunderstood and assumed she wasn't listening, resulting in consequence points and missed learning. The ensuing isolation and vulnerability she experienced reinforced her identity as 'not one of them'. She often held herself to account, feeling blame, shame and anger for her negative experiences of school wellbeing.

Lizzy could however identify occasions when she belonged to her peer community - through their shared love of music and books. She described her pleasure in discovering new artists with friends and impressed me with her extensive reading lists (Figure 4.6).

Lizzy articulated the support she needed to be included in her school community. She suggested that if teaching staff understood different neurodiverse experiences, they would be more tolerant (e.g., 'not picking' on children), show more understanding and develop different approaches to supporting pupils in lesson.

### 4.2.3.2 Superordinate theme 2: All of my cages

The themes emerging here were complex and multi-faceted, describing Lizzy's feelings of entrapment, failure and ensuing emotional recovery. There was a pervasive aura of powerlessness and hopelessness that permeated her narratives.

Underlying many of her school experiences was a residual anxiety which she described as stealing her attention in class and getting her into trouble with her teachers. As a result of zoning out in lessons, teachers often asked her difficult questions which she wasn't prepared for and couldn't answer. The consequent attention from the rest of the class, and her feeling of being 'centre stage', further exacerbated her anxiety. Her emotional and behaviourial responses in that moment were difficult to regulate, leaving her exhausted – in a state of emotional fragmentation. Recovery following these crises, was often prolonged and necessitated time on her own, away from the classroom and other social environments.

The regularity of these difficult experiences generated a dread of going to school – of not knowing what the day would bring, how others and herself might

react and what the emotional or social consequences might be. This had an accumulative negative impact on Lizzy's wellbeing where the start of the day would be difficult to cope with, despite her supportive family. At points, she seemed to lack hope that school could ever change for her. She also noted that she was a bright student who was in top set for most subjects however expectations to socially and behaviourally conform, the emotional labour of holding herself together and missing learning (when she was zoning out), left her feeling a failure who struggled to cope with the pressures of school.

Release from these 'cages' was achieved by listening to her music - she carried her Airpods with her everywhere. As a stress-reliever, high volume music 'drowned out' and 'closed off' the world for a while, helping her to reset and feel more able to cope. Other calming strategies included crochet, at home, as well as deep breathing techniques.

Supporting factors for her wellbeing at school were described as creation of a safe space with no pressures and attuned adults who showed they cared and listened to pupils. The library was cited as one such recovery room.

### 4.2.4 Introducing 'Hermione'

Hermione is a 13-year-old autistic girl who participated in this research as a co-researcher and data participant. Figure 4.8 synthesises her positive and negative emotions related to experiences of school wellbeing, organised by frequency of language use. Figure 4.9 showcases the creative visual prompts that supported Hermione's thinking during her interview. Figure 4.10 illustrates emerging themes from

her interview. Hermione's mother sat close by throughout the interview to offer moral support but did not join the discussion.

**Figure 4.8**

*Visual analysis of Hermione's experiences positive and negative wellbeing*
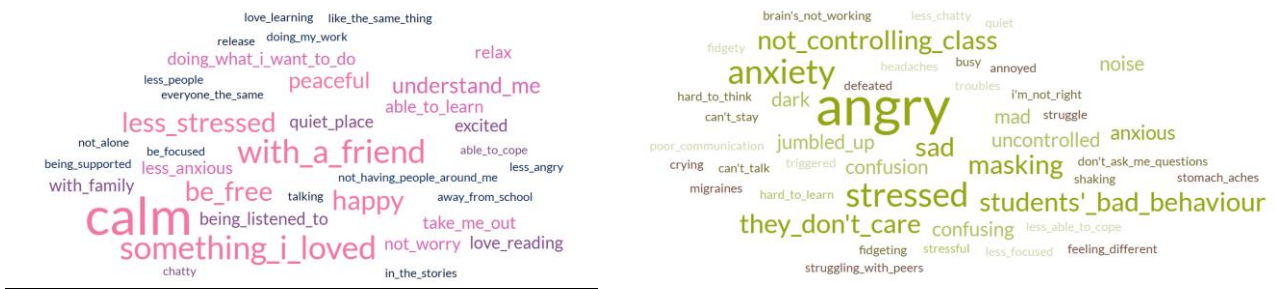


**Figure 4.9**

*Visual prompts to support Hermione's interview*

**Figure 4.10**

*Themes identified from Hermione's interview*
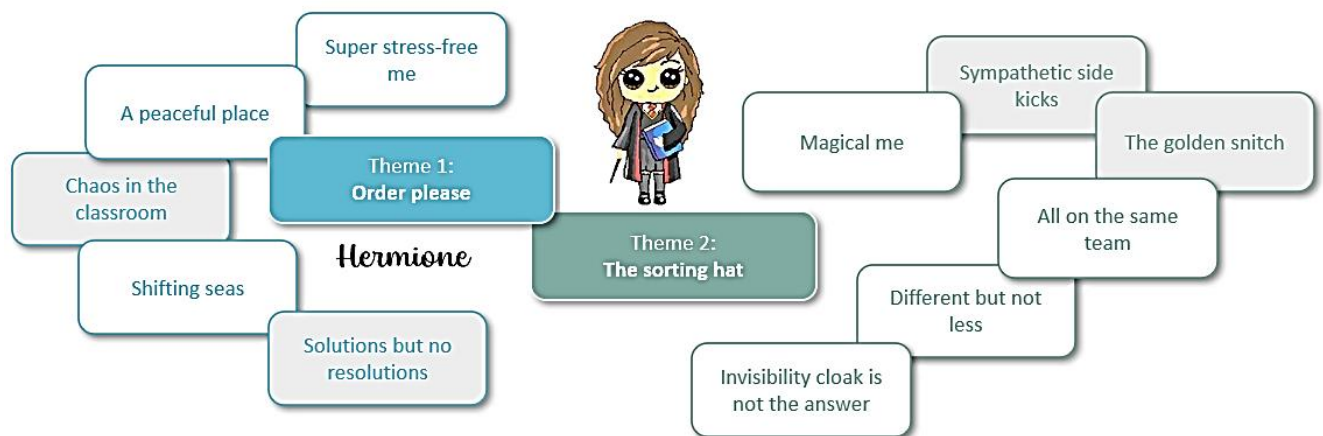


## 4.2.4.1  Superordinate theme 1:  Order please…

Hermione's outlook on wellbeing was unique in that it was mainly situated within positive school experiences. She began her reflections thinking about a day with good wellbeing, where she was the very best version of her self – sociable, mentally alert, learning – and free from stress.  Her colourful painting of the Hummingbird, which she bought to interview, represented the happiness and peace she felt on a day of positive wellbeing.

Discussion around the symbolism of the hummingbird painting led to further reflection around supporting factors for wellbeing in the classroom.   In Hermione's school, uncontrollable student behaviour triggered her own anger and distress around the injustice and helplessness of missed learning opportunities. To cope with these intense feelings, she frequently left the classroom and sought support in the autism resource base, perhaps unconsciously drawing parallels between the flight of the Hummingbird. She posited that the independence of the Hummingbird illustrated her wish to learn

alone, rather than in large groups or the classroom. Conversely, teachers that controlled the chaos in the classroom, created an orderly learning environment that was stable, peaceful and predictable for her.

Sharing more of her narrative around shifting emotions, Hermione described how the second painting represented a day with poor wellbeing.  In this painting the confusion she felt when her brain was uncontrollably awash with jumbled emotions, thoughts and behaviours was akin to the dark, messy swirls on the canvas. Painting at home was described as a calming and relaxing activity, an opportunity to zone out away from the chaos of the learning environment.

To alleviate the anger and stress she often felt in class, Hermione was offered a Time Out card so that she could temporarily leave a worrying situation. However, Hermione explained that this approach was not inclusive or fair as the premise that she must 'fix herself' did not fundamentally address the core issue of the poor behaviour of the other students. She suggested that the solution should be to restore order in the classroom. Available alternatives such as learning in small groups in the school's resource base were rejected as the level of work for other students learning here was significantly below the academic achievements of Hermione and staff seemed unable to provide more challenging learning that matched her attainment level. Ultimately, Hermione felt frustrated and disappointed that her school system could not accommodate her needs. Not feeling supported to be her best self, affected her sense of belonging and acceptance in the school community, negatively impacting her wellbeing.

### 4.2.4.2   Superordinate theme 2:  The sorting hat

The second theme emerging from Hermione's interview also drew on her desire for positive experiences of wellbeing at school. Inspired by her love of the Harry Potter stories, she spoke enthusiastically about developing her social identity and belonging through shared interests with other fans. She drew thoughtful and insightful comparisons between herself and some of the key characters (e.g., the free and calming nature of 'Luna' and the studious and ethical stance associated with 'Hermione'). Interestingly, she also noted that many of the characters from this magical realm had found ways to be their authentic selves, which, she explained, helped them overcome the adversity their differences sometimes represented. She observed it was important to be true to yourself, to recognise your own potential and power.

Key to enabling this was the close friendships built throughout the storyline. She related this to her own experiences of friendship, especially the acceptance she felt from friends that really listened and understood how to encourage her when she was struggling. Alongside their sympathy, advocacy support was also important to Hermione who recalled that in the midst of an emotional crisis, it was difficult to calm and think how you might be feeling, let alone explain what you needed.

A second potential support mechanism identified was talking to trusted adult allies however this was viewed as unrealistic given the lack of training for school staff on neurodiversity. Hermione's ultimate hope was for individualised and highly attuned assistance which promoted inclusion and acceptance.

Importantly, such support should not spotlight difference. It was important to her that everyone felt 'on the same team' – focused on learning and promoting what worked for autistic pupils rather than blanket applications of whole school SEND strategies.

Finally, Hermione acknowledged that when her wellbeing was compromised, it was sometimes difficult for her to share her feelings. Repeated experiences of not feeling heard or listened to had eroded her faith in supporting adults. Consequently, masking had become a way of managing fluctuating emotions and hiding how defeated she sometimes felt by her autism. Interestingly, this revelation came right at the end of the interview, after she had detailed the many ways in which her positive wellbeing was supported. I reflected that she had required a significant amount of time with an attuned adult to reveal this protective strategy. More detailed discussion of masking her struggles and feelings highlighted consequences of heightened hyper vigilance and anxiety, withdrawal from friends who may spot unauthentic behaviours and feeling invisible to adults who potentially could help. Physical manifestations of this inner turmoil were repeated migraines, stomach pains and tiredness. Keeping it together during the school day and then releasing emotions at home eventually garnered the attention of her parents who supported Hermione to address difficulties at school.

In summary, Hermione's desire to enjoy her learning experiences at school and to fit in with her peers, on her own terms, were key to her school wellbeing. The adaptations to environmental and relational support that could further meet her

individual needs would adhere to most school policies, cultures and statutory guidance under reasonable adjustments.

### 4.2.5 Introducing 'Ron'

Ron is a 15-year-old girl who has only recently been diagnosed with autism. She participated in this research as a data participant and so shared her views without any prior involvement with the study, unlike other co-researchers who had time throughout the design process to begin formulating their concept of wellbeing. During her interview she was supported by her mother. Whilst still enrolled at a mainstream school, Ron had recently struggled to attend school regularly. Her mother shared that whilst school had been supportive initially and provided support for Ron's emotional wellbeing and mental health, fines for non-attendance were accumulating.

Figure 4.11 synthesises Ron's positive and negative emotions related to experiences of school wellbeing, organised by frequency of language use. Figure 4.12 illustrates emerging themes from her interview.

**Figure 4.11**

*Visual analysis of Ron's experiences positive and negative wellbeing*

**Figure 4.12**

*Themes identified from Ron's interview*
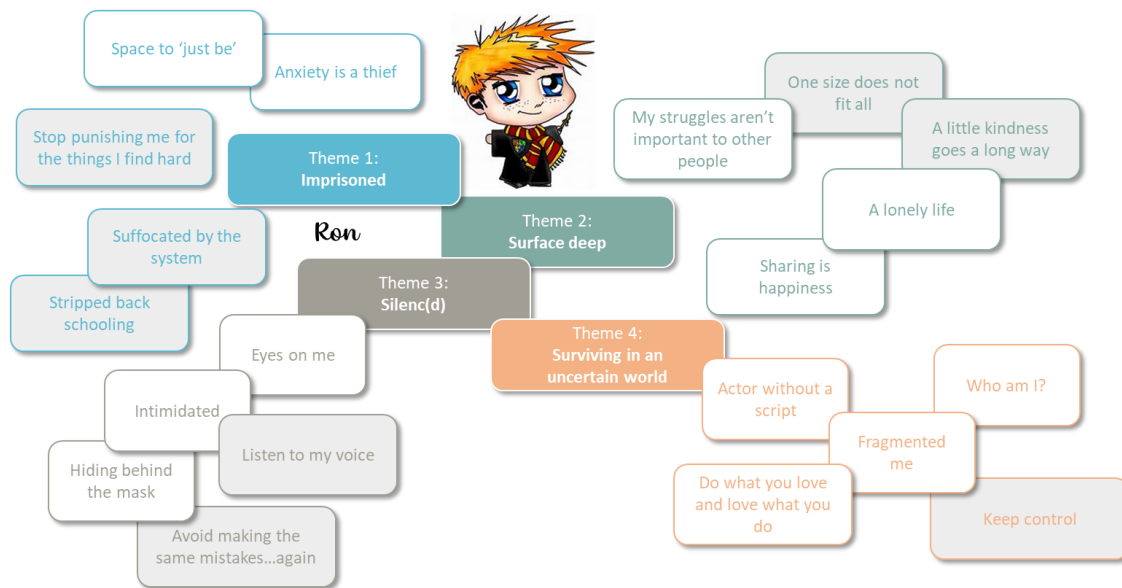


## 4.2.5.1 Superordinate theme 1: Imprisoned

Themes here reflected Ron's sense of entrapment, confined by characteristics of her autism and the inflexibility of the school system to adapt and support her. Her narrative felt suffocated – delivered in short frenetic bursts, detailing the daily overload of pressures - time limits, teachers' expectations, punitive threats of detention and fines and unrealistic quantities of homework. She described feeling 'unable to breathe' and 'being on edge' the whole day. Trying to learn in this context created significant anxiety, beginning each morning at home as she contemplated the repetitive and inescapable experiences awaiting at school. The relentless effort of staying alert in lessons and maintaining her focus on work was exhausting – her overwhelming anxiety 'drained' her energy and cognitive and emotional capacity.

Understandably, this made the school day feel really hard for Ron. She seemed irritated that situations which could seem easy for a 'normal' person felt very hard for her. Examples of this included sharing ideas with partners in class (which were difficult for her to predict and handle) or coping with internal exclusions (the isolation and associated anxiety spiralled her into crisis mode). Her perceived injustice for being penalised at school was attributed to the nature of her autism, with the system failing to make suitable accommodations.

She identified a 'stripped back' model of schooling in which she could attend for the basics of learning, without 'extra' team or social activities, that would support her wellbeing. This idea was born out of positive experiences in primary school, where learning felt less collaborative and there were more opportunities for focused spaces and individual activities. In particular, she recalled art lessons where she could produce individual pieces, escaping or zoning out from the rest of the class.

**4.2.5.2   Superordinate theme 2:  Surface deep**

This reflected Ron's isolation and vulnerability within her school and peer communities, especially when her experiences and views were not heard and validated. The sense of having to cope alone was palpable throughout her narrative, reflecting a deep emotional and social disconnect from support networks. Her associated wellbeing seemed fragile, reflecting her need for more than short-term, superficial support.

Accumulative experiences of not being noticed or supported when she was struggling had left her feeling less prioritised than other pupils with SEN. When help had been offered, it was inconsistently applied and the 'one size fits all' approach didn't meet her individual needs. Attitudes of staff were reported as dismissive, viewing her behaviour through a 'choice' lens rather than as a signal that she wasn't coping with her day. The emotional impact of fighting for appropriate support on multiple fronts was only made bearable via a few key adults who took the trouble to get to know her on a personal level. These teachers worked with her to identify individualised and strengths-based strategies rather than trying to mould her into an 'idealised' student. Inherent in this collaborative approach was a respect for her voice, lived experiences and partnership-working with family.

Alongside this recount of school wellbeing, Ron also spoke about her lack of connection with peers and difficulties maintaining friendships. She described finding it tricky to maintain common ground with other girls her age whose interests simply didn't match her own. In addition, her perceptions of their lack of authenticity and the constant switching of focused pursuits (to keep up with peers or social trends) were difficult to reconcile, limiting her remaining peer pool. A deep-rooted belief of being ostracised by other girls and the fluid nature of learning groups in secondary school also contributed to her loneliness. The importance of close connections was associated with being safe and happy – it was sometimes easier to retain these comforting feelings with just one friend, reassuring and kind adults or even her pets.

### 4.2.5.3 Superordinate theme 3: Silence(d)

Within this theme, it became apparent that to protect her school wellbeing, a tried and tested survival mechanism was masking – becoming an alternative version of herself that could outwardly reject the judgement of others. In essence, the notion of being silenced was partly inner compassion versus a call for recognition of the damage to self-esteem caused by camouflaging.

The purpose of hiding behind a mask was to disguise her intense emotions of panic and social anxiety. Panic was generated by the thought of potential detentions or teachers acting unpredictably (e.g., shouting in the classroom). Social anxiety was experienced when adults tried to help at her desk or she was asked to volunteer answers in class – both scenarios resulting in feeling paralysed with fear, noticed and judged by peers. However, the effort of creating a more confident, resilient (camouflaged) persona was defined as 'ruinous', resulting in meltdowns at home.

To counteract these damaging effects on her wellbeing, Ron speculated that support should include listening to autistic girls, building trusting relationships in which 'what works' for them could be explored. Through creating a higher level of neurodiversity awareness amongst school staff, she hoped that autistic girls' triggers and traumas could be avoided.

### 4.2.5.4  Superordinate theme 4:  Surviving on an uncertain world

Ron's final theme considered the role of psychological, emotional and social safety on her wellbeing. Uncertainty around her autistic identity and low confidence coupled with disability-related bullying left her feeling unsafe, sad and stressed. She described the effort required to regulate conflicting, jumbled emotions as sending her to the edge of insanity.  Behind the mask, she was experiencing a 'full blown in-society attack', feeling angry, fearful, judged and despairing, especially when adults seemed oblivious to her pain and distress. Perhaps the worst effect of camouflaging was being stuck without the right words to express how she felt, especially when kind adults asked her how they could help.


Accumulated experiences of being let down by adults at school also created a relational environment of mistrust and volatility. Help was arbitrary at best, irregular most of the time as different teachers were perceived as not understanding or taking the trouble to find out what her needs were. Instability was also generated by uncontrollable learning environments in which other students created distractions, making it difficult to concentrate on her learning. To survive, Ron retreated into creative projects, often for other people, where she could thrive: feeling successful and in control.

## 4.3　Group experiences of wellbeing

Co-researcher analysis of the Group Experiential Themes (GETs) revealed four superordinate themes (Figure 4.13). These themes collectively begin to create a shared meaning of how autistic adolescent girls conceptualise their school wellbeing and the supporting factors.  It should be noted that during the participatory workshops, co-researchers agreed that the titles of the themes, should be enabling and action oriented. This was seen as an important reclamation of power – a strong message of intent and autonomy.

**Figure 4.13**

*Group Experiential Themes*
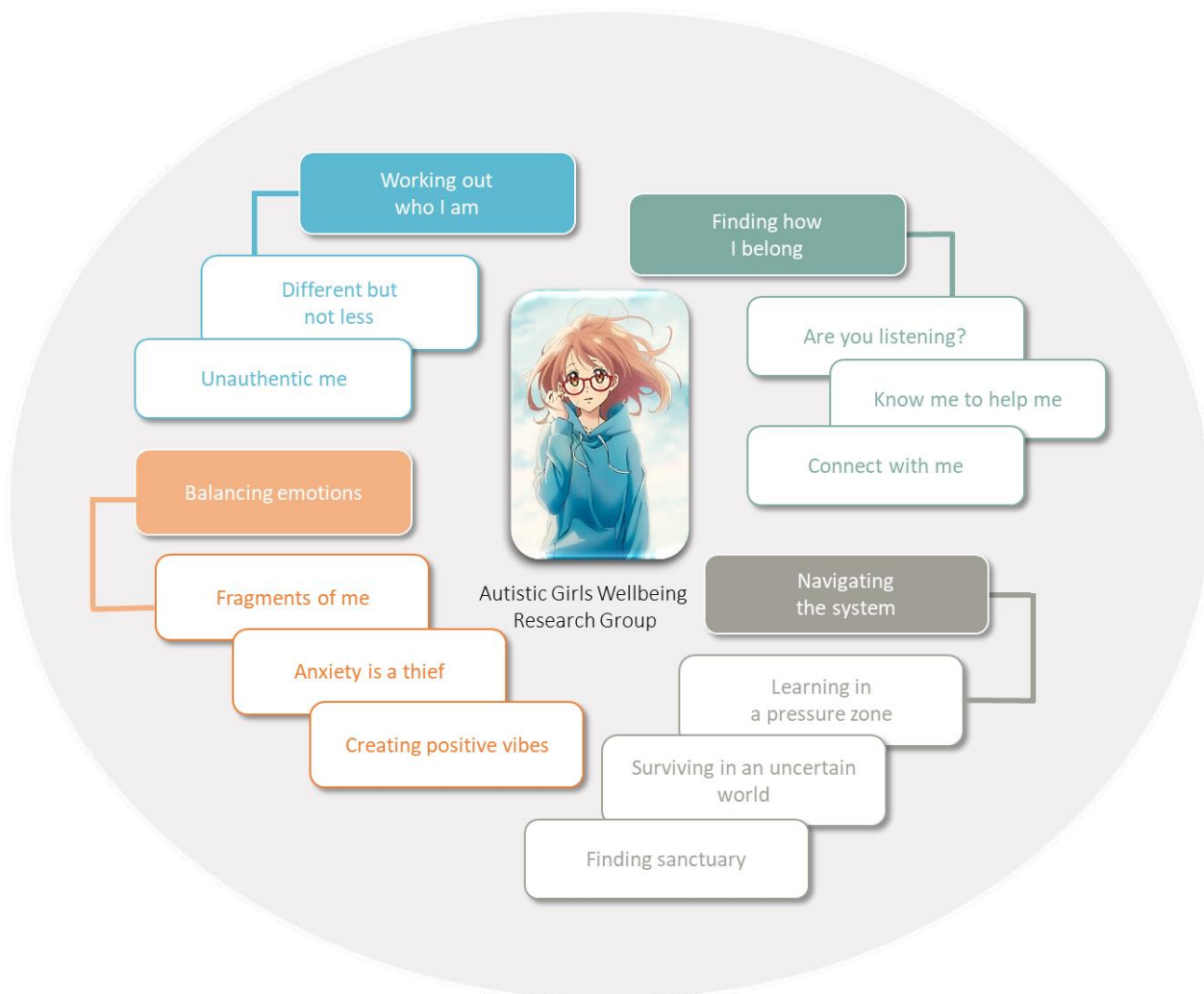
### 4.3.1 Superordinate Theme 1: Working out who I am

Wellbeing at school encompassed and indeed necessitated discovering a secure identity, sense of purpose and self-esteem. The sub-themes described here represent the collective and problematic journey towards self-discovery that the autistic girls in this study experienced. Top of mind for all the girls was a sense of standing apart from their peers – a recognition of differences in how they saw the world and how the world saw them. Equally important to their wellbeing was the emotional endeavour of balancing the authenticity with which they could present their true selves, versus portraying an aspirational, archetypical persona.

#### 4.3.1.1 Subordinate Theme 1: Different, but not less

To begin the arduous adolescent task of working out who you are, young people typically compare and contrast their emerging ideas of self with feedback from their peers and wider society. As far as the autistic girls in this study were concerned, a key barrier to this trial and error, exploratory process was diverging discrepancies in the way others understood their behaviour. As Lizzy shared: *"I remember the first day she gave me a consequence point because I was looking out of the window…but I was just a bit zoned out"* (Lizzy, pg. 5). For Ron, peer review that explicitly focused on her autism created a public, deficit-based persona that was hard to break away from: *"You're made fun of with horrible names because of your disability. It's not fair. You're treated differently and it really brings down your confidence"* (Ron, pg. 22)*.*

For Ivy, feedback on her evolving identity was fearfully anticipated: *"I heard the whole class talking about someone behind their back and I realised this is probably what happens to me…I know if anything happens, I'll really struggle to get over it."* (Ivy, pg. 9*). Constantly feeling judged further highlighted differences in how others understood and responded to the girls' autistic identity but also how the girls internalised these experiences: *"I kind of feel paranoid. Everyone's judging me all the time, and everyone sees everything …everything that's wrong with me"* (Ivy, pg. 12)*.

However, some of the girls retaliated against the defining dimensions of autism, actively associating with other aspects of their identity, as explained by Hermione:

> *I just feel like I don't want to be like everyone else… so the autism doesn't define me. I'm in top set and I do clubs and lots of other stuff. I don't go round telling people about my autism because I don't want them to first judge me on that. (Hermione, pg. 13)*

This contrasted to Ivy's reality in which wearing a highly visible autism lanyard was construed as a protective, identifying mechanism at school.  To shift the narrative to 'different but not less', and promote inclusive attitudes to neurodivergence, the girls recommended updated training for school staff, based on their real-life experiences, as explained by Lizzy: *"I think teachers need more education on neurodiversity in general. Because if teachers understand what the children actually have to go through, maybe they'll be more understanding?"* (Lizzy, pg. 6).

### 4.3.1.2  Subordinate Theme 2: Unauthentic me

To counteract being misunderstood, the girls shared their strategies for disguising difference and the associated difficulties containing their emotions. *"I just keep everything to myself. It creates less drama, so it's easy for me"* (Lizzy, pg. 11).

Ron described how she disassociated from classroom experiences: *"Whenever I was masking at school, I just sat at my desk listening. I wasn't listening. I was just waiting to get the day over and done with, to go home and cry about it"* (Ron, pg. 32). Hiding behind a mask was another strategy:

> *I mask to not let anyone see how mad or sad I feel at school even though I love learning. I don't really trust anyone at school. To manage my emotions, I hide how I feel – even until recently from my Mum (Hermione, pg. 24).*

There appeared to be a dual purpose to the girls' masking behaviours - working at a surface level in concealing difficulties coping with their school day but also conserving their emotional equilibrium. However, the consequences of maintaining an incongruent identity on their emotional wellbeing was evident and only alleviated with supportive networks of trusted allies.

### 4.3.2 Superordinate Theme 2: Balancing emotions

This led to the second theme where wellbeing at school also required autistic girls to conquer their fluctuating emotional states, retaining a balanced, resilient state of being. Maintaining this equilibrium relied heavily on external support, which was not always available.

#### 4.3.2.1 Subordinate Theme 1: Fragments of me

A common experience for the girls was the extreme effort of unpicking, managing and recovering from intense fusions of emotions throughout the school day. Their narratives were filled with fragmented feelings of sadness, anxiety, anger, stress and despair:

> *A day at school with poor wellbeing – I'm usually sad. I'm kinda angry. I'm less chatty and more quiet. I'm less able to cope. I'm more stressed out. I've got heightened anxiety and headaches. I'll be getting quite fidgety. I'll be less focused. and I'll be just like having troubles. I'll be quite stressed (Hermione, pg. 8).*

Feeling this way frustratingly depleted their energy, cognitive and social capacities: *"When someone upsets me it makes my wellbeing worse. It might hurt my feelings, it might frustrate me, I just get like stressed out or upset by things a bit more so that makes everything feel worse"* (Katniss, pg. 8). The rollercoaster impact continued into home life too: *"I just found everything an obstacle. And by the end of the day, I'd be tired. Homework would freak me out. I would get angry at my Mum and sister. I'll be driving myself literally insane"* (Ron, pg. 15).

### 4.3.2.2 Subordinate Theme 2: Anxiety is a thief

In addition to the co-occurring conditions of anxiety that two of the girls were diagnosed with, all the girls revealed the underlying stealth with which stress and anxiety seized their school wellbeing. *"I get really anxious – this happens all the time and whilst I'm in lessons. I literally can't think of what I'm doing with the work"* (Ivy, pg. 2)*.*  Katniss, with a sense of frustration, also reflected on this:  *"I can't concentrate on my work when I'm stressed and anxious and I usually do good work"* (Katniss, pg. 5).

For some, anxiety about adverse environmental or teaching conditions distracted them from their learning, as described by Hermione: *"The behaviour of the other students causes me extreme stress because I go to school to not mess around*" (Hermione, pg. 24*)* and Ron: *"You barely have time to learn at school…school becomes this massive prison that you're forced to stay awake in"* (Ron, pg. 34)*.*

For others, inflexible school policies or support strategies exacerbated their anxiety. *"Sanctions really stressed me out. It feels like you can't breathe and you're on edge the whole time. It really doesn't help an autistic girl because I was likely to panic in detention. It just really scares you"* (Ron, pg. 31)*.* Ivy reflected: *"There's no right choice that will sway my needs. I could hold up my Time Out pass so that I can walk to the Resource Centre but then I'd feel really nervous, and I haven't tried that yet"* (Ivy, pg. 10)*.*

Endurance strategies such as zoning out enabled the girls to be visibly but not mentally present: *"I'm thinking of every single possible thought, except for the work – I zone out "* (Lizzy, pg. 5)*. This had an accumulative daily effect on concentration and engagement: *"In school, 'she's' not there and every day the teachers expect you to be there but because you're so drained from the day before, you barely get enough sleep and then you're expected to listen"* (Ron, pg. 35)*.

Interestingly, none of the girls identified school staff as co-regulators for their anxiety, although friends who knew them well could step in and advocate on their behalf. Without trusted adult relationships at school, it seemed unlikely that the girls might reveal these experiences with anxiety and thus, the negative emotional -cognitive-behaviourial cycle and masking continues unabated.

### 4.3.2.3  Subordinate Theme 3: Positive vibes

Space to balance their emotions came from a variety of creative outlets. For Lizzy: *"When I'm having a really, really bad day or I've got a lot on my mind that I want to close off for a bit, I turn up the volume on my music…that helps me reset and feel better"* (Lizzy, pg. 12*) and Katniss: *"In the talent show, I sang 'On my own' from 'Les Miserables'. I enjoy singing so I felt joyful, and it helps relieve stress. When other people say that's really good, it makes you feel proud and happy"* (Katniss, pg. 1).

For both girls, music, drama and singing acted as a sensory shield to the rest of the world. They both recognised the power and energy that positive vibes created within their mental health as well as their own autonomy to access and influence these wellbeing strategies.

### 4.3.3  Superordinate Theme 3: Finding how I belong

Wellbeing at school depended on building relational networks that were trustworthy, empowering and sustainable. Autistic girls shared their desire for belonging via relationships in which they had a voice, their views were validated, and they enjoyed a meaningful connection to others. Feeling accepted and having their needs acknowledged and supported by others was important to their inclusion in the school and peer community.

#### 4.3.3.1   Subordinate Theme 1: Are you listening?

Building on the previous theme around balancing emotions, it took the participants considerable effort and courage to reach out for adult support at school. Three of the girls spoke about feeling intimidated when trying to give their opinions or ask for help, explaining that it was difficult to present your truth when it seemed no-one was listening, as described by Ron: *"I think I've been so used to not asking for that much at all at school…No-one's really bothered to listen – they just give strategies which worked only for the first week. They haven't really tried to properly help"* (Ron, pg. 30)*.* Feeling their experiences were invalidated or even ignored was a common occurrence: *"Some teachers can see I'm upset…they don't do anything about it…why do you feel like you shouldn't always try and listen to and help a student?"* (Katniss, pg. 4)*.*

Almost as intimidating as not being listened to: *"I've asked for support and not really got any back so…I did try and tell them"* (Hermione, pg. 9), or acknowledged was the girls' experiences of feeling 'dealt with' and de-prioritised: *"It's like we told them…they gave us a few strategies and then nothing else happened for the rest of the year. I would have wanted more but I wasn't top of their list."* (Ron, pg. 16)*.*

A common difficulty encountered by the girls was finding the right words to express their needs: *"For kids who don't want to talk, they won't talk, and they'll find it really awkward. And then when people ask why you aren't talking, you're too scared to say why…just traumatic"* (Ron, pg. 23). Ivy added: *"I get really nervous about talking. Talking to people is an everyday part of life and I kind of feel sad that I have this thing stopping me from saying more than a few words to people*" (Ivy, pg. 2)*.*

The more their anxiety accumulated, the harder it became to articulate what they needed to anyone who may be listening: "*On a bad day, it's hard to explain how you are feeling…when you're in the moment, it's very difficult to calm yourself down and think. So, when you're trying to explain it to someone you don't actually know, and you don't know what to do* (Hermione, pg. 11)*.* However, Ivy described feeling more comfortable talking with adults: *I find it easier generally to talk to adults but even that's getting harder and harder now that I'm growing up and I just feel really self-conscious no matter who I talk to.* (Ivy, pg. 11)*.*

Even talking to peers was described as challenging, for example, *"Even with my friends who I know really well, I find it hard, verging on the impossible, to say more than really basic stuff like 'hello' and 'how are you"* (Ivy, pg. 11) and often loaded with social communication nuances that left the girls feeling unheard and mis-understood:

> *It just makes me feel like I have nothing to say because when this girl came up to me and said 'why are you saying this?'...in the moment I'm lost for words, and I can't think of anything. I just freeze up (Lizzy, pg. 9).*

It seems unsurprising that given the effort taken to share their views and have them validated by others, it may have felt less demanding for the girls to mask their concerns, as previously identified. However, the onward effect of being unable to share views and participate fully or confidently in peer discussions was isolation and in some cases withdrawal: *"I had two friends but one of them didn't hang out with me at all and so I had only one real friend for the whole of the year. I had to stick with him every day…it was just really sad, and I became very lonely"* (Ron, pg. 35).

This felt a stark contrast to the strong sense of belonging to their families and ensuing responsiveness and support experienced by the girls, as Hermione describes here: *"Family is important because I can talk to them. They understand. They listen. They'll be trying to give me ways to cope and help the situation"* (Hermione, pg. 15).

Lessons from this resulted in a plea from Hermione which seemed to encapsulate the simplicity of listening to the voices of autistic girls: " *Do things that make you feel accepted when you're in school…just them [teachers] knowing can help"* (Hermione, pg. 9).

### 4.3.3.2  Subordinate Theme 2: Know me to help me

Too often, when help was provided, it felt generic or basic, often missing the mark: *"I can use the Time Out card…leave the classroom for 5 minutes and come back in but then I'm still angry coz I'm back in class where it's still the same" (*Hermione, pg. 5), and in some cases creating further difficulties:

> *Just small things in class that people think work…really don't. They should look in detail and depth at what works for them and what doesn't…coz if they go ahead and do something that will be a nightmare for them, it will probably traumatise them for a week or so (Ron, pg. 24).*

Where the girls' views were sought and they were invited to work collaboratively with adults, the ensuing support strategies were highly valued and appreciated: "*The student support teacher helps me tell teachers about things. I'm pretty involved in decisions because they like ask me"* (Katniss, pg.11*).* Consequently, the girls felt understood: "*It makes me happier when they [teachers] understand what I'm going through – they don't pick on me so much and they can try different approaches to getting me back into the lesson"* (Lizzy, pg. 8)*.*

Of fundamental importance to the success of collaborative working was sustained connections with key adults that were invested in getting to know the girls:

> *Become a bit personal with me…just get to know me. I would like it if you knew my name…it's just a general thing. Just because I'm quiet, I'm still in your class for a whole year or two – you should know my name (Ron, pg. 19).*

Ivy described her ideal teacher as: *"understanding, warm, comforting. I think it would make me feel safer. I do have teachers like that, and I feel really safe and welcome in their lessons"* (Ivy, pg. 12)*.*

As in previous themes, there was a repeated call for staff to proactively improve their knowledge around the needs of girls with autism. Reflections from the girls' experiences highlighted this as an immediate concern, as explained by Katniss here:

> *They don't know…most teachers don't know how to deal properly with someone who's got autism. People with autism sometimes can get more affected or upset or stressed out by certain things and that you need to be patient with us (Katniss, pg. 11).*

Staff support should always be individualised: *"When you're in a position like that, dealing with young children and teenagers, they really should be aware…know what an autistic person's triggers are…how they deal with things…how they live"* (Ron, pg. 25)*.*

### 4.3.3.3 Subordinate Theme 3: Connect with me

Social situations presented challenges that affected the girls' confidence and resilience: "*I'm struggling with peers in general…there's lots of people who really bring down your confidence. I found that happened to me. It's really hard*" (Hermione, pg. 24). They worried about a mutual disconnect and being isolated from their peer group:

> *I'm not very good at social situations. I tend to mess up. It impacts the other person and I feel really awful about it. Sometimes someone tries to make fun of me…people just like giving me dirty looks and saying stuff about me. It makes me feel alienated (Lizzy, pg. 6).*

Essential to successful connections with peers were shared interests, such as Harry Potter for Hermione: "*When I went to the Harry Potter Studio, I was in a place where everyone else is the same…everyone likes the same thing…so you're not alone*" (Hermione, pg. 14). Building on shared interests created a strong sense of belonging, validation and acceptance which seemed important to the girls' wellbeing: "*She was a tomboy too and when all the other girls liked dresses and nails (which wasn't my thing), being with her was different and she played the games I wanted to play*" (Ron, pg. 6)*.*

### 4.3.4 Superordinate Theme 4: Navigating the system

Whilst the previous three themes highlighted person-centered reflections around identity, belonging and emotions, this final group theme invites a holistic examination of the effect of surviving in a secondary school system on wellbeing. Support at school was conceptualised through attuned and individualised strategies

which circumvented the unpredictable nature of sensory, relational, cultural and emotional challenges of secondary school life.

### 4.3.4.1 Subordinate Theme 1: Pressure zone

A significant challenge for many of the girls was juggling internalised pressure to do well in their learning alongside high expectations from their school. This led to conflict and tension. Difficulty containing the resulting anxiety and frustration seemed to affect their ability to cope with the high cognitive load of school life, as explained here:

> *They've put me in top set for a subject I'm awful in, so they have high expectations of me. It's pressurising – like if I don't do well, they'll be disappointed in me. If I don't do well, then I've failed. I don't really feel happy about that (Lizzy, pg. 1).*

> *We'll do a really large amount of work to a really high standard in a small amount of time … and then because I'm a perfectionist and if I don't do as well as I can, then I'd start over. I feel disappointed in myself. Sometimes this feeling becomes quite overwhelming (Katniss, pg. 8).*

Homework presented an additional burden, especially given the effort required by the girls to survive the school day and recover from camouflaging their differences and emotions: *"It's unreasonable… like they give us a ridiculous amount of class work and then there's a massive amount of homework…and they have ridiculous expectations of us"* (Katniss, pg. 8)*. Often this felt beyond their control: *"We're starting GCSE so I kinda have to worry about and remember the homework in case the teachers don't put it online and trying to get the rest of my work done to the best of my ability"* (Ivy, pg. 3)*.

For three of the girls, the accumulative effect of these conflicting pressures was emotional based school non-attendance: *"Usually, I don't wanna be in school. Having had bad days at school before, it just makes me not want to go because if something bad happened the day before, then who knows what the day would bring" (Lizzy, pg. 4).* Hermione also shared: *"I spoke to Mum and Dad and asked if they can speak to school about home school as I did not want to go as things have been" (Hermione, pg. 25).* Pressure to attend and school's inflexible responses added tension to the family unit: *"I found it very hard and difficult the whole time. It feels like you can't breathe and you're on edge the whole time. I think the only reason I went in was because my Mum would have been fined…more" (Ron, pg. 13).*

## 4.3.4.2   Subordinate Theme 2: Surviving in an uncertain world

Uncertainty in the classroom was generated by poorly behaved students and teachers struggling to maintain an orderly learning environment. Girls described the sensory overload that noisy peers created and the subsequent distractions to their learning:

> *I know this isn't the teachers' fault but some of my teachers don't have control of the classroom at all. Most students believe they can just talk all the way through…which is annoying for kids who wanna get the lesson over and done with…without any hassle. That really stresses me out. It's quite overwhelming and I can't focus properly. It's not fair on people who have problems with the surroundings (Ron, pg. 9).*

> *Yeah, the students in the class, they're not that well behaved and the noise as well. That can just trigger me to be angry coz they don't really behave that well. It's not controlled. It should be a peaceful environment and teachers should stop it before it gets to that extreme (Hermione, pg. 7).*

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> *I had a teacher in science who just every now and then…he would just shout. Like from talking to shouting. It really freaked me out. It was just too much, and I couldn't leave. I was shaking – it was awful (Ron, pg. 10).*

The way that teachers responded to the girls' sensory and emotional needs sometimes lacked empathy: *"Instead of just instantly assuming and shouting at someone, like think more about it…you just don't know how this feels"* (Ron, pg. 9). Student's requests for adjustments were not always honoured: *"My teacher makes loud noises with his hands, and he can always see that I'm looking annoyed, but he just laughs and carries on"* (Katniss, pg. 3).

At other times, anticipatory anxiety for unplanned changes to the timetable or impromptu tests caused a problem, as explained by Hermione:

> *Yeah I don't like not knowing what's gonna happen ahead. It's really quite scary in my opinion. I need to know what's happening. If I don't then all I'm feeling is anxiety and then I'm not learning anyway. When we're given surprise tests or a quiz or something to do under a time limit, that's just not possible. It would just send me into tears if anything like that happened. (Hermione, pg. 11).*

Revitalising or calming strategies which helped regulate anxiety and stress caused by the school system included music, craft and breathing: *"I usually listen to my playlist. I listen a lot to the same tunes depending on what mood I am in. With music I can listen to it and still be aware of what's going on around me. It doesn't cut me off completely"* (Katniss, pg. 5). It was noticeable that these strategies could be independently activated with supportive school policies in place: *"I use my 5 minutes Time Out card – it just gives me a chance to reset*

*and not have to deal with what's going on in the classroom. I can literally just sit outside and take a deep breath and try and re-focus" (Lizzy, pg. 4).*

### 4.3.4.3 Subordinate Theme 3: Sanctuary

To restore the girls' wellbeing at school, they found safe spaces where they could escape from the noise, pressure and social demands, as described by Ivy: *"The library is kinda quiet and less social obligations than anywhere else as no-one really comes to talk to me, so it gives me time to re-charge. It's sort of welcoming and safe"* (Ivy, pg.4) and Hermione: "*I struggle with the noise in the atrium at lunchtimes when I have to mix with the older years" (Hermione, pg. 25).*

Their quest was not always easy: *"Trying to find a place which is quiet is hard. Because at school there's a lot of people everywhere. Put me in a room where it is more calm…a room where there's less people"* (Hermione, pg. 18).

However, refuge didn't always have to be a physical place: *"When I watch the whole series, I just forget about life…I travel into the screen, and I am there. I am free"* (Ron, pg. 19). Immersion in fantasy realms represented opportunities for alternative experiences: *"Sometimes the worlds I read about are harder than the world I live in but it's sort of easier to be in that world"* (Ivy, pg. 5).

## 4.4  Summary

The key findings in this chapter described how autistic adolescent girls construct their wellbeing at school around key themes related to identity, managing emotions, belonging and navigating their learning and social environments. School factors that support the girls' wellbeing were identified throughout.

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*Wellbeing is a political choice. It is the outcome of policies,
institutions, economies and ecosystems in which people live.
Wellbeing requires a whole-of-society approach involving actions
across all levels.*

*Catalyse and support this movement by ensuring that people and
communities are enabled to take control of their health and lead
fulfilling lives with a sense of meaning and purpose, in harmony with
nature, through education, culturally relevant health literacy,
meaningful empowerment and engagement.*

World Health Organisation (2021).

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## 5.1   Overview

This chapter begins by responding to the research question and ends with a
clear call to action for stakeholders in the wellbeing of autistic girls at secondary
school. The extent to which this study links to the existing literature base and
theoretical foundations of wellbeing, adolescent development and autism are
reviewed, followed by critical analysis of the strengths, limitations, opportunities and
barriers of the research within the study's paradigm and research methodology.
Implications for transformative practice are also discussed.

### 5.1.1 Review of the aims of the research

The research question addressed in this study was:

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**What are the lived experiences of adolescent autistic girls'**

**wellbeing at school and what factors support this?**

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Appendix 2.8 recaps the aims of the research project, from the dual perspectives of the co-researchers (who shared their hopes and aims for the project across the first three co-planning workshops) and this researcher.

## 5.2 What are the lived experiences of adolescent autistic girls' wellbeing at school?

The primary aim of this study was to use a participatory approach to empower adolescent autistic girls to make sense of their school wellbeing experiences and identify supporting school factors. Implications for school support have been discussed in detail in the implications for practice. Also, of interest to stakeholders of autistic girls' wellbeing may be the participatory methodology used and key learnings on how to empower and emancipate the views of this unique community.

Findings from this research suggest that the lived experiences of autistic girls' wellbeing in their mainstream secondary schools are situated in four main themes which continue to align within a developmental and environmental framework: *Working out who I am; balancing emotions; finding how I belong*; and *navigating the system*. These are now explored further in relation to the existing literature base and psychological theories relating to wellbeing, autism and adolescent development.

Figure 5.1 provides a visual mapping of the four key themes emerging from this study, onto an eco-systemic model of the individual, social, school and community environments (Bronfenbrenner & Bronfenbrenner, 2009). It is noticeable that not all of the key themes start from a within-person focus. Equally important is the influence of multiple eco-systems on different factors in a theme.

### 5.2.1 Positive and negative wellbeing at school

Co-researchers requested a graphic representation of the feelings or emotions associated with their wellbeing, via a word cloud (see Figure 3.12 for an example). As this visual synthesis highlights the frequency of words used, it became clear that overall, a stronger negative association with school wellbeing was made. This was despite a balanced research approach to exploring their experiences.

This may indicate that despite schools' efforts to identify issues and adapt their practice, there are still significant barriers to wellbeing at school for these girls. The key themes underlying these experiences of school wellbeing are now discussed in the light of identified literature and theories.

**Figure 5.1**

*Systemic overview of adolescent autistic girls' lived experiences of school wellbeing (Connolly, 2024)*
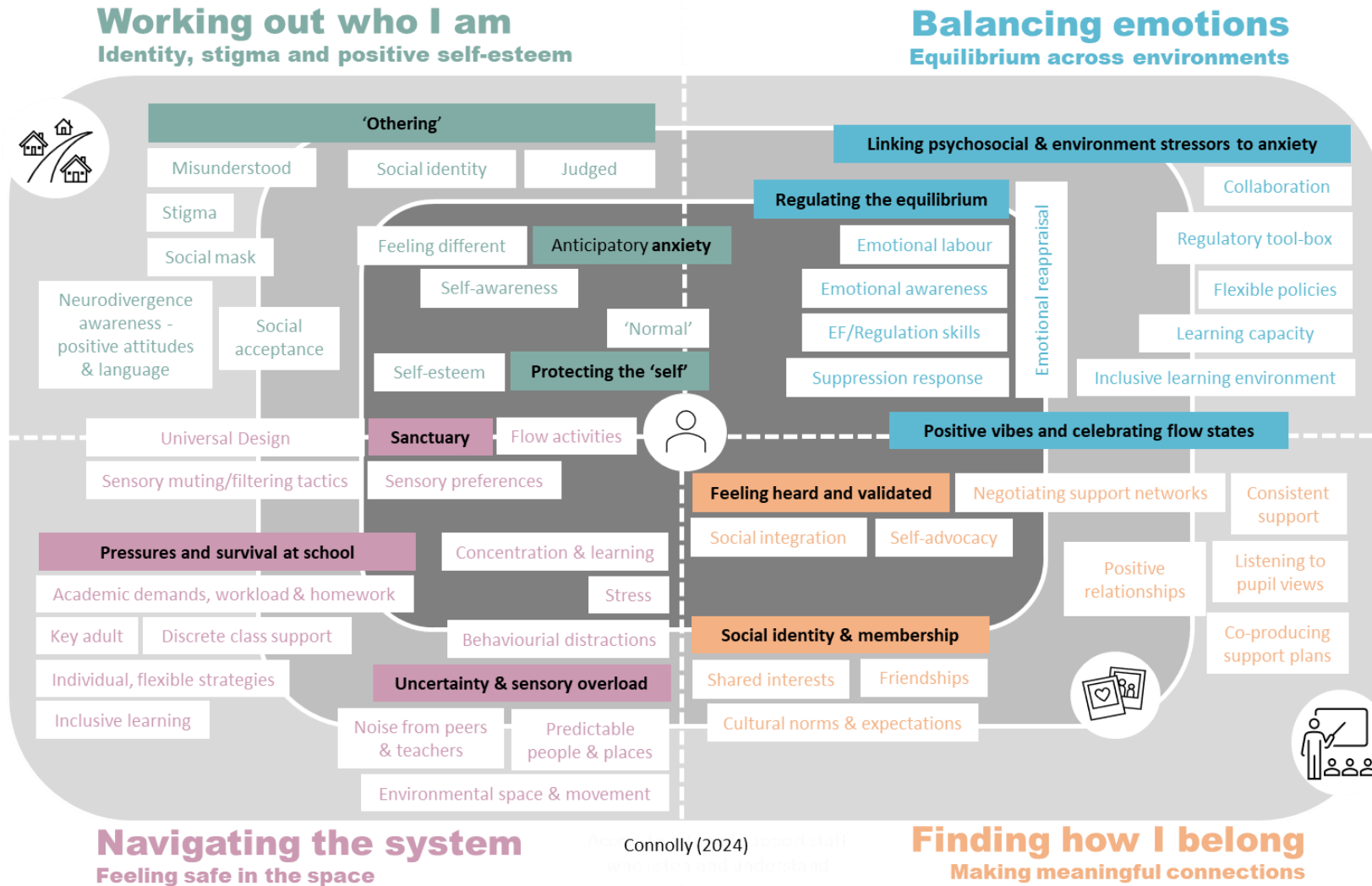
### 5.2.2 Theme 1: Working out who I am – identity, stigma & positive self-esteem

Participants in this study revealed their stigmatising experiences of feeling different from others, and what that meant for their emerging self-concept during adolescence. Inherent within this self-exploration was the impact on their anxiety and general wellbeing of presenting an unauthentic and misunderstood version of themselves each day at school. Coping strategies for experiencing autism as a stigmatising identity included concealment, masking and reframing.

#### 5.2.2.1 'Othering' and anxiety

A late diagnosis of autism in secondary school typically coincides with a transitional period of developmental and social turmoil where survival depends on stabilising identity (Erikson, 1968) and successfully bonding with others (Tierney et al., 2016) to avoid social isolation (Brennan de Vine, 2022). Findings from this research indicated that wellbeing at school was twice impacted by the girls' journey of developing self-awareness and identity. Firstly, by feeling constantly judged by their peer group and teachers, and secondly by being misunderstood, with their behaviours interpreted via a neurotypical lens (e.g., 'zoning out' implying disrespecting the teacher rather than a restorative act).

In addition to their own sense making around feeling 'different', anticipatory anxiety of being judged and found lacking was often internalised, resulting in the girls feeling paranoid and watchful. These early experiences are troubling given wider evidence that some autistic women develop negative internalised views of themselves as 'wrong' or 'flawed' based on their experiences of being misunderstood by others (Yau et al., 2023), which can lead to significant mental

health issues. Early experiences at school of having to meet the expectations of others may also foster feelings of distrust and being unworthy of accessing support, which could restrict their wellbeing provision (Yau et al., 2023).

As a contributor to poor wellbeing for autistic girls, social anxiety from peer evaluation has been broadly evidenced. From a clinical perspective, anxiety symptoms in teenage girls are often accelerated by comparisons and expectations from others (Jackson et al., 2022). Research in schools by Tomlinson et al., (2022) reported anxiety, alongside a range of other secondary mental health difficulties, arising from their interviewees' awareness of being different from peers. Moyse (2021) also reported on the tension and anxiety autistic girls felt by not wanting to stand out as having different learning needs from their peers versus growing self-awareness of their need for discrete adult support. In all cases, there is an inherent social injustice and power imbalance in the 'othering' experienced by autistic girls at their secondary school that clearly impacts their wellbeing.

### 5.2.2.2 Protecting the 'self'

Construction of autistic identity may have an adaptive function, in line with the adolescent developmental tasks of building social identity and self-concept (Duszak, 2002; Erikson, 1968). Three different adaptations to protecting the stigmatized[26] self, via different routes to identity creation, are now discussed, along with associated impact on wellbeing.

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[26] Stigma can be defined as a socially constructed concept that is experienced by minoritised groups, who may feel discredited and less valuable in society. Stigma can be internalized by an autistic individual or enacted on them by others (Turnock et al., 2022).

Evidence suggests that stigmatisation and marginalisation can be avoided where discursive distance is created between the self and constructions of autism (Morgan, 2023). For example, in this study, one of the participants flagged attending extra-curricular clubs as a core feature of her social identity which may seem incongruous to the known social interaction difficulties associated with autism.

A normativity discourse related to a sense of belonging within their autistic community partially facilitates autistic girls' wellbeing. According to respondents in Halsall et al's study (2021), dual attendance at an autism resource base in a mainstream school had a positive impact on wellbeing, with enablement of authentic self as autistic students learned alongside their neurodivergent peers. However, later integration with neurotypical peers in the mainstream environment necessitated concealment of differences, resulting in a lack of belonging to both neuro-typical and autistic peer communities (Halsall et al., 2021).

Finally, the incongruence and emotional labour of hiding their authentic self behind a social mask was difficult for some of the girls in this study to deal with. Inherently, it felt like the school environment was positioned as a hostile world in which the authentic self could not be revealed, and adults could not be trusted to respond appropriately and supportively. This aligns with existing research in which revealing one's diagnosis of autism resulted in 'babying' by teachers (Myles et al., 2019) or discrimination through problem-based language by school professionals (Moyse, 2021).

Protective behaviours were described as containing emotions and waiting for a safe space or person to release emotional tension. These school-based experiences were presented in stark contrast to the sense of belonging gained in different social worlds outside the school gates which the girls in this study individually reflected on.

Findings from this qualitative research supplement quantitative analysis on the positive relationship between higher satisfaction with autistic identity and high psychological wellbeing as well as lower social anxiety (Cooper et al., 2022). However, the discovery of 'self' seems compromised by systemic roadblocks related to local and societal attitudes towards neurodivergence and lack of ownership by school staff for promoting positive perceptions and social acceptance of autistic identity.

Recognising the complex challenges of helping members of a stigmatised group build self-esteem (Cooper et al., 2017) is especially important when adapting wellbeing interventions in school. School leaders arguably have a role to play in improving wellbeing by de-stigmatising autism and supporting girls to develop a positive self-esteem.

The importance of thinking about the language and key messages used to describe autism, in challenging stigma and preventing internalised low self-esteem, needs to be considered by supporting adults at school as part of CPD and systemic practice. Whole school approaches focusing on neuro-affirming

school culture promotes acceptance, tolerance and diversity (Barker et al., 2021; Bond & Hebron, 2016; Botha et al., 2020).

### 5.2.3  Theme 2: Balancing emotions – equilibrium across environments

Following on from the anxiety-ridden quest to find a positive sense of self, the effort of dealing with other emotional states (often fluctuating intensely throughout the school day) was described. Environmental-based anxiety also featured in the girls' wellbeing narratives and whilst relational support from peers somewhat restored their school experiences, an absence of trusted adults was reported to exacerbate the negative emotional-cognitive-behavioural cycle.  On an optimistic note, the autistic girls described 'positive vibes' emanating from restorative activities, such as performance or arts, and recognised their agency in accessing these 'sensory shields' for their wellbeing.

#### 5.2.3.1   Regulating the equilibrium

The emotional labour of coping with their school day was evident in this study. Aside from their intense feelings, a secondary impact on the girls' wellbeing, was frustration at their lack of emotional awareness and regulation skills and the effect this had on their social and learning capacity, both at school and home.

Difficulties maintaining a balanced state of emotional wellbeing at school has not been specifically identified in existing research for autistic girls' wellbeing although Halsall et al. (2021) noted the emotional cost of masking (resulting in frustration and anxiety at school and sometimes, anger and exhaustion at

home). Therefore, the finding that autistic girls experience difficulties with their wellbeing because they are trying to balance their emotional equilibrium at school may represent a unique contribution to the evidence base. The broader literature was examined to understand the psychological underpinnings of this phenomena.

It is well documented that autistic individuals use emotional regulation strategies less frequently than their neuro-typical peers, resulting in higher symptoms of internalising and externalising issues (Jahromi et al., 2012; Rieffe et al., 2011). However, the wellbeing of autistic young people may be influenced by the amount to which they can re-appraise their emotional memories versus supressing them (Cai et al., 2019). This relies on psychological flexibility, using executive functioning skills such as working memory and shifting (McRae et al., 2012).

Whilst in the longer term being able to think again about emotional situations and see them in a different light may improve positive wellbeing, supressing regulatory responses can be beneficial in the short term. For example, individual needs sometimes disrupts a pattern of spiralling negative emotions to put some distance between themselves and a stress trigger (Butler et al., 2003) such as the camouflaging strategies employed by autistic girls. However, when suppression of regulatory responses becomes a habitual pattern, the young person is likely to need support to learn different ways to cope with stressful situations, to reduce anxiety and depression (Cai et al., 2019).

A different but connected psychological lens in which to view the emotional imbalance experienced by autistic girls' is by understanding their emotional awareness. In typically developing young people, emotional awareness enables young people to monitor their emotions, understand triggers and respond appropriately to the physical arousal of feelings (Rieffe et al., 2008).

However, autistic young people sometimes have a fragmented understanding of their emotional experiences and are therefore less likely to pay attention to the value of emotions or notice how external bodily sensations are linked to an emotion evoking scenario (Rieffe et al., 2011). Further to this, autistic young people are more likely to mask their emotional states if they feel that expressing them will not meet their goals or be helpful in maintaining relationships (Rieffe et al., 2011).

There are few studies that explore sex differences in emotion awareness however the attentional aspect of monitoring the emotional states of others may be neurologically linked to identifying and describing one's own state of emotions within the shared network model of empathy (Preston, 2007). This can result in a reduced ability to recognise and label emotions (a.k.a. alexithymia[27]) which has been identified in higher levels amongst autistic women than men (Ketelaars et al., 2016). This affects a female's ability to recognise low intensity visual emotions in others and regulate their own emotions, leading to poorer psychological health (Weiner et al., 2023).

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[27] Alexithymia creates difficulties identifying and communicating one's own emotions and has been linked to anxiety, depression and emotional dysregulation in adolescent girls (van der Cruijsen et al., 2019)

These difficulties coincide with a developmental period in which challenging relationships and extended social interactions become important to autistic girls. Due to increasing recognition of the overlap between the suggested female phenotype[28] of autism and alexithymia (Poqruéusse et al., 2018), wellbeing support for adolescent autistic girls could improve their emotional equilibrium through psychoeducational programmes that focus on recognition and expression of the facial emotional expressions of others (Cook et al., 2013; Costa et al., 2017), recalling emotional memories (Luminet et al., 2006) and cognitive re-appraisal[29] of emotional situations (Patil et al., 2016).

Empowering the girls to develop a repertoire of regulatory strategies to flexibly suit their individual needs (Bonanno et al., 2004) would potentially decrease suppression tactics, enable the girls to adapt their regulatory response to any given situation and reduce anxiety and frustration (Cai et al., 2019). Looking beyond a within-person perspective, recognising the role of the environment and other people in creating stressors that contribute to emotional dysregulation is also important.

### 5.2.3.2   Linking psychosocial, environmental stressors and anxiety

Girls in this study described the effect of psychosocial and environmental stressors (e.g., from the poor behaviour of peers, inflexible school policies and lack of support from teachers) on their anxiety and subsequent difficulties focusing on their work. This extends findings from Higgins (2022) who

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[28] Critics of the concept of a female autistic phenotype suggest that some of the difficulties of being an autistic female originate in society's culture expectations of women's behaviour (Bargiela et al., 2016).
[29] Cognitive re-appraisal requires the individual to look again [at an emotional situation] and re-interpret it to alter the way they think about it (Lazarus & Alfert, 1964).

suggested that disrupted learning (because of the poor behaviour of other students) created classroom anxiety, and somewhat aligns with collaboration difficulties reported by Moyse (2021), resulting in disengagement with group work when the poor behaviour of their peers impacted the girls' concentration on the task.

Similarly, Sproston et al., (2017) reported parental perceptions on the impact of 'naughty' classmates who distracted their girls' learning experiences and suggested that a greater level of student-teacher interaction and flexibility in teaching style might enhance student engagement for everyone. Additionally, enhancing partnership working between all pupils has been posited as a useful way to appreciate individual talents and improve peer interactions more generally (Moyse, 2021) although girls in this study said they found working with peers anxiety provoking.

Failure to promote an inclusive learning and social environment at school may result in emotionally based school non-attendance for some autistic girls (O'Hagan et al., 2022), including those in this study. Inflexible school policies including receiving inappropriate sanctions, was repeatedly flagged as exacerbating anxiety throughout the literature (Goodall & MacKenzie, 2019: Sproston et al., 2017). Wider wellbeing issues of integrating a sense of safety and discipline within the school climate[30] were acknowledged by Barker et al.,

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[30] School climate has been described within a theoretical research framework as the multi-layered environment in which learning, physical, safety and social experiences occur (Rudasill et al., 2018).

(2021) in their review of the role of school culture in supporting pupil mental health.

### 5.2.3.3  Creating positive vibes and celebrating flow states

Girls in this study described how their creative interests (e.g., reading, painting, listening to music, drama and craft) helped balance their emotions and provide external validation, as well as a shared sense of belonging.   Previous research suggests autistic children's interests may serve as a coping mechanism against school stress (Goodall, 2018a; Humphrey & Lewis, 2008) and help bring a reluctant learner back into the classroom, (Gunn & Delafield-Butt, 2016).

Attentional strengths related to task immersion and 'flow states'[31] are often reported for autistic individuals (Rapaport et al., 2023). Research shows that encouraging students to access activities at school, which are intrinsically linked to their preferred interests, can support their learning and wellbeing (Wood, 2021). This helps students relax and make sense of their world (Gunn & Delafield-Butt, 2016), as well as improving their emotional wellbeing (Winters-Messiers et al., 2007).

Being able to independently access such activities at school could further support wellbeing by increasing individual agency (Seers & Hogg, 2021),

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[31] Individuals working in a state of 'flow' experience an automatic, effortless and highly focused state of creativity, according to Csikszentmihalyi (2013).

encouraging peer engagement (Wood, 2021) or simply providing comfort (Wassall & Burke, 2022).

### 5.2.4 Theme 3: Finding how I belong - making meaningful connections

This theme encompassed aspects of school belonging, validation and meaningful connections with teachers and peers, which supported the girls' autistic identity and inclusion. Shared interests were cited as a core facilitator to maintaining friendships. The effect on wellbeing of feeling understood and accepted was lower anxiety and reduced need for camouflaging their authentic self.

#### 5.2.4.1 Feeling heard and validated

A fundamental barrier to school wellbeing was identified by girls in this study through their experiences of not being listened to or having their views validated by those that could help. Exclusion from conversations about wellbeing, lack of attuned response from teachers and feeling 'fobbed' off with generic support strategies were also reported, in line with existing research (Brennan de Vine, 2022; Tomlinson et al., 2022). A lack of social integration could be an early indicator of poor wellbeing because throughout adolescence, autistic girls rely on peer influence (Chodkiewicz & Boyle, 2017) and adaptive social skills to help them navigate the demands of the secondary education system and adult relationships (Brennan de Vine, 2022; Tierney et al., 2016).

Difficulties sharing views, building self-advocacy skills and negotiating support networks have been previously reported (Moyse, 2021; Myles et al., 2019). Nonetheless when girls were empowered to share their experiences of

neurodivergence and wellbeing, increased sense of school belonging and higher wellbeing were achieved (Brennan de Vine, 2022; Moyse, 2021; Myles et al., 2019).

Another barrier to developing school belonging was a lack of understanding from teachers about the heterogenous nature of girls' autism (van Herwegen et al., 2019). Generic wellbeing strategies were posited as a response to drawing on autistic behavioural stereotypes (Humphrey & Lewis, 2008). Specific issues with inconsistent support from supply teachers were also raised, resulting in anxiety about having to justify misconstrued regulatory behaviours (Tomlinson et al., 2022). Given the unique individual and contextually relevant experiences of autistic wellbeing, it is key that the voice of the young person informs their support plan (O'Hagan et al., 2022).

Working collaboratively with others to define their wellbeing needs and co-producing a support plan helped the girls feel their contributions were recognised and valued (Moyse, 2021). Understanding that autistic girls value their wellbeing over their academic achievement may go some way to redressing the foci in schools (Moyse, 2021), in line with guidance promoting wellbeing from the Department for Education (2021).

### 5.2.4.1   Social identity and membership

An important adolescent developmental task is the creation of a social identity (Blakemore & Mills, 2014), leading to community membership. Autistic young people construct their social identity based on fitting in with cultural norms and expectations (Ringland et al., 2016) and their subsequent sense of belonging is reinforced through positive relationships with peers and teachers (O'Hagan et al., 2022).

Secondary school often represents challenges in dealing with deteriorating or changing relationships because of diverging interests in friendship groups (especially with non-autistic peers) according to Myles et al., (2019). A lack of shared interests serves to distance autistic girls from their peers (Myles et al., 2019; Tierney et al., 2016) but where structured and safe clubs are facilitated by adults at school, autistic girls found it easier to overcome social interaction difficulties and cultivate new friendships (Brennan de Vine, 2022; Cook et al., 2018).

As social demands of relationships increase, autistic girls may find it difficult to cope with the subtleties of emotional cues such as eye rolling or shared glances (Dean et al., 2013) and maintain friendships (Cook et al., 2018; Sedgewick et al., 2015; Tierney et al., 2016). Yet the emotional support and comfort offered by friendships is integral to positive school wellbeing and happiness for girls with autism (Brennan de Vine, 2022; Myles et al., 2019; Pickup, 2021; Sedgewick et al., 2015).  Indeed, sharing interests with friends and feeling accepted have been recorded as protective factors for mental health (Brennan

de Vine, 2022; Myles et al., 2019) resulting in improved mood, reduced anxiety and feeling more motivated to attend school (Brennan de Vine, 2022).

Girls in this study found it tricky to create meaningful connections with supporting adults at school. Other studies also highlighted unsupportive relationships with teaching staff (Goodall, 2018a; Hummerstone & Parsons, 2021). However, staff who understand the girls' autism make a profound difference to their wellbeing (Goodall & MacKenzie, 2019). Listening to the girls' views around their confidence in social interactions, sense of belonging and peer-related interests helps school staff adapt the group environment, so it becomes a safer space for autistic girls. This may include cross-peer and cross-neurodiversity friendship networks, as recommended by Halsall et al., (2021) which generalises belonging. Extending friendships to other social activities outside of school is also important (C. Ryan et al., 2021). See also Section 5.5.2.4.

### 5.2.5  Theme 4: Navigating the 'system' – feeling safe in the space

Recent advice issued by the Department for Education (2021) highlighted the important influences of the school culture and ethos, and environment on pupil wellbeing. This raises questions around to what extent can wellbeing be truly separated from the context in which it occurs? Girls in this study flagged systemic issues related to feeling overwhelmed by the unpredictability of school life and the sensory environment. Seeking sanctuary, whether in physical or metaphorical spaces provided brief wellbeing respite from the pressures of navigating the school system.

### 5.2.5.1     Pressures and survival at school

Stress and anxiety caused by academic demands was common within the experiences of girls in this study and across the literature base (Horgan et al., 2023) with increased workload (Saggers, 2015), demand anxiety leading to perfectionism (O'Hagan et al., 2022) and additional burden of homework (Neal & Frederickson, 2016), particular triggers for poor wellbeing.

Survival relies on discrete support in class (Moyse, 2021) rather than working in smaller groups outside of the class (Saggers, 2015). Teachers who respond individually and flexibly to the student's needs, facilitate opportunities for safe, collaborative conversations and who promote inclusive learning and environments (Goodall & MacKenzie, 2019; Hull et al., 2017; Jacobs et al., 2021; Jarman & Rayner, 2015) play an important role in creating positive wellbeing experiences for autistic girls in secondary schools. Given the limited time that different teachers have with individual young people at secondary school, having a key adult that the girls can trust and who is accessible creates confidence to ask for help (Jacobs et al., 2021).

### 5.5.2.2  Uncertainty and sensory overload

The transition to secondary school creates a novel context for the wellbeing of autistic teenage girls, with the environment itself often presenting a significant challenge (Mandy et al., 2016). Many secondary school environments are dynamic open plan settings which are typically designed with the sensory profile of neurotypical students in mind (Ashburner et al., 2008; Jarman & Rayner, 2015).

Evidence suggests that environmental challenges of moving to a larger mainstream setting include feeling overwhelmed by the physical size of the buildings and site (Makin et al., 2017), and being in closer proximity to more children who are moving with greater frequency around the site (Birkett et al., 2022), resulting in feeling 'out of place' (J. Davidson, 2010, p.306), stressed (Goodall, 2018) and experiencing sensory overload (Clince et al., 2016). In addition to the distracting behaviour of other students (previously discussed), sensory overload contributed to poor emotional and physical wellbeing for the girls in this study.

Neurological differences in sensory processing mean that autistic students can experience environmental stimuli differently to neurotypical individuals (Donnellan et al., 2013). Noise from peers and teachers, has been noted as a consistent problem, impacting concentration and learning (Jacobs et al., 2021). When supporting sensory wellbeing, it is critical that teachers take time to understand that sensory differences vary between autistic individuals and there is not one common profile (Crane et al., 2009).

### 5.2.5.2    Sanctuary

Where autistic students have become spatially or relationally marginalised within their mainstream school, they often search for spaces of sanctuary (Birkett et al., 2022). Sensorial navigation of the school environment can be likened to the camouflaging strategies used to avoid stigmatisation or bullying (Cook et al., 2018) within autistic girls' relational spaces.

Sanctuary may provide short term relief from emotional overload but in excluding themselves from their peers by finding different spaces in which 'to be', autistic girls risk longer term wellbeing issues from social isolation and a decreasing lack of belonging (Birkett et al., 2022; Brennan de Vine, 2022).Such challenges have been previously noted where girls attend mainstream secondary settings with autism resource bases (Symes & Humphrey, 2011). However, some mainstream schools have tailored, more intimate spaces for autistic pupils that provide a refuge from the sensory overload of navigating the main educational spaces (Sproston et al., 2017).

Previous studies highlight that in the absence of specific neurodivergent-friendly spaces, autistic children actively seek sanctuary in quieter, more ordered spaces (Birkett et al., 2022), with the school library an often-cited favourite (Humphrey & Lewis, 2008). Sensory 'tactics' (de Certeau, 1984) include muting environmental noise by using headphones or filtering the physical space to find more comfortable micro spaces (S. Ryan & Räisänen, 2008). Finding refuge in focused or 'flow' activities, such as reading, playing music or crafting (mentioned by the girls in this study), also creates a transformational, metaphorical safe space (e.g., a self-designed, agentic 'production' of space) according to de Certeau (1984). This further reinforces Goodall's notion that inclusion can be 'a feeling, not just a place', (2018b, p. 1661).

In addition to examining the inclusivity of shared environments within secondary schools (Birkett et al., 2022), supporting adults should also understand individual sensory sensitivities and preferences so that wellbeing provision can be fully tailored (J. Davidson, 2010).

## 5.3 Theoretical implications

This study raises important questions around the ontological status and social construction of autism, wellbeing and gender stereotypes. As experienced by the girls in this research, the deficit status of autism and normative bias of neurodiversity generally in schools has a significant influence on how teachers and other supporting adults receive and respond to issues of autistic wellbeing.

Through highlighting the socio-cultural, environmental and developmental demands on wellbeing for autistic teenage girls, as well as reframing their coping strategies as differences and agentic in nature, it is possible to challenge perceptions of autistic pathological dysfunction and position school wellbeing within the context of a social disability and neurodiversity paradigm (Seers & Hogg, 2021). Maintaining a holistic perspective and systematically examining the impact of the school environment, policies and practice, relationships, and culture and climate using an Ecological Systems model (Bronfenbrenner & Bronfenbrenner, 2009) may go some way to conceptualising autistic girls' wellbeing as a unique multi-dimensional construct (Figure 5.1).

Whilst aligned with a developmental perspective of adolescent tasks and using an eco-systemic framework, no single theory of wellbeing underpinned this research.

However, a positive psychological approach to wellbeing encompassing emotional, social and psychological wellbeing as well as cultural and community awareness was incorporated throughout.

Future research with a broader sample of teenage autistic girls could examine the validity of this systematic overview of wellbeing which incorporates the individual (identity), relational (belonging), community (acceptance and inclusion), environmental (sensory and safety) and academic elements discovered through the lived experiences of girls in this study. A longer-term perspective of exploring the interlocking dynamics of family, staff and community wellbeing may further catapult wellbeing practice beyond the school gates.

## 5.4  Critical reflections

A robust critique of the value and impact of this study utilised the researcher's reflections to analyse the strengths, limitations, opportunities and barriers of the chosen methodology and findings.

### 5.4.1  Strengths

#### 5.4.1.1  Community generated research

First and foremost, this project emanated from the autistic community, personal interest and professional educational psychology practice. Recognising that the voices of adolescent autistic girls were missing from the literature and practice-based evidence inspired the research topic, paradigm and resulting methodology. The findings illustrated distinct areas of autistic wellbeing practice which schools and supporting professionals need to take

note of. Whilst this was a short-term research project, it built knowledge and created change for and by the autistic community.

Critical to the creation of new and meaningful knowledge was the emancipation of CYP's voices – an acknowledgement that challenges fundamental assumptions and power relations in the school system about the role of young people in actively shaping their education (Cook-Sather, 2006). By elevating participation in the research beyond 'student voice', this study showcases the capability, ambitions and potential for CYP leading transformative and socially just action in schools.

### 5.4.1.2 Efficacy of participatory research methods

Aligned to the transformative paradigm of this research, it felt important to help future researchers understand to what extent participatory research methods lead to effective working with autistic young people (Beresford et al., 2004). It was also hoped that reasonable adjustments which facilitated gaining pupil voice and promoting autistic community assets would be highlighted.

The participant-led approach used in this study is also a strength as the co-researchers' needs could be flexibly accommodated at each interaction point (Buttimer, 2018b). Despite initial concerns about relinquishing control to the co-researchers, the more responsive the sessions became in terms of accommodating the co-researchers' interests and ideas, the more engaged they were in the design of the study, as seen in these extracts from the research diary – see Appendix 3.1. However, it should also be acknowledged that the

participatory process is complex and messy – resulting in a limitation in terms of attrition rates towards the end of the project (Limitations, Table 5.1).

Extracts from the researcher's diary also recorded the reasonable adjustments most valued by all researchers in this study (Appendix 3.2 for more details).

Four key adjustments were valued by co-researchers in this study:

- *Creating a safe psychological space* – thinking about boundaries and agency
- *Improving accessibility* – being technologically and creatively flexible
- *Thinking time* – acknowledging differences in processing time and the role of social anxiety in formulating responses and joining the conversation
- *Quality of relationships* – opportunities to share stories, get to know each other and build a community.

Co-researchers were also instrumental in guiding the dissemination process though revisiting how to share the findings of the study at key points during the study (e.g., when thinking about the purpose and value of sharing their own interview summaries with their schools). Despite the lower co-researcher participation - by the end of the workshop series – consideration of who should receive the findings and what use they may make of them was a valuable discussion (see Figure 5.3). More regular review of the dissemination process (perhaps incorporated in the hopes and goals) may have enabled more consistent co-researcher input.

### 5.4.1.3  Reflexivity and reflective practice

As discussed, critical to identifying what worked well was review (in individual and guided supervision) of the researcher's reflective diary. The artistry of professional reflexivity has been helpfully defined by Thompson and Pascal (2012) as a way of looking back to ensure that professional knowledge has been used to the full, the practitioners' actions are compliant with what they know and value, and there are opportunities to learn and develop. It is a core skill mandated by EPs' regulatory body that practitioner psychologists 'be able to reflect and review their practice' (Health & Care Professions Council, Standards of Proficiency, 2015, 11.1, p12).

A key benefit of this researcher's reflective process has been in emancipating herself from the dominant discourses and psychology around autism and wellbeing and becoming critically aware of how her professional and research practice, values and chosen paradigm may influence power relations and sense-making narratives of others. This is illustrated in more detail via Appendix 3.3, which uses Rowley et al's., (2023) Framework for Critical Reflective EP Practice.

Two key learnings have been noted. Firstly, the value of creating a safe community space for collaborative working with vulnerable young people from a marginalised community. Enabling their views to guide the participatory research process was a humbling experience that has elevated this researcher's appreciation for co-productive and agentic ways of working. Secondly, in adopting a transformative paradigm and aligning the values of

respect, beneficence and social justice to co-produce a new shared construct of wellbeing has felt satisfying and meaningful work which has supported the researcher's own wellbeing. However, this researcher has also become more aware that social justice action is equally dependent on the value of equity in each individual's system and the EP's ability to transcend powerful discourses that shape how society treats different identity groups.

### 5.4.2 Limitations

Within the real-world context of this thesis project, which was conducted whilst this researcher also completed training placement activities, the following limitations and future actions have been identified (Table 5.1).

### 5.4.3 Strategic and systemic barriers to and opportunities for change

It has been acknowledged that 'institutional resistance' (p. 84) to participatory research with YP (and its outcomes) is likely given the potential for spotlighting their marginalised experiences within traditional practice (Groundwater-Smith et al., 2015). The critical research agenda adopted in this study highlighted difficulties that autistic girls experience in navigating their respective school systems.

However, findings also clearly illustrate the opportunities for collective participation to reshape power relations in schools (Plow, 2012) and re-distribute the 'political ecology' (France, 2004), which co-researchers in this study experienced through the variety of contextualised evidence of school wellbeing – both positive and negative. The opportunities and barriers identified here relate to the wider systemic impact of this research (Figure 5.2).

**Table 5.1**

*Limitations and critical reflection*

| What happened: | Limiting because: | Future action: |
| --- | --- | --- |
| **Research proposal not community led:** No participatory input into the focus for the literature review, ethics, recruitment processes or materials. | • Could have influenced early engagement as well as initial direction of the research process. | Autistic community advisory panel. |
| **Narrow participant characteristics:** lack of diversity in participant pool, despite nationwide search. Intersectional invisibility with no cultural perspective on autistic wellbeing outside of White British community. All participants intellectually able. | • Voluntary recruitment methodology may have invited interest from parties more culturally invested in discussing their autism and wellbeing. | Broaden sphere of recruitment to actively target different communities. |
| **Authenticity of member checking:** Participants individually reviewed their interview summary and reverted with any comments for discussion. | • Hidden power imbalance – did participants feel they couldn't question the summary results? Self-report bias? | Consider other ways to member check – triangulate with other stakeholders. |
| **Co-researchers' right to not participate[7] in different elements of co-production:** Co-researcher drop-out at later stages of project (e.g., only three co-researchers at sessions 4-5). One co-researcher attended Session 7. | • Less opportunity to collectively member check group themes – potentially impacting hermeneutic validity.<br>• Lack of holistic perspective on participatory modality or transformative action. | Reduce time in-between workshop sessions to maximise retention.<br><br>Larger co-researcher base. |

**Figure 5.2**

*Opportunities and barriers of using a participatory and community-led research approach. Informed by extracts from reflective research diary.*



## 5.5 Implications for practice and call to action

A key aim for this research was emancipating the views of autistic girls at secondary schools to help professionals understand how they conceptualise wellbeing and the school factors that support this unique construct (Appendix 2.8). Consequently, and in line with the transformative paradigm woven throughout this study (Mertens, 2007), implications for practice unite with a strong and detailed call to action for professionals who can influence autistic wellbeing. Figure 5.5. summarises actions for schools arising from this discussion.

### 5.5.1  Dissemination of research findings

This study set out to create sustainable and socially just action, therefore to this end, session seven of the co-research process focused on transformative action, which was defined as both a reflective celebration of what had been achieved and discussion of future steps. The priority for social change, was that the study should initially benefit the female participants and their schools (Reason & Bradbury, 2008) and this was discussed when they member-checked their data. Figure 5.3 highlights the target fields of knowledge transfer and desired outcomes.

Within the first year of completing this study, the research will be disseminated to:

- *Participants' schools* –individual case summaries and Visual Community Brief

- *EP and school colleagues* - presentation in LA service and local/national conferences, publication in EP press and social media

- *Wider communities* - thesis repository – open access for any interested parties and links to autism charities

A key consideration for the dissemination of the research is to ensure it is accessible to the originating community.  It has been previously acknowledged by Gubrium and Harper (2013) that the drive for change will be dependent on the accessibility of the outcomes of the research and how the community make sense of key findings. Consequently, this researcher intends to work closely with colleagues in her local authority to ensure that the research is accessed by a broad audience base (e.g., Visual Community Brief). Figures 5.1, 5.5 and the Visual Community Brief have been developed in accordance with guidance for researching with the autistic community which recommends using a variety of media including visuals when disseminating

**Figure 5.3**

*Who' and 'what' of target fields of knowledge transfer*

**Who needs to know:**
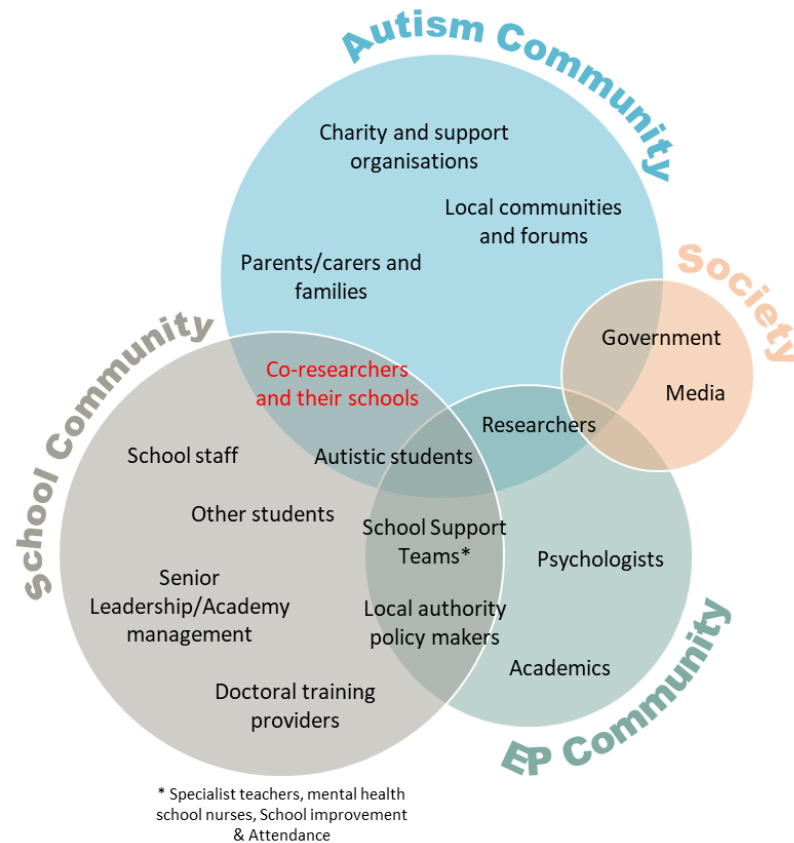


**What they could do with this knowledge:**

*Co-researchers*: Use their data summaries to advocate for their wellbeing needs in their schools and promote school awareness of wellbeing factors.

*Schools:* Review how pupil voice is harnessed to improve the inclusivity of wellbeing practice and policy – see Implications for Practice' section.

*Psychologists:* Hold in mind the impact of identity, belonging, managing emotions and the physical, learning and social environments on the school wellbeing for autistic girls when working individually, in groups or systemically. Utilise participatory research methods with marginalised young people to redress power relations, bring social justice and challenge the language and attitudinal norms related to neurodiversity and wellbeing.

*Local authorities:* Work holistically and collaboratively with service users to support the strategic improvement of wellbeing services for autistic girls at mainstream secondary schools.

*Autistic communities*: Celebrate participatory approaches as an advocacy vehicle for using lived experiences to improve the experiences of young people.

findings (Gowen et al., 2019). The implications for practice within different audience bases are now discussed.

### 5.5.1.1 Autistic community as knowledge holders

Participatory research with marginalised communities can be transformative in process and outcome, according to Nixon et al., (2021). This is widely acknowledged, if not practised, when community-based participatory research commits to empowering the community, because the research emanates from the autistic community's concerns (Minkler, 2012). Emancipating lived experiences necessitates collaborative knowledge production with CYP (Tisdall, 2012) – an approach this study fully embraced, resulting in enhanced understanding of how to effectively co-produce research with autistic girls (Table 3.5, Appendices 2.5 and 3.2).

### 5.5.1.2 Experiences as co-researchers

A key consideration in all participatory work is the level of co-production experienced by participants. A ground-up approach helps ensure that participation is not rhetorical (e.g., consultation rather than collaboration) and achieves social justice goals by harnessing young peoples' authentic interests (Ground-Water Smith et al., 2015). To this end, during Session Six, co-researchers were invited to reflect on the level of participation they had experienced. Descriptors used in Figure 3.5 were shown to the co-researchers, to explore if there were differences in their experiences across the study. Figure 5.4a highlights their reflections within the 'collaborator' participatory type whilst

Figure 5.4b summarises their final reflections on the different participatory types.

Interestingly the co-researcher's experience of participation at the 'collaborator' level differed to the intention to facilitate the full ownership of the research. This difference between intended practise versus lived experience as a co-researcher may be partly attributed to the multi-faceted, complex nature of participatory inquiry itself, in which different social worlds are dynamically shifting (Groundwater-Smith et al., 2015). There may have been a variety of reasons why full collaboration was not achieved.

Firstly, attrition rates towards the end of the research process may have limited the participatory analysis as the view of only one co-researcher was captured. Secondly, Milbourne's work with young people in community settings (2009) highlighted that there was a triad of trust necessary for the broader aims of participatory work. For co-researchers in this study, feeling psychologically safe was a key facilitator to their participation and it should be acknowledged that the girls were navigating the hierarchical and power dynamics of relationships with new peers as well as an unfamiliar adult.

Finally, given the relative short-term nature of this study, time to build relationships was limited and somewhat relied on the professional skills of this researcher in collaborating with young people. The research design could have been co-developed earlier to ensure that benefits of participation were more

**Figure 5.4a**

*Co-researcher participation net*
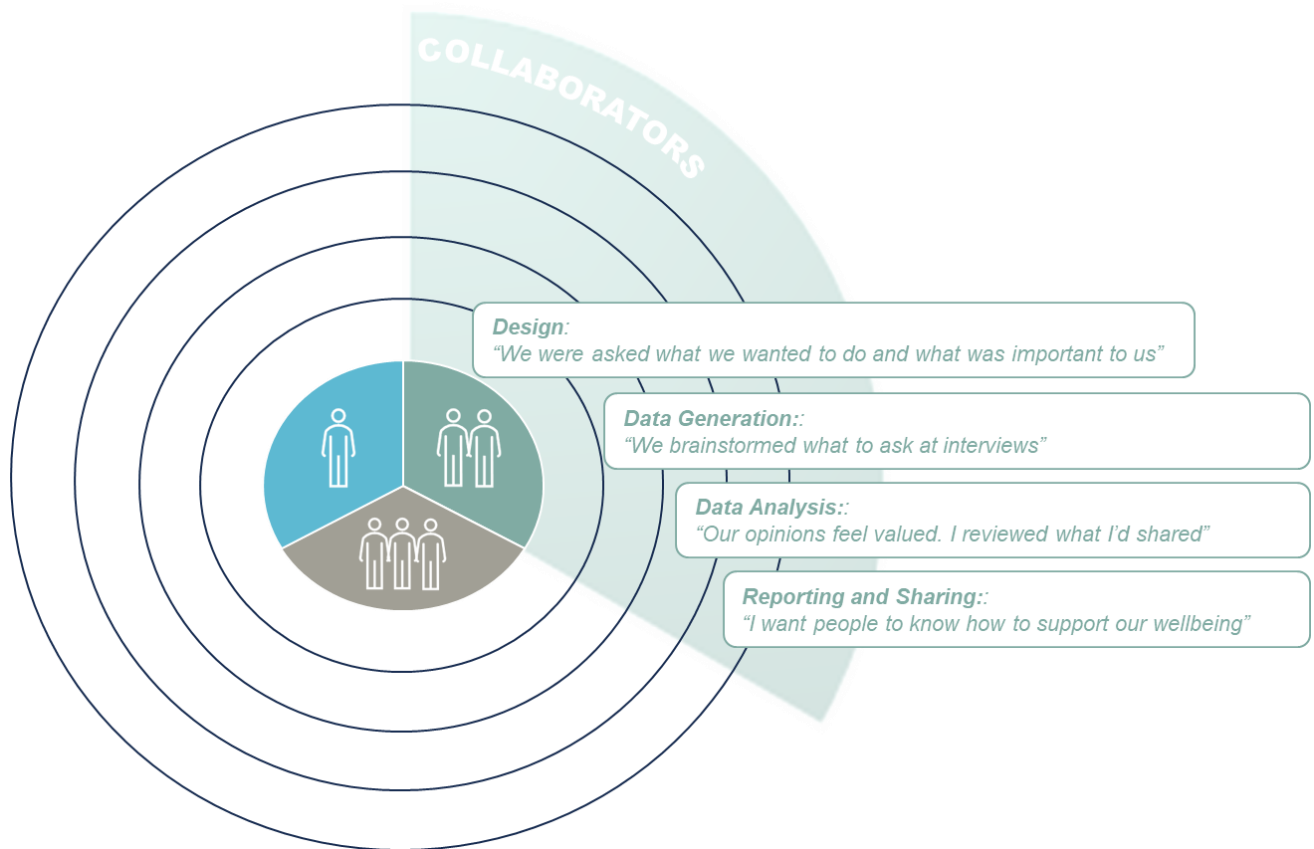


**Figure 5.4b**

*Co-researcher reflections on participation*

equally distributed towards co-researcher 'ownership' (Sanders & Munford, 2009). Sequential reflections on participatory experiences at each stage of the project could have been more helpful in eliciting the researchers' experiences.

### 5.5.2 Co-creating positive wellbeing experiences at school

The importance of embracing the lived experiences of autistic co-researchers in this study is critical to enhancing schools' understanding of different approaches to promoting girls' wellbeing (Dillon et al., 2016). Findings from this study highlight the benefits of co-creating support in school that is gender-specific and developmentally sensitive, via both a whole school approach to autistic girls' wellbeing, alongside honouring the individual differences girl-by-girl (Tierney et al., 2016). Further to this, incorporating whole class approaches or interventions helps create a more inclusive way for all pupils to develop wellbeing-related knowledge and skills (Bennett et al., 2024).

Four core areas of school support were recognised through this study: develop awareness of autistic wellbeing, build a community space, honour individual views and conduct regular reviews of wellbeing. Figure 5.5 plots specific actions to support autistic girls' wellbeing within schools' graduated approach – the assess, plan, do and review tool outlined in the SEND Code of Practice (Department for Education and Department of Health and Social Care, 2014).

**Figure 5.5**

*School factors that support adolescent autistic girls' wellbeing (Connolly, 2024)*



Figure content:

**ASSESS**

Develop awareness of autistic girls' school wellbeing

- Utilise first-hand autistic experience in school training/CPD
- Promote neurodiversity-affirming policy, practice and language
- Assess inclusive practice within learning, the environment, culture and climate and wellbeing policy and practice
- Celebrate autistic achievement and identity

*Supports wellbeing by:* Reducing stigma and encouraging a culture of inclusivity and celebration of difference

*Supports wellbeing by:* Maintaining an active agenda and whole school approach

**REVIEW**

Review wellbeing support

- Review whole school approaches regularly, in line with the changing student population and their needs
- Consider ways to explore collaboratively with service users the political-socio-cultural influences on school wellbeing beyond the school gates
- Monitor staff wellbeing to ensure continuity of good practice throughout the school system
- Regularly update and share pupil records

**Co-creating positive wellbeing experiences for autistic girls**

**PLAN**

Build a community space for autistic girls' wellbeing

*Supports wellbeing by:* Creating space for shared identity and improving self-esteem, acceptance and belonging in the community

*Supports wellbeing by:* Validating and supporting individual experiences

- Explore the extent to which individuals can present their authentic self vs masking.
- Explore individual needs and support related to emotional regulation and expression, flow states and sensory tactics.
- Understand the community norms, values and beliefs which influence autistic wellbeing.
- Set up individual check ins with trusted staff
- Co-create, share and regularly review individual wellbeing strategies

**Honouring individual views**

- Empower autistic voice and shared experiences
- Create a person-centered environment which meets the social interaction, regulatory and sensory needs of autistic girls
- Develop peer support networks based on shared interests
- Promote (the achievements of) Autism role models

**DO**

Connolly (2024)

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### 5.5.2.1 Develop whole school awareness of support factors for autistic girls' wellbeing

School staff play an important role in the participation and engagement of autistic pupils in their learning (Efthymiou & Kington, 2017) and yet consistently, studies highlight a lack of confidence amongst school staff in their initial and ongoing training for supporting autistic pupils (Ravet, 2018). This skews our understanding of how autistic girls present which further reduces efficacy of support for wellbeing in school (Moyse & Porter, 2015).

Further to this, Turnock et al., (2022) flagged the covariance between professional and public understanding of and response to autistic behaviours, which may necessitate increased responsibility on school staff to challenge their bias and beliefs and so ensure that their own improved understanding and attitudes are role modelled to the student communities in their respective schools. This will help create a neuro-affirming environment for autistic girls, leading to improved wellbeing through reduced relational distress and discomfort (Barnes, 2019).

Neurodiversity educational campaigns, autism acceptance training and anti-stigma approaches have begun to address general perceptions of differences in neurodivergent styles of communication and socialising in educational settings (Jones et al., 2021; Ranson & Bryne, 2014). However, as highlighted by the girls in this study, autism awareness training needs to move beyond the basics to capture the nuances of how normative attitudes towards both autism and female stereotypes (which don't recognise the challenges of

intersectionality) damage wellbeing.  Current research with autistic individuals reflects that experiences of stigma create poor wellbeing by heightening the presence of camouflaging behaviours to mask autistic characteristics, reducing self-esteem, increasing anxiety and limiting social connections (Turnock et al., 2022).

A culture shift in improving whole school attitudes towards celebrating the differences that autism brings to the community (Kapp et al., 2013), honouring individual preferences for stigma-reducing identity first language (Botha et al., 2020) and showcasing highly visible neuro-affirming messages (DeBrabander et al., 2019) are key to celebrating neurodiversity and thus improving autistic girls' wellbeing in school.

Psychoeducational programmes that incorporate first-hand autistic perspectives can help neuro-typical peers understand how social interactions can align through shared experiences (Sarge et al., 2020), negating double empathy issues described by Milton (2012). Similarly, using participatory approaches to include the personal stories and insights of autistic individuals has made online training tools more effective at addressing implicit attitudes and bias towards inclusion (Gillespie-Lynch et al., 2021).

In addition to consulting with autistic service users to ensure their wellbeing needs are represented in training programmes, collaborative practice could extend to autistic girls presenting in training sessions (Driver & Chester, 2019). An increased sense of agency from co-creating training and support

programmes can have a positive effect on school wellbeing for autistic girls (Brennan de Vine, 2022). Finally, the role of school leadership in creating and promoting a supportive wellbeing ethos and culture is needed (Demkowicz et al., 2023: Jessiman et al., 2022) for whole-school approaches to be successfully sustained.

### 5.5.2.2 Build a community wellbeing space

From early female advocacy within an online autistic community at the birth of the neurodiversity paradigm (Singer, 1998) to more current research, having a collective positive autism identity creates a protective mechanism for wellbeing (Cooper et al., 2017). This may be especially important at a time when adolescent students are developing their sense of self. Girls with autism may also be struggling with the dichotomy of celebrating versus masking their differences so they can belong within their school community (Tierney et al., 2016). Studies highlight that autistic girls' often feel a reduced sense of social connectedness to their school community, impacting their wellbeing through isolation and loneliness (Brennan de Vine, 2022).

A key benefit of this study was that it provided an online forum for the girls to meet other female autistic students and in doing so, create a safe shared space to explore their experiences of wellbeing. This reinforces evidence that autistic females find online neurodivergent communities provide a shared space for comfort and cultural identity, where they can feel validated and accepted (Haney & Cullen, 2017).

Feeling accepted by others and empowered to explore one's identity has a positive impact on autistic women's wellbeing by increasing confidence and pride in who you are, generating a sense of belonging and reducing the need to conform or mask (Bargiela et al., 2016; Leedham et al., 2020). However, generally in secondary schools there is an absence of peer support groups, beyond access to a resource base, (anecdotal evidence from professional practice, in absence of research evidence). In recent research by Demkowicz et al., (2023), autistic participants requested that they are involved in facilitating this community space however also recognised that the culture shift needed for this takes time, investment and staff training.

Autism friendly spaces have been described as an enhanced person-centered environment (Lai et al., 2020) that utilise the seven principles of universal design[32] (Milton et al., 2016). According to Turnock et al (2022) autistic spaces designed in this way facilitate more comfortable social interactions (e.g., sensory-reduced stimuli, predictability, rules for social engagement). Schools can support wellbeing by facilitating safe social spaces in which autistic girls can enjoy activities with others – this is also an important facilitator for forming friendships (Cook et al., 2018; Moyse, 2021) and builds confidence in being part of a peer community.

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[32] The philosophy of universal design (UD) is closely aligned to the Social Model of Disability which both recognise that the environment (and design of) should eliminate accessibility and inclusivity barriers rather than make post-design reasonable adjustments. UD incorporates principles such as equitable, flexible and intuitive use, perceptible information, tolerance of error, low physical effort and design that is comfortable (Milton et al., 2016).

Other sources of community support can emanate from autistic adult role models. A recent study in the experiences of autistic teachers highlighted their unique value in facilitating the inclusion of autistic students, acting as role models across school (Wood & Happé, 2023). The authors concluded that schools need to develop a significantly more inclusive culture so that autistic teaching staff feel comfortable revealing their own neurodivergence (Wood & Happé, 2023).

### 5.5.2.3  Honour lived experience

To validate individual differences, respond with appropriate support and build a cohesive picture of the collective needs in a school, it is necessary to co-create wellbeing provision. Equally it is important not to ask autistic girls to conform to neurotypical ideals of emotional or social wellbeing behaviours – this maintains societal stigma (Gillespie-Lynch et al., 2021).  Autistic individuals should be recognised as agents of change in their wellbeing without reinforcing deficit-focused views of the autistic individual's responsibility to alter their behaviour (Mitchell & Snyder, 2015; Olsson & Nilholm, 2022;).

Harnessing the lived experiences of autistic girls when reviewing school policy and practice will be key to building a more inclusive system that improves wellbeing by reducing demands within the mainstream environment (Horgan et al., 2023).

### 5.5.2.4 Review wellbeing support

Girls in this study raised the issue of wellbeing support that is offered but not regularly reviewed. This doesn't accommodate the contextual reality that situations and needs are changeable, and circumstantial. Considering the eco-systemic influences of broader culture is also key to ensuring that wellbeing support is regularly reviewed through a wider cultural lens – this has been shown to reduce stigma around autism and thus improves girls' wellbeing (Turnock et al., 2022).

However, developing a strong autistic identity that ameliorates the effect of cultural attitudes towards neurodiversity may be more challenging for pupils living in some communities. For example, research highlights that Somalian families living in the UK may defer seeking support for their autistic children because externalising behaviours are less tolerated by their local community (Ellen et al., 2018). Similarly, families from Black American communities report autism stigma leading to shame and denial (Burkett et al., 2015) whilst Asian communities report lower levels of autism acceptance (Kim, 2020).

For autistic girls growing up in these communities there may be a double stigmatising experience of concealing autistic characteristics from their family due to differences in cultural attitudes and tolerance but also expectations and pressure to align with gender stereotypes (Bargiela et al., 2016). Working with local communities to understand how their beliefs and values frame attitudes towards autism can help overcome barriers to wellbeing, enabling a collective acknowledgement and celebration of neurodiversity, and increasing support

seeking behaviours (Turnock et al., 2022), that has potential to extend the scope of wellbeing beyond the school gates.

School staff wellbeing is reported to be low[33], presenting a significant challenge to the stability and consistency of wellbeing support for pupils. Girls in this study flagged that the relationships between teacher and student wellbeing are complex and inter-related (Harding et al., 2019). For example, positive teacher-student relationships are known to reduce student depression (Plenty et al., 2014), boost feelings of safety (Jamal et al., 2013) and contribute to school belonging (Aldridge & McChesney, 2018).

However, teachers with poor mental health may be 'present' but unable to maintain a positive and supportive learning environment, manage pupils' behaviour effectively (Jennings & Greenberg, 2009) or model positive emotions and behaviour (Jamal et al., 2013). Relational approaches to wellbeing are hard to maintain when high rates of staff absenteeism can restrict development of supportive longer-term relationships with students (Jamal et al., 2013). Roffey argues that students and teacher wellbeing may be 'two sides of the same coin' and that factors supporting student wellbeing are also likely to work well for teachers' wellbeing (2012).

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[33] The 2023 Teacher Wellbeing Index showed that 78% of all education staff are stressed at work (Education Support, 2023). Trends in teachers' mental health in England whilst poor have remained stable across the long-term (Jerrim, et al., 2021).

### 5.5.3  Educational Psychologists as agents of change

As scientist practitioners who use their psychological skills and knowledge for the benefit of CYP (Fallon et al., 2010), EPs have a distinct role to instigate change for autistic girls (O'Hagan & Bond, 2019).  A recent report on the impact of EP services for the Department of Education (2023) highlighted a range of ways that EPs work collaboratively with stakeholders to: inform assessment pathways for autism; support parents to understand and respond to their children's autism-related behaviours; and promote autism awareness groups and training in schools. This breadth of work should showcase the neurodivergent constructs of teenage girls' wellbeing explored in this research.

#### 5.5.3.1  Digging below the surface

During consultation, EPs collaborate with CYP, their families and schools to create shared understanding and solutions to concerns. Examining the functionality of neuro-affirming language and behaviour to flag the implications of a lack of belonging and unauthentic identity could highlight previously unknown risks to autistic girls' wellbeing.

Utilising EPs' specialist skills in working in culturally sensitive ways with young people can help relate individual wellbeing issues to highly personalised intervention support. Working at a systemic level, EPs' may propose school-wide initiatives that support the equitable development of services, training or attitudes that benefit the wellbeing of the school's autistic community. EPs are also well positioned to highlight staff wellbeing which is often overlooked and

under-supported in the school system yet has a known bi-directional effect on pupil wellbeing (Roffey, 2012).

### 5.5.3.2 Supporting school staff to conduct person-centred and participatory approaches

The core functions of EP work can be applied at individual, group and organisation levels, according to Fallon et al., (2010). Therefore, EPs can support school staff use group participatory approaches, rather than working with young people directly (Khawaja, 2022). With a neighbourhood psychology model, this researcher could facilitate the collective training and supervision for SENCOs to use participatory methodology such as focus groups to collegiately examine their adaptations and support for autistic wellbeing.

### 5.5.3.3 Promote neuro-affirming awareness and attitudes

EPs often partner with link professionals in the local community (Bond et al., 2017), to provide autism training for staff (Barrett, 2006). Emancipating the experiences of autistic girls within training programmes facilitates a nuanced understanding of how to recognise difficulties with wellbeing and tailor support, and begins to address social discourses and stereotypes around female autism.

The longer-term benefit of helping school staff reframe their thinking around autistic girls' wellbeing is a reduction of gatekeeper bias (described by Cridland et al., 2014) which often prevents referral to the diagnostic pathway. Working

collectively with autistic female students can identify social justice issues around wellbeing within a particular school context which may lead to reallocation of resources via training or whole school systemic adaptations.

### 5.5.3.4 Evidence-based practitioners

As frontline practitioners supporting wellbeing systems, EPs also create evidence-based practice through their role as researchers.  Whilst it is still relatively rare for EPs to be involved in large scale research studies that impact service delivery (Topping & Lauchlan, 2013), there is a clear argument for using EPs' research skills to improve the wellbeing outcomes of children and their families at local and national levels. Since 2006, when the training programme for EPs migrated to the three-year doctoral route, it has been a requirement that all trainees complete a research thesis (National College for Teaching & Leadership & Health Education England, 2016). Consequently, there is a growing database of theses focusing on the experiences of autistic girls.

As Roffey (2015) suggests, EPs can be agents for change as both advocates for holistic wellbeing for individual children and as a 'critical friend' challenging school systems and policies.  As in this study, research by EPs that contributes to student wellbeing at an ecological level in schools creates further opportunities to promote the agency and voice of autistic young people in shared decision making around resource allocation as well as promoting the intrinsic value of harnessing the voices from marginalised communities.

### 5.5.3.5  Directions for future research

Future research could re-examine this tentative construction of autistic wellbeing in different communities to broaden understanding of wellbeing from an intersectional perspective. A targeted research project within the LA could provide a nuanced understanding of the local and systemic landscape for autistic girls' wellbeing needs in mainstream secondary schools.

Further research into the efficacy of using participatory approaches to co-develop school practice with communities of young people is essential. The participatory methods of working with autistic young people are still under-researched and there needs to be more practice-based evidence to elevate awareness and acceptance of collaborative working (in line with the requirements of the SEND Code of Practice) as well as deliver social justice for this community.

Future studies exploring psychosocial phenomena could also pay more attention to the emotional data generated during the research. Using IPA methodology invites the researcher to utilise their foreconception as a vehicle for acknowledging the potential implications of their own experiences when interpreting the data and encourages analysis of emergent influences during initial encounters with the transcribed text and during exploratory noting. However, incorporating a psychoanalytical lens unlocks deeper exploration of the unconscious thoughts, feeling and motivations from both the participant and the researcher, which is often missing in a traditional social science interview (Brett, 2018). Hollway describes this creative use of self in research through applying psychoanalysis during the researcher's reflective activities to embrace the principle of subjective knowing (with

all of its emotional perceptions) as a 'dialogue in the relational communication of body-based emotional experience' (pg. 2, 2016). In this way the foreconception can be reframed as laying out the narratives that underpin the researcher's own experiences which may influence the flow (or 'transfer') of unconscious dynamics between the analyst and the interviewee (Hollway, 2016). Becoming aware, as a researcher, of how these different levels of emotional data may creep into the analytical process would arguably strengthen the hermeneutic validity of a study.

## 5.6  Conclusion

This study created a psychologically safe community space to explore the lived experiences of school wellbeing for teenage autistic girls attending mainstream secondary schools. By using a participatory approach within a transformative paradigm, participants became co-researchers who shaped the study design and outcomes towards a social justice agenda.  From the lived experiences of the co-researchers in this study, a nuanced construction of school wellbeing has been conceptualised.

These factors have been identified by the girls in this study as important to supporting their wellbeing:

- Exploring authentic autistic identity by removing stigma and building self-esteem and universal acceptance
- Balancing emotions to ensure positive states of flow and reduced emotional labour of coping with the school day
- Building a sense of belonging through making meaningful connections with peers and adults at school
- Feeling safe whilst navigating the complex school system and all of its uncertainties.

To achieve social justice action and help remove inequities in achieving wellbeing, schools can support adolescent autistic girls' through:

- Developing whole school awareness of how these factors impact the wellbeing of autistic girls
- Creating a positive, neurodivergent-welcoming and community environment
- Honouring lived experiences and voices in co-creating tailored wellbeing support programmes
- Reviewing wellbeing support.

The transformative power of emancipating the voices of autistic girls should be noted and gives credit to the value of working with the autistic community to research their interests and needs.

**May your voices be heard and respected …**

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Yau, N., Anderson, S., & Smith, I. C. (2023). How is psychological wellbeing experienced by autistic women? Challenges and protective factors: A meta synthesis. *Research in Autism Spectrum Disorders, 102.* 102101. https://doi.org/10.1016/j.rasd.2022.102101

Young, H., Oreve, M. J., & Speranza, M. (2018). Clinical characteristics and problems diagnosing autism spectrum disorder in girls. *Archives de Pédiatrie, 25*(6), 399-403. https://doi.org/10.1016/j.arcped.2018.06.008

Yué Chūdōng Fang. (2017). *Dreamy skies and anime eyes.* [Free download of visual image]. https://backiee.com/wallpaper/anime/57739

Zener, D. (2019). Journey to diagnosis for women with autism. *Advances in Autism, 5*(1), 2-13. https://doi.org/10.1108/AIA-10-2018-0041

Zhang, Y., Li, N., Li, C., Zhang, Z., Teng, H., Wang, Y., Zhao, T., Shi, L., Zhang, K., Jinchen Li, X., & Sun, Z., (2020). Genetic evidence of gender difference in autism spectrum disorder supports the female protective effect. *Translational Psychiatry, 10*(4), 1-10. https://doi.org/10.1038/s41398-020-0699-8

# Appendices

## Appendix 1. Information supporting the Literature Review

**Appendix 1.1 – Critical synthesis of papers identified in literature search**

| |
|---|
| **FIRST PAPER READ:**<br><br>**The mainstream school experiences of autistic girls and adolescents (Tomlinson et al., 2022)**<br><br>Tomlinson, C., Bond, C., & Hebron, J. (2022). The school experiences of autistic girls and adolescents. *European Journal of Special Needs Education, 37*(2), 323-339.<br><br>https://doi.org/10.1080/08856257.2019.1643154 |
| Study design: Multiple-case study design |

| 1. **Does the study address a clearly focused question/hypothesis?** | **Yes** | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| Setting? | All participants attended the same co-educational mainstream secondary school in England. This school has been identified for good autism practice. | | |
| Perspective? | Forefronting the voice and viewpoints of the autistic girls themselves. The views of parents and the school psychotherapist were also sought. | | |
| Intervention or phenomena? | Phenomena – exploring the girls' secondary school experiences | | |
| Comparator/control? | None | | |
| Evaluation/exploration? | Exploring autistic girls' experiences of school using a range of different methods | | |

| 2. **Is the choice of qualitative method appropriate?**<br>Is it an exploration (e.g., behaviour/reasoning/beliefs?)<br>Do the authors discuss how they decided which method to use? | Yes<br><br>Yes – first author met girls and discussed different data collection methods |
|---|---|
| 3. **Is the sampling strategy clearly described and justified?**<br>Is it clear how participants were selected?<br>Do the authors explain why they selected these particular participants? | Three pupils recruited via SENCo<br>No<br><br>Brief information about each participant (pupils in year 10-11). |

| | | |
|---|---|---|
| | Is detailed information provided about participant characteristics and about those who chose not to participate? | |
| 4. | **Is the method of data collation well described?**<br>Was the setting appropriate for data collection?<br>Is it clear what methods were used to collect data?<br>Type of method?<br>Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | Yes – the girls were interviewed at school following a week-long data collection period using their chosen and preferred method (e.g., photo elicitation, diary accounts or art-based method). Semi-structured interview followed up with another interview using the researcher's knowledge of the autism literature. No detail provided of how interview schedule was generated although the questions can be viewed – on request. |
| | Were the methods modified during the study – why? | Unclear |
| | Triangulation of data? | Yes – with mothers and school psychotherapist –all participant's views coded . |
| | Data saturation? | No |
| 5. | **Is the relationship between the researcher(s) and participants explored?**<br>Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data?<br>Were any potential power relationships involved? | Not specified<br><br>Yes – addressed by first researcher initially meeting with participants to form a rapport and discuss different data collection methods. Adults' views also collected – unclear if autistic girls were aware of this and what impact this may have had on their responses. |
| 6. | **Are ethical issues explicitly discussed?**<br>Is there sufficient information on how the research was explained to participants?<br>Was ethical approval sought?<br>Are there any potential confidentiality issues in relation to data collection? | Yes<br><br>Yes<br><br>No |
| 7. | **Is the data analysis/interpretation process described and justified?**<br>Is it clear how themes and concepts were identified in the data? | Yes – through inductive thematic analysis |

| | |
|---|---|
| Was the analysis performed by more than one researcher? | Yes |
| Are negative/discrepant results taken into account? | Yes |

| | |
|---|---|
| **8. Are the findings credible?** | |
| Are there sufficient data to support the findings? | Yes |
| Are sequences from the original data presented (e.g., quotations) and were these fairly selected? | Yes – quotations and thematic maps are shown |
| Are the data rich (participants voices foregrounded)? | Yes |
| Are the explanations for the results plausible and coherent? | Yes |
| Are the results of the study compared with those from other studies? | Yes |

| | |
|---|---|
| **9. Is any sponsorship/conflict of interest reported?** | No |

| | |
|---|---|
| **10. Finally…consider:** | |
| Did the authors identify any limitations? | Yes – participants needed additional support and prompting from the researcher – answers often brief. Need more research on accessible methods. |
| Are the conclusions the same in the abstract and the full text? | Yes |

**Summary**

This small-scale study provides an overview of the experiences of three autistic girls who all attended the same mainstream secondary school in the UK. The participants were prompted to think about their school experiences using a range of different methods. Power dynamics were addressed through an initial meeting with the first researcher which covered getting to know each other as well as discussing how they might like to start thinking about their school experiences, in preparation for the data collection phase. The researchers reported that even with accessible methods, it was somewhat difficult for the participants to extend their brief responses. Consequently, during a follow-up interview, this researcher used their knowledge of the autism literature to further prompt and extend discussion.

Data analysis was conducted by the researchers and is presented individually as key themes for each case study (e.g., individual thematic maps, quotations and narrative). A hybrid approach was taken - it is somewhat unclear which themes were developed from the interviews and which were introduced from the researchers' knowledge of the autism literature. It is also unclear whether themes are weighted towards girls' or adults' perspectives as all data was coded and integrated during analysis. Within the cross-case analysis there was some discussion of similarities and differences in the girls' experiences.

The findings are helpful for this literature search, identifying key components of wellbeing within the girls' school experiences such as self-identity, friendships, relationships with teachers, feeling supported and anxiety.

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Study design: Qualitative focus groups

| 1. **Does the study address a clearly focused question/hypothesis?** | <mark>Yes</mark> | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| **S**etting? | 9 at mainstream secondary school, 1 in final year of mainstream primary school, all in the UK. | | |
| **P**erspective? | Girls' - exploring the girls' secondary school experiences of friendships. | | |
| **I**ntervention or phenomena? | Phenomena – perceptions of friendship | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploratory | | |
| 2. **Is the choice of qualitative method appropriate?** Is it an exploration (e.g., behaviour/reasoning/beliefs?) Do the authors discuss how they decided which method to use? | Yes<br><br>Yes – focus groups chosen to encourage open communication between participants. Data source triangulation through running 2 focus groups. Investigator triangulation through 2 different professions in research team. | | |
| 3. **Is the sampling strategy clearly described and justified?** Is it clear how participants were selected? Do the authors explain why they selected these particular participants? Is detailed information provided about participant characteristics and about those who chose not to participate? | Yes – from a community service for children with ASD. Relevant for research aims – girls views only. Yes – autistic diagnosis, aged 12-15 yrs, no intellectual disability, English as first language. | | |

| 4. Is the method of data collation well described? | |
|---|---|
| Was the setting appropriate for data collection? | Yes – familiar community setting. |
| Is it clear what methods were used to collect data? | Semi-structured focus group |
| Type of method? | Qualitative data. |
| Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | 2 members of research team drafted the interview guide with 4 themes. |

| 5. Is the relationship between the researcher(s) and participants explored? | |
|---|---|
| | Yes – through methodology – see above. |
| Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data? Were any potential power relationships involved? | However, little other critical reflection |

| 6. Are ethical issues explicitly discussed? | |
|---|---|
| Is there sufficient information on how the research was explained to participants? | Yes |
| Was ethical approval sought? | Yes |
| Are there any potential confidentiality issues in relation to data collection? | No |

| 7. Is the data analysis/interpretation process described and justified? | |
|---|---|
| Is it clear how themes and concepts were identified in the data? | Yes – thematic analysis |
| Was the analysis performed by more than one researcher? | Yes |
| Are negative/discrepant results taken into account? | Yes – resolved by consensus. |

| 8. Are the findings credible? | |
|---|---|
| Are there sufficient data to support the findings? | Yes |
| Are sequences from the original data presented (e.g., quotations) and were these fairly selected? | Yes |
| Are the data rich (participants voices foregrounded)? | Yes |
| Are the explanations for the results plausible and coherent? | Yes |
| Are the results of the study compared with those from other studies? | Yes |

| 9. Is any sponsorship/conflict of interest reported? | No |
|---|---|
| **10. Finally…consider:**<br>Did the authors identify any limitations?<br><br><br><br><br><br><br><br><br>Are the conclusions the same in the abstract and the full text? | Limitations: perspective not reality, lack of knowledge around access to and impact of social skills training on friendships, findings can't be generalised to specialist settings where intellectual disabilities may add further difficulties in making friends. Focus group setting could pose participation problems for autistic girls although these were anticipated and managed. One participant from primary school.<br>Yes |
| **Summary**<br><br>Small scale study offering first-hand accounts of friendship experiences of adolescent autistic girls attending mainstream secondary school. Findings were not discussed with links to school wellbeing however school support and intervention was included. Overall relevance to this research study are low. | |

<br>

| THIRD PAPER READ:<br><br>**Exploring how a sense of belonging is constructed in the accounts of autistic girls who attend mainstream school in England (Brennan De Vine, 2022)**<br><br>Brennan De Vine, N. (2022). *Exploring how a sense of belonging is constructed in the accounts of autistic girls who attend mainstream school in England.* [Doctoral Dissertation, UCL]. EThOS<br><br>http://isni.org/isni/000000050963156X<br><br>https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.864030 |
|---|
| Study design: Qualitative semi-structured interviews with quantitative background measures |

<br>

| 1. Does the study address a clearly focused question/hypothesis? | <mark>Yes</mark> | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| **S**etting? | Mainstream secondary schools in UK | | |
| **P**erspective? | Voice of autistic adolescent girls | | |
| **I**ntervention or phenomena? | Phenomena – sense of belonging | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploration | | |

| | | |
|---|---|---|
| 2. | **Is the choice of qualitative method appropriate?**<br>Is it an exploration (e.g., behaviour/reasoning/beliefs?)<br><br><br><br><br><br><br>Do the authors discuss how they decided which method to use? | Study provides an exploratory platform for autistic girls to construct feeling a sense of belonging and identifying the barriers and facilitating factors to that sense as well as impact on wellbeing. Author describes that this is important to the autistic community and needed to extend a small but growing literature base. Methods also in line with epistemological stance. |
| 3. | **Is the sampling strategy clearly described and justified?**<br>Is it clear how participants were selected?<br>Do the authors explain why they selected these particular participants?<br>Is detailed information provided about participant characteristics and about those who chose not to participate? | Purposive sampling methods to recruit 18 participants from schools across England.<br><br>Yes<br><br>Yes – recorded in a table – note that diversity not achieved.<br>One participant withdrawn as parents did not return their consent form. |
| 4. | **Is the method of data collation well described?**<br>Was the setting appropriate for data collection?<br>Is it clear what methods were used to collect data?<br>Type of method?<br>Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | Qualitative design chosen to provide a means to hear the voices of the participants and evidence provided of this method used with population. Semi-structured interviews chosen to gain first person views of individual experiences, conducted over 2 sessions. Participatory approach discussed in light of reducing power imbalances between researcher and co-researchers. An advisory group used to design study, communication means and analyse data, reducing researcher bias.<br>Background quantitative measures used to provide a clear picture of individual context. |
| 5. | **Is the relationship between the researcher(s) and participants explored?**<br>Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data?<br>Were any potential power relationships involved? | Yes – see above use of advisory research group to reduce bias and balance power dynamics. Participants offered a choice of ways to contribute and given time after an introductory meeting to complete pre-measures and individual activities. Researcher used adapted SHoWED protocol to construct meaning <u>with</u> participants. Participants offered a range |

| | | of communication methods to increase agency |
|---|---|---|
| **6. Are ethical issues explicitly discussed?** Is there sufficient information on how the research was explained to participants? Was ethical approval sought? Are there any potential confidentiality issues in relation to data collection? | | Research methodology explained via initial consent forms and session one interview with researcher. Ethical approval granted. Pseudonyms used to protect participant identity and confidentiality |
| **7. Is the data analysis/interpretation process described and justified?** Is it clear how themes and concepts were identified in the data? Was the analysis performed by more than one researcher? Are negative/discrepant results taken into account? | | Data analysed using Thematic Analysis – clear explanation of the value of an inductive analytical process. Co-researchers were sent a transcript to identify initial codes and had opportunities to check sub-themes/themes. Coding checked by researcher supervisors. |
| **8. Are the findings credible?** Are there sufficient data to support the findings? | | Yes – 18 participants. |
| Are sequences from the original data presented (e.g., quotations) and were these fairly selected? | | Yes |
| Are the data rich (participants voices foregrounded)? | | Yes |
| Are the explanations for the results plausible and coherent? | | Yes |
| Are the results of the study compared with those from other studies? | | Yes |
| **9. Is any sponsorship/conflict of interest reported?** | | No |
| **10. Finally…consider:** Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text? | | Yes – diversity of participants (class/ethnicity). Measure used designed for a US population and as scores reflected a general negative sense of belonging, this may have influenced their perceptions of belonging. Yes |

**Summary**

An interesting participatory study forefronting the views of adolescent autistic girls' feeling of a sense of belonging to school. Captured within a Life-World Framework which aimed to 'humanise' the lived experiences of the participants and using an Autism Advisory

Group (AAG) to represent the views of the community and maximise engagement and participation.

Data analysis was conducted with the help of the AAG and is presented as four key themes (e.g., thematic maps, quotations and narrative). A limitation was the lack of diversity in the research population, with all girls belonging to middle-class families and only one participant identifying as a non-white ethnicity. Background measures indicated overall low sense of belonging therefore findings may be construed in this light.

The findings are helpful for this literature search, identifying key components of wellbeing within the girls' experiences of school belonging.

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**FOURTH PAPER READ:**

**The social experiences and sense of belonging in adolescent females with autism in mainstream school (Myles, Boyle & Richards, 2019)**

Myles, O., Boyle, C., & Richards, A. (2019). The social experiences and sense of belonging in adolescent females with autism in mainstream school. *Educational and Child Psychology, 36*(4), 8-21

Study design: Qualitative semi-structured interviews

| 1. **Does the study address a clearly focused question/hypothesis?** | <mark>Yes</mark> | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| **S**etting? | Mainstream secondary schools in UK | | |
| **P**erspective? | Voice of autistic adolescent girls | | |
| **I**ntervention or phenomena? | Phenomena – social experiences and sense of belonging | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploration | | |
| 2. **Is the choice of qualitative method appropriate?** Is it an exploration (e.g., behaviour/reasoning/beliefs?) Do the authors discuss how they decided which method to use? | The study aimed to explore the social experiences of adolescent autistic girls attending mainstream secondary schools. Author leans on previous research suggesting that semi-structured interviews are effective in seeking the views of young people with autism as a reason to choose this method themselves. | | |
| 3. **Is the sampling strategy clearly described and justified?** Is it clear how participants were selected? Do the authors explain why they selected these particular participants? | Purposive sampling methods to recruit 8 participants from 3 mainstream schools by asking SENCos to pass on recruitment materials to students. | | |

| | | |
|---|---|---|
| | Is detailed information provided about participant characteristics and about those who chose not to participate? | Yes<br><br>Yes – recorded in a table – no information about ethnicity/diversity |
| 4. | **Is the method of data collation well described?**<br>Was the setting appropriate for data collection?<br>Is it clear what methods were used to collect data?<br>Type of method?<br>Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | Semi-structured interviews chosen according to recommendations from previous studies – see above.<br>Each participant interviewed on 2 occasions to build rapport and trust with time in between used for individual reflection on a researcher-provided 'Feelings of Belonging' worksheet. Thematic analysis used – no explanation given for this choice or how it fits with author's research epistemology. Interview protocol provided in Appendices and a hierarchical focusing used to build on participants responses, but key themes identified as prompts from the literature search. |
| 5. | **Is the relationship between the researcher(s) and participants explored?**<br>Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data?<br>Were any potential power relationships involved? | Hierarchical focus in interview to develop exploration of topic – see above.<br><br>No discussion of power relationships. |
| 6. | **Are ethical issues explicitly discussed?**<br>Is there sufficient information on how the research was explained to participants?<br>Was ethical approval sought?<br>Are there any potential confidentiality issues in relation to data collection? | No information given regarding processes relating to ethical consent, although ethical approval granted by a university body |
| 7. | **Is the data analysis/interpretation process described and justified?**<br>Is it clear how themes and concepts were identified in the data?<br>Was the analysis performed by more than one researcher?<br>Are negative/discrepant results taken into account? | Data analysed using Thematic Analysis. No further information on data analysis given. |
| 8. | **Are the findings credible**?<br>Are there sufficient data to support the findings? | Yes – 8 participants.<br><br>Yes |

| Are sequences from the original data presented (e.g., quotations) and were these fairly selected? | Yes |
| Are the data rich (participants voices foregrounded)? | Yes |
| Are the explanations for the results plausible and coherent? | Yes |
| Are the results of the study compared with those from other studies? | |
| **9. Is any sponsorship/conflict of interest reported?** | No |
| **10. Finally…consider:**<br>Did the authors identify any limitations? | Yes – small sample size across a large age range of secondary pupils. Amount of support needed varied, although impact of this not discussed. Possibility discussed that pupils accounts did not fully represent their lived experiences. |
| Are the conclusions the same in the abstract and the full text? | Yes |

**Summary**

A small-scale study revealing the first-hand experiences of social belonging for autistic secondary aged females.

Suggest links between perceived peer acceptance, friendship and social competence and belonging – with an emphasis on quality over quantity of friendships. Social difficulties experiences by the participants may add to their feelings of exclusion in school.

Data analysis conducted by the researcher – no discussion of whether there might have been any issues with double empathy in using thematic analysis.

The findings are somewhat helpful for this literature search, identifying key components of social belonging (although not explicitly linked to wellbeing) which undoubtedly may have an impact on school experiences. However, there was no focus on how schools might support the girls' experiences.

**FIFTH PAPER READ:**

**Autism and the U.K. secondary school experience (Dillon et al., 2016)**

Dillon, G. V., Underwood, J. D. M., & Freemantle, L. J. (2016). Autism and the U.K. Secondary School Experience, *Focus on Autism and Other Developmental Disabilities, 31*(3), 221-230. https://doi.org/10.1177/1088357614539833

Study design: Mixed method study

| 1. **Does the study address a clearly focused question/hypothesis?** | Yes | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|

| | | |
|---|---|---|
| | **S**etting? | Mainstream secondary schools in UK |
| | **P**erspective? | Voice of autistic young people and non-autistic young people |
| | **I**ntervention or phenomena? | Phenomena – UK secondary school experience |
| | **C**omparator/control? | None |
| | **E**valuation/exploration? | Exploration |
| 2. | **Is the choice of qualitative method appropriate?**<br>Is it an exploration (e.g., behaviour/reasoning/beliefs?)<br>Do the authors discuss how they decided which method to use? | The study examined the self-reported school experience of students on the autism spectrum across different areas such as: social skills, relationship with teaching staff, school functioning and interpersonal ability.<br>Interviews used to expand on answers from the quantitative measures already completed. |
| 3. | **Is the sampling strategy clearly described and justified?**<br>Is it clear how participants were selected?<br>Do the authors explain why they selected these particular participants?<br>Is detailed information provided about participant characteristics and about those who chose not to participate? | Purposive sampling methods to recruit 14 autistic participants (3 girls, 11 boys) and chronologically and gender matched control group of non-autistic peers. All attending one mainstream school. Control group nominated by school staff; ASD group selected for autism diagnosis by the school's director of inclusion.<br><br>Yes for those that participated. No further data given of those who chose not to. |
| 4. | **Is the method of data collation well described?**<br>Was the setting appropriate for data collection?<br>Is it clear what methods were used to collect data?<br>Type of method?<br>Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | Yes.<br><br>Self-report measures favoured for gaining an understanding of educational issues by those directly affected.<br>Yes  semi-structured interviews<br>Yes<br>Yes. |
| 5. | **Is the relationship between the researcher(s) and participants explored?**<br>Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data? | Researcher worked in the school setting. No other power relationships discussed. |

| | |
|---|---|
| Were any potential power relationships involved? | |
| **6. Are ethical issues explicitly discussed?** Is there sufficient information on how the research was explained to participants? Was ethical approval sought? Are there any potential confidentiality issues in relation to data collection? | No  Unknown Unknown |
| **7. Is the data analysis/interpretation process described and justified?** Is it clear how themes and concepts were identified in the data? Was the analysis performed by more than one researcher? Are negative/discrepant results taken into account? | Data analysed data driven content analysis.  Yes – second coder.  Yes – consensus agreement reached. |
| **8. Are the findings credible?** Are there sufficient data to support the findings? Are sequences from the original data presented (e.g., quotations) and were these fairly selected? Are the data rich (participants voices foregrounded)? Are the explanations for the results plausible and coherent? Are the results of the study compared with those from other studies? | Only 3 female autistic participants  Yes   Yes  Yes  Yes |
| **9. Is any sponsorship/conflict of interest reported?** | No |
| **10. Finally…consider:** Did the authors identify any limitations?    Are the conclusions the same in the abstract and the full text? | Yes small sample size and low generalisation of findings to other school settings.    Yes. |
| **Summary** A unique study comparing secondary school experiences of autistic young people and their peers. Concerns over lack of information relating to ethics and consent. Somewhat limited by lack of differentiation of data differences between male and female autistic pupils however, some direct quotations exemplified the female voice.  The few quotes identified from female autistic participants are useful to understand their perspective on helpful school support. However perhaps the biggest drawback is a lack of reflection around their school experiences and wellbeing. |

Study design:  Qualitative online survey

| 1. **Does the study address a clearly focused question/hypothesis?** | <mark>Yes</mark> | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| **S**etting? | Online questionnaire | | |
| **P**erspective? | Voice of autistic young people and non-autistic young people | | |
| **I**ntervention or phenomena? | Phenomena – Covid-19 related school changes and impacts on emotional wellbeing | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploration | | |
| 2. **Is the choice of qualitative method appropriate?** Is it an exploration (e.g., behaviour/reasoning/beliefs?) Do the authors discuss how they decided which method to use? | The study explored autistic and non-autistic young people experiences of school changes and the relationship of these changes during the pandemic to their well-being. Changes that were advantageous were highlighted. | | |
| 3. **Is the sampling strategy clearly described and justified?** Is it clear how participants were selected? Do the authors explain why they selected these particular participants? Is detailed information provided about participant characteristics and about those who chose not to participate? | Volunteers for an open invitation to participate in an online survey. No restrictions on pupil's intellectual functioning on co-morbid conditions given as exclusion criteria. Yes – for those that completed the online survey. 4 girls (mean age of autistic youth = 15:12 yrs) | | |
| 4. **Is the method of data collation well described?** Was the setting appropriate for data collection? | Yes. Yes | | |

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| | | |
|---|---|---|
| | Is it clear what methods were used to collect data?<br>Type of method?<br>Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | Yes<br>Yes<br><br>Unknown – see below for informal consultation with community. |
| 5. | **Is the relationship between the researcher(s) and participants explored?**<br>Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data?<br>Were any potential power relationships involved? | Informal consultation from the autistic community during the conception of the study and survey development only.<br><br><br><br>Unknown. |
| 6. | **Are ethical issues explicitly discussed?**<br>Is there sufficient information on how the research was explained to participants?<br>Was ethical approval sought?<br>Are there any potential confidentiality issues in relation to data collection? | Yes<br><br><br>Yes<br>Unknown |
| 7. | **Is the data analysis/interpretation process described and justified?**<br>Is it clear how themes and concepts were identified in the data?<br>Was the analysis performed by more than one researcher?<br>Are negative/discrepant results taken into account? | Data analysed by 2 authors using thematic analysis.<br><br>Yes – second coder and different methods used (by hand/software). Two quotes linked to each code to ensure coherence in interpretation of the data.<br><br>No discrepancies found. |
| 8. | **Are the findings credible?**<br>Are there sufficient data to support the findings?<br>Are sequences from the original data presented (e.g., quotations) and were these fairly selected?<br>Are the data rich (participants voices foregrounded)?<br>Are the explanations for the results plausible and coherent?<br>Are the results of the study compared with those from other studies? | Only 4 female autistic participants<br><br>Yes<br><br><br>Yes<br><br>Yes<br><br>Yes |
| 9. | **Is any sponsorship/conflict of interest reported?** | No |

| 10. Finally…consider: | Yes – survey methodology was the only |
| --- | --- |
| Did the authors identify any limitations? | method available due to pandemic restrictions on travel and interaction. Length of response varied between participants and only 4 female autistic participants. Researchers were not autistic and therefore interpretation may not reflect the autistic participants' experiences and meaning. |
| Are the conclusions the same in the abstract and the full text? | Yes. |

**Summary**

An interesting study which reflects on how the changes brought about by the Covid-19 pandemic impacted school wellbeing for autistic participants.

Specific quotes were identified from female autistic participants which are useful to understand their perspective on helpful school support. Links to wellbeing mainly through the emotional impact on wellbeing of the sensory environment in school, difficulties with social situations, freedom when learning at home to use their own wellbeing strategies to focus on learning, balancing wellbeing needs with making new friends at school upon return after lockdown and finally, reflections on extending the pandemic restrictions into current practice.

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**SEVENTH PAPER READ:**

**Looking behind the mask: Social coping strategies of girls on the autistic spectrum (Tierney et al., 2016)**

Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. *Research in Autism Spectrum Disorders, 23,* 73-83. https://doi.org/10.1016/j.rasd.2015.11.013

Study design: Semi-structured interviews

| 1. Does the study address a clearly focused question/hypothesis? | Yes | Can't tell | No |
| --- | --- | --- | --- |
| **S**etting? | Participants attended a mix of settings but seven out of 10 attended mainstream secondary school. | | |
| **P**erspective? | Forefronting the voice and viewpoints of the autistic girls themselves. | | |
| **I**ntervention or phenomena? | Phenomena – social coping strategies | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploring the girls' use of social management strategies such as masking. | | |

| 2. Is the choice of qualitative method appropriate?<br>Is it an exploration (e.g., behaviour/reasoning/beliefs?)<br>Do the authors discuss how they decided which method to use? | Yes - behaviours<br><br>Yes – interview questions created from existing knowledge of literature base. |
|---|---|
| 3. Is the sampling strategy clearly described and justified?<br>Is it clear how participants were selected?<br>Do the authors explain why they selected these particular participants?<br>Is detailed information provided about participant characteristics and about those who chose not to participate? | 25 participants contacted, 10 recruited. Girls that were unable to give their consent, unwell or didn't want to participate or didn't meet inclusion criteria not included in study.<br><br>Brief information about each participant provided. |
| 4. Is the method of data collation well described?<br>Was the setting appropriate for data collection?<br>Is it clear what methods were used to collect data?<br>Type of method?<br>Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)?<br><br>Were the methods modified during the study – why?<br><br>Triangulation of data?<br><br>Data saturation? | Girls interviewed face-to-face. Parents could be present, but interviewer made it clear that the girls views would be prioritised.<br>Semi-structured interviews. Interview questions piloted with two autistic girls<br><br>Unclear<br><br><br>No<br><br>Researcher describes triangulating results with clinical and empirical experience<br><br>No |
| 5. Is the relationship between the researcher(s) and participants explored?<br>Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data?<br>Were any potential power relationships involved? | A research journal was maintained with notes made after each interview to record any bias, beliefs, assumptions.<br><br>Researcher discussed presence of parents in room and how this may have influences/inhibited participants responses, this may have been balanced by facilitating a richer discussion and |

| | |
|---|---|
| | reduced potential anxiety or the participant. |
| **6. Are ethical issues explicitly discussed?** Is there sufficient information on how the research was explained to participants? Was ethical approval sought? Are there any potential confidentiality issues in relation to data collection? | Details of ethical approval and informed consent give. Yes No – pseudonyms used. |
| **7. Is the data analysis/interpretation process described and justified?** Is it clear how themes and concepts were identified in the data? Was the analysis performed by more than one researcher? Are negative/discrepant results taken into account? | Yes – through IPA Yes – three transcripts were checked by an independent researcher for transparency. No. |
| **8. Are the findings credible?** Are there sufficient data to support the findings? Are sequences from the original data presented (e.g., quotations) and were these fairly selected? Are the data rich (participants voices foregrounded)? Are the explanations for the results plausible and coherent? Are the results of the study compared with those from other studies? | Yes Yes – quotations and thematic maps are shown Yes – parents voices included as secondary data and clearly identifiable. Yes Yes |
| **9. Is any sponsorship/conflict of interest reported?** | No |
| **10. Finally…consider:** Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text? | Yes – participants were all high functioning autistic females (as in other papers analysed) meaning that they may have more adaptation skills than others. Generalization from IPA methodology may be limited. Participants self-selected. Yes |

**Summary**

Clinical-based study therefore language used fits medical/deficit model. Issues with social communication (e.g., mutual misunderstandings and difficulties fitting into secondary friendship norms) associated with female presentation – no discussion/challenge of these norms.

Supports and extends previous research with some novel findings around girls' motivation to make friendships. Links to wellbeing discussed throughout so of some use to this literature search.

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Study design: Semi-structured interviews

| 1. Does the study address a clearly focused question/hypothesis? | <mark>Yes</mark> | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| Setting? | Participants attended a mix of settings but six out of 11 attended mainstream secondary school. | | |
| Perspective? | Forefronting the voice and viewpoints of the autistic girls themselves. | | |
| Intervention or phenomena? | Phenomena – friendship motivations, challenges and the role of masking | | |
| Comparator/control? | None | | |
| Evaluation/exploration? | Exploring the girls' experiences of learning, friendships and bullying. | | |
| **2. Is the choice of qualitative method appropriate?** Is it an exploration (e.g., behaviour/reasoning/beliefs?) Do the authors discuss how they decided which method to use? | Yes – reasoning around experiences  No. | | |
| **3. Is the sampling strategy clearly described and justified?** Is it clear how participants were selected? Do the authors explain why they selected these particular participants? Is detailed information provided about participant characteristics and about those who chose not to participate? | Participants recruited from mainstream and special schools in England via purposive sampling of schools, word of mouth as well as a charity newsletter. Voluntary basis.  Brief information about each participant (and parent) is provided. | | |

| 4. | **Is the method of data collation well described?** | |
|---|---|---|
| | Was the setting appropriate for data collection? | Unclear – no information given. Semi-structured interviews. Followed previous study with boys. |
| | Is it clear what methods were used to collect data? | |
| | Type of method? | Unclear |
| | Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? | No although interview schedule available on request. Probes used. |
| | | No |
| | Were the methods modified during the study – why? | |
| | Triangulation of data? | No |
| | | Unknown |
| | Data saturation? | |
| 5. | **Is the relationship between the researcher(s) and participants explored?** | None discussed. |
| | Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data? | |
| | Were any potential power relationships involved? | Potential for parental involvement to inhibit/extend girls participation but not explicitly discussed. |
| 6. | **Are ethical issues explicitly discussed?** | |
| | Is there sufficient information on how the research was explained to participants? | Details of ethical approval and informed consent give. |
| | Was ethical approval sought? | Yes |
| | Are there any potential confidentiality issues in relation to data collection? | No – pseudonyms used. |
| 7. | **Is the data analysis/interpretation process described and justified?** | Yes – through thematic analysis |
| | Is it clear how themes and concepts were identified in the data? | Yes – agreement achieved through iterative process. |
| | Was the analysis performed by more than one researcher? | |
| | Are negative/discrepant results taken into account? | |
| 8. | **Are the findings credible**? | |
| | Are there sufficient data to support the findings? | Yes |
| | Are sequences from the original data presented (e.g., quotations) and were these fairly selected? | Yes – quotations and thematic maps are shown |

| | |
|---|---|
| Are the data rich (participants voices foregrounded)? | Yes |
| Are the explanations for the results plausible and coherent? | Yes |
| Are the results of the study compared with those from other studies? | Yes |
| **9. Is any sponsorship/conflict of interest reported?** | No |
| **10. Finally…consider:**<br><br>Did the authors identify any limitations?<br><br><br><br>Are the conclusions the same in the abstract and the full text? | Yes – Interview basis of data collection may have limited participation of girls with poorer communication skills. Mentioned participatory research for future.<br><br>Yes |

**Summary**

Interesting study which compared the experiences of bullying, learning and friendship for girls in mainstream and specialist settings.

Of interest to this literature search are novel findings relating to how girls with autism perceive friendships – as about comfort within shared activities based on mutual interests (as opposed to deep reciprocal relationships). Some implications for school support discussed in relation to recognising and acting on bullying earlier as well as providing opportunities for the girls to enjoy their friendships. Impact of this would be that girls would feel more comfortable and likely reduce masking.
Uncomfortable language used re: social 'inadequacies', reflecting dominant deficit model. Some difficulties unpicking where themes came from (parents/pupils) as often attributed to both but made clearer from reading direct quotations.

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**NINTH PAPER READ:**

**"Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators (Halsall, et al., 2021).**

Halsall, J., Clarke, C., & Crane, L. (2021). "Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators. *Autism, 25*(7), 2074-2086.
https://doi.org/10.1177/13623613211012819

Study design: Semi-structured interviews

| 1. Does the study address a clearly focused question/hypothesis? | **<mark>Yes</mark>** | ~~Can't tell~~ | ~~No~~ |
|---|---|---|---|
| **S**etting? | Participants attended mainstream schools but also accessed an internal specialist resource base. | | |
| **P**erspective? | Forefronting the views of the autistic girls. | | |
| **I**ntervention or phenomena? | Phenomena - camouflaging | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploring the girls' experiences of camouflaging. | | |
| **2. Is the choice of qualitative method appropriate?** Is it an exploration (e.g., behaviour/reasoning/beliefs?) Do the authors discuss how they decided which method to use? | Yes – reasoning around experiences <br><br> No. | | |
| **3. Is the sampling strategy clearly described and justified?** Is it clear how participants were selected? Do the authors explain why they selected these particular participants? Is detailed information provided about participant characteristics and about those who chose not to participate? | Purposive sampling <br><br> Brief information about each participant (and parent) is provided. 8 triads of pupil, parent and educator. | | |
| **4. Is the method of data collation well described?** Was the setting appropriate for data collection? Is it clear what methods were used to collect data? Type of method? Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? <br><br> Were the methods modified during the study – why? <br><br> Triangulation of data? <br><br> Data saturation? | Unclear – no information given. Scaling, probes from quantitative questionnaire used to inform questions. Ideal school described. Accommodations made for accessibility including use of visuals/cartoons. Questions for parents and educators developed from previous literature. <br><br> Unclear – although a pilot test for the autistic girls was conducted with pupils at a different resource base. <br><br> Yes with parents and educators. <br><br> Authors suggest so. | | |
| **5. Is the relationship between the researcher(s) and participants explored?** | | | |

| | |
|---|---|
| Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data? Were any potential power relationships involved? | One of the researchers met the girls prior to interview to conduct standardised assessment. Observations of girls in class was also conducted.<br><br>Not discussed. Parent and teacher interviews conducted separately to girls. |
| **6. Are ethical issues explicitly discussed?**<br>Is there sufficient information on how the research was explained to participants?<br>Was ethical approval sought?<br>Are there any potential confidentiality issues in relation to data collection? | Details of ethical approval and informed consent give.<br>Yes<br><br>No – pseudonyms used. |
| **7. Is the data analysis/interpretation process described and justified?**<br>Is it clear how themes and concepts were identified in the data?<br>Was the analysis performed by more than one researcher?<br>Are negative/discrepant results taken into account? | Yes – through thematic analysis<br><br>Yes, all three involved– agreement achieved through iterative process. |
| **8. Are the findings credible?**<br>Are there sufficient data to support the findings?<br>Are sequences from the original data presented (e.g., quotations) and were these fairly selected?<br>Are the data rich (participants voices foregrounded)?<br>Are the explanations for the results plausible and coherent?<br>Are the results of the study compared with those from other studies? | Yes<br><br>Yes – quotations and thematic maps are shown<br><br>Yes<br><br>Yes<br><br>Yes |
| **9. Is any sponsorship/conflict of interest reported?** | No |
| **10. Finally…consider:**<br>Did the authors identify any limitations?<br><br><br><br><br>Are the conclusions the same in the abstract and the full text? | Yes – small sample size, compromising generability. Discussion whether the girls were using camouflaging techniques during their interview.<br><br>Yes |
| **Summary**<br><br>A multi-perspective study examining the camouflaging experiences of autistic girls attending mainstream school and an autism base within the school. Camouflaging techniques described as simple (on phone) to complex (planning scripts). Use of | |

camouflaging described as inconsistent resulting in the girls neither fitting in with mainstream peers or their resource base peer group.

Camouflaging learning needs in the classroom resulted in vicious cycle of missed learning, teacher unawareness and under-achievement. Suggested support increasing staff awareness, adopting a person centered approach, reducing stigma and demands and increasing acceptance of difference.

Impact on wellbeing discussed in relation to exhaustion experienced due to camouflaging as well as high anxiety experienced at school, relating to uncertainty of success of camouflaging attempts.

NB: Be aware that thematic analysis combined views of all participants (parents, educators and girls).

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**TENTH PAPER READ:**

**Missing: the autistic girls absent from mainstream secondary schools (Moyse, 2021).**

Moyse, R. (2021). *Missing: the autistic girls absent from mainstream secondary schools.* [Doctoral dissertation, University of Reading].

Study design: Mixed methods incorporating individual case studies

| 1. Does the study address a clearly focused question/hypothesis? | Yes | Can't tell | No |
|---|---|---|---|
| **S**etting? | Participants attended mainstream schools. | | |
| **P**erspective? | Forefronting the views of the autistic girls. | | |
| **I**ntervention or phenomena? | Phenomena – school non-attendance | | |
| **C**omparator/control? | None | | |
| **E**valuation/exploration? | Exploring the girls' experiences of school non-attendance. | | |
| 2. **Is the choice of qualitative method appropriate?** Is it an exploration (e.g., behaviour/reasoning/beliefs?) Do the authors discuss how they decided which method to use? | Yes – reasoning around experiences  No. | | |
| 3. **Is the sampling strategy clearly described and justified?** Is it clear how participants were selected? | Purposive and snowball sampling from NHS records, local charities, posts on social media and researchers own | | |

| | |
|---|---|
| Do the authors explain why they selected these particular participants? Is detailed information provided about participant characteristics and about those who chose not to participate? | connections within her autistic community. Brief information about each participant (and parent) is provided from initial request for information, through to 10 participants. |
| **4. Is the method of data collation well described?** Was the setting appropriate for data collection? Is it clear what methods were used to collect data? Type of method? Is there sufficient detail of the methods used (e.g., how many topics/questions were generated and whether they were piloted)? Were the methods modified during the study – why? Triangulation of data? Data saturation? | Three participatory opportunities per participant created multiple opportunities to discuss and create meaning. Yes – Ideal School activity, life chart, interview question generation, interview 1, second interview – thematic analysis. No No but some contextualisation via analysis of NHS records assessment – as per mixed methods approach. Focus on quality of strong information power rather than saturation. |
| **5. Is the relationship between the researcher(s) and participants explored?** Did the researcher critically reflect on their role and any relationships with participants particularly in relation to formulating research questions and collecting data? Were any potential power relationships involved? | Participatory approach employed – accommodations made to improve accessibility of research process for participants via an Autism Advisory Group. Interview activities scaffolded subsequent questions. Yes. Additional ethical consideration discussed, and accommodations explained. |
| **6. Are ethical issues explicitly discussed?** Is there sufficient information on how the research was explained to participants? Was ethical approval sought? Are there any potential confidentiality issues in relation to data collection? | Details of ethical approval and informed consent give – voluntary participation Yes No – pseudonyms used. |
| **7. Is the data analysis/interpretation process described and justified?** Is it clear how themes and concepts were identified in the data? | Yes – through thematic analysis No. |

| Was the analysis performed by more than one researcher?<br>Are negative/discrepant results taken into account? | Unclear. |
|---|---|
| **8. Are the findings credible?**<br>Are there sufficient data to support the findings? | Yes |
| Are sequences from the original data presented (e.g., quotations) and were these fairly selected? | Yes – quotations and thematic word maps and thematic theme maps are shown |
| Are the data rich (participants voices foregrounded)? | Yes |
| Are the explanations for the results plausible and coherent? | Yes |
| Are the results of the study compared with those from other studies? | Yes |
| **9. Is any sponsorship/conflict of interest reported?** | No |
| **10. Finally…consider:**<br>Did the authors identify any limitations? | Yes – self-selection by participants may have limited diversity of sample.<br>Research tools may have been limiting. |
| Are the conclusions the same in the abstract and the full text? | Yes |

**Summary**

A robust participatory approach underpinned this small-scale study into the reasons why autistic girls are absent from school. This methodology resulted in prioritisation of female autistic voices through co-creation as well as participation in the research process.

Key findings included: tension between wanting to fit in but also be recognised and valued (e.g., hidden but wanting to be seen); tension between support strategies that temporarily removed the girls from stressful situations without addressing the root cause of stress; and tension between inconsistent responses from teachers – sometimes inadvertently returning the pupil to an unsafe place or person. The study highlighted a direct correlation between lack of appropriate support at school and deterioration of mental health as well as an ideal school in which wellbeing is prioritised rather than academic achievement.

Recommendation for enhanced school support to support wellbeing were discussed.

**Appendix 1.2 – Description of thematic synthesis process**

Stage 1:    Read Findings and Discussion of each study and extract text related to developmental and systemic framework - create initial codes by translating concepts from one study to another to generate a code bank.

Stage 2:    Develop descriptive themes by looking for similarities and differences between codes – generate group code that describes meanings of initial codes. Keeps close to original findings of studies.

Stage 3:    Apply analytical themes within developmental and systemic conceptual frameworks – dependent on judgement of researcher.

Reflections:    Initial thoughts from researcher

(J. Thomas & Harden, 2008)

**Appendix 1.3 – Summary of thematic synthesis of literature base**

List of studies:

| 1 | The mainstream school experiences of autistic girls and adolescents (Tomlinson et al., 2022) |
|---|---|
| 2 | Perceptions of friendship among girls with Autism Spectrum Disorders (Ryan et al., 2021) |
| 3 | Exploring how a sense of belonging is constructed in the accounts of autistic girls who attend mainstream school in England (Brennan De Vine, 2022) |
| 4 | The social experiences and sense of belonging in adolescent females with autism in mainstream school (Myles, Boyle & Richards, 2019) |
| 5 | Autism and the U.K. secondary school experience (Dillon et al., 2016) |
| 6 | Autistic and non-autistic young people's and caregivers' perspectives on COVID-19 related schooling changes and their impact on emotional wellbeing: An opportunity for change? (Ozsivadjan et al., 2022) |
| 7 | Looking behind the mask: Social coping strategies of girls on the autistic spectrum (Tierney et al., 2016) |
| 8 | Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings (Cook et al., 2017). |
| 9 | "Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators (Halsall, et al., 2021). |
| 10 | Missing: the autistic girls absent from mainstream secondary schools (Moyse, 2021). |

| Dev. Tasks | Eco-systemic influence | Descriptive theme (no. of study) | Analytical theme | Researcher reflections Eco-systemic, developmental and multi-domain wellbeing factors |
|---|---|---|---|---|
| **Identity** *Developing a clear sense of who you are* | Young Person | • New 'label' (1, 10)<br>• Masking learning differences (9)<br>• Emotional cost of masking (3, 4, 7, 8, 9) | **Who am I really?** *Secondary school experiences create opportunity to explore emerging autistic identity* | Significant emphasis on autistic girls needing to adapt their behaviours to achieve self-acceptance. Incongruent with early adolescent developmental phase or late diagnosis? Perhaps reinforcing the unacceptability and stigmatisation of an authentic autistic self in school. Eco-systemically, lack of discussion around societal attitudes influencing school communities in the social acceptance of autistic wellbeing. Focus on emotional and social wellbeing. Lack of cultural or intersectional criticality. |
| | Peer and Social | • Camouflaging social differences (3, 8, 9)<br>• Hidden but needing to be seen by adults (9, 10)<br>• Social clubs (4, 7) | | |
| | Family and School | • Neurodivergent acceptance (7)<br>• Triangulated approach (7) | | |

| Dev. Tasks | Eco-systemic influence | Descriptive theme (no. of study) | Analytical theme | Researcher reflections Eco-systemic, developmental and multi-domain wellbeing factors |
|---|---|---|---|---|
| **Autonomy** *Feeling in control* | Young Person | • Distorted autonomy (4, 10) | **Am I in control?** *Judged and discriminated against versus control of the neurodivergent agenda and support* | Building confidence and self-advocacy skills to feel comfortable defending or advocating for personal wellbeing requires accumulated positive systemic and relational experiences which may be incongruent with the reality of school life in mainstream secondary settings. Fails to consider wider societal factors influencing attitudes towards neurodivergent students, acknowledge power relations between students and adults in school or the role of student compliance in a behaviourist-led system. |
| | Peer and Social | • Owning the agenda (1, 3) • Agency to choose coping strategies (1, 6, 10) | | |
| | Family and School | • Pupil choice in learning (5) | | |
| | Young Person | • Stress from academic and learning pressures (1, 10) | **How do I navigate the secondary school system?** *Academic, relational learning and sensory demands* | Wellbeing dependent on coherent and predictable whole school awareness, adoption and adaptation within a neuroaffirming culture. Celebration and respect for individual differences is key, as modelled by key adults. Pressures on wellbeing seem complex and multi-layered, beyond control of the individual, more aligned with the neo-liberalism market forces driving school's competitive focus on academic attainment. |
| | Peer and Social | • Views validated and trusted (3) | | |
| | Family and School | • Collaborative or group working (3, 5, 7, 10) • Accommodation of individual needs (1, 3, 9) • Attuned adult relationships (1, 3, 9) • Whole school training (1, 3) • Value of pupil passport (1) | | |
| | Young Person | • Regulating sensory overload (1, 3, 4, 7) • Emotional wellbeing and stress (1, 6) • Coping mechanisms (3) | **How can I manage sensory challenges?** *Little understanding of the emotional and social impact of dealing with sensory challenges* | Mastery of the environment seems particularly challenging and relies on the individual finding alternative space to reduce sensory overload and support regulation needs. Reduced social coherence in the perception and organisation of neuro-affirming social spaces which further restricts opportunities for social inclusion if designated space creates sensory tensions. Autonomy and agency of choosing alternative spaces may be limited to the structural design of the school environment as well as student policies around engagement, attendance and behaviour. Lack of architectural oversight on building design and functionality. |
| | Peer and Social | • Isolation (3) | | |
| | Family and School | • Sensory-safe spaces (1) | | |

| Dev. Tasks | Eco-systemic influence | Descriptive theme • (no. of study) | Analytical theme | Researcher reflections Eco-systemic, developmental and multi-domain wellbeing factors |
|---|---|---|---|---|
| **Belonging** *Establishing a place in society* | Young Person | • Friends who understand and accept me (1, 3, 4) • Lacking social confidence to lead the social agenda (7) | **Where do I belong?** *Acceptance, authenticity, inclusion and shared interests.* | Social integration is key to belonging to school and peer communities and most successful when authentic self and real shared interests guide integration. Consistency of positive relations with staff and collaborative approaches with individuals to create inclusive support, environments and opportunities is key but also relies on social interaction and communication skills which some autistic girls find tricky to navigate. Masking behaviours meet short term purposes and environmental mastery of social context but with longer term detrimental effects on personal growth and friendship retention. |
| | Peer and Social | • Camouflage true self or differences to fit in (7) • Acceptance reduces camouflaging (9) • Shared interests and activities (3, 4, 7, 8, 10) • Repeated cycles of failed friendship (7) | | |
| | Family and School | • Co-production of personalised support (1) • Treated with respect and understanding (4, 5) • Extended experiences beyond school (2) • Adapted group/club environments (3, 4) | | |

**Appendix 1.4 – Detailed example of thematic synthesis**

Study One: The mainstream school experiences of autistic girls and adolescents (Tomlinson et al., 2022)

| Stage 1 - Examples of initial coding | Stage 2 – Descriptive themes *(code book)* | Stage 3 – Analytical themes |
|---|---|---|
| *"Even though I've got autism, I find it hard to accept it…and I don't really like to tell people" – 'reluctant to share her diagnosis with others' (p. 330).* <br> *'Diagnosis had led to a greater understanding of their individual needs' (p. 334).* | Value of a new 'label' | Who am I really? |
| *"A lot of my friends are different to me…like more mature. I just feel like I'm not up to them yet…so I'm mainly friends with younger students" – '[name] perceived herself as less mature than her peers' (p. 330).* <br> *'[name] shared that she identified with others with additional needs, as illustrated by her close relationships with a member of staff with ADHD and with peers who identified as SEN' (p. 334).* | Friends who understand and accept me + supporting factor for belonging | Where do I belong? |
| *'[Name] to choose not to communicate with peers using [social media]' – "You don't have a lot of social cues…it's hard for me to tell if somebody's being sarcastic" (p. 328).* <br> *'Reluctance to use social media as a means of interacting with friends, largely due to the challenges with social communication' (p. 330).* | Owning the [communication] agenda | Am I in control? |
| *"So normally I take an extra five minutes to just go somewhere like the toilets" – 'better at making her own adaptations to manage her anxieties' (p. 328)* <br> *' [Name] demonstrated great insight into her own needs and shared personal modifications she made to reduce her anxiety, ranging from proactive use of ear defenders to self-removal from lessons if an unfamiliar member of staff was present' (p. 333).* | Agency to choose coping strategies | |

| Stage 1 - Examples of initial coding | Stage 2 – Descriptive themes and descriptions *(code book)* | Stage 3 – Analytical themes |
|---|---|---|
| *'Accommodations shared by [name] included a pass to leave lessons, flexibility in exam arrangements and the provision of a designated space for support with learning' (p. 328).*<br>*"I've only known two teachers who read it" – 'inconsistency of individual accommodations' (p. 328).*<br>*"I've got a card which says I need help or I'm OK…extra transition days for those with special educational needs" – 'acknowledge the importance of personalised accommodations to facilitate her educational experience' (p. 330).* | Accommodation of individual needs | How do I navigate the school system? |
| *"People higher in the school think…well I don't need to do it now because we've got curriculum support staff…leave to that lot" – 'mainstream teachers had absolved themselves of responsibility for pupils with SEN…expressed frustration at some teachers lack of autism knowledge and misconception that her brain works the same as others' (p. 333).* | Urgent need for whole school training | |
| *"Whenever I feel anxious, staff know how to help me" – 'trust seemed to be facilitated through taking time to get to know {name} and understand her individual needs' (p. 330).*<br>*"I was really upset…she spent all of break time with me…that's why I began to trust her because she gave up her time for me" – ' trust was facilitated through taking time to get to know [name] and understand her individual needs' (p. 330).*<br>*"She basically sorts my life out for me" – 'weekly sessions with the school psychotherapist' (p. 333).* | [Trust built from] attuned adult relationships | |
| *'Tests and exams appeared to create stress specifically issues with remembering all the necessary information and the pressure of teaching staff insisting on a uniform approach to exam preparation' (p. 328).*<br>*"Exams are evil…the teachers just don't shut up about them" – 'exam experiences as an intense source of stress' (p. 331)* | Emotional wellbeing and stress from academic and learning pressures | |
| *"Teachers who read it [the pupil passport], understand it" (p. 328).* | Value of pupil passport | |

| Stage 1 - Examples of initial coding | Stage 2 – Descriptive themes and descriptions *(code book)* | Stage 3 – Analytical themes |
|---|---|---|
| *'Sensory issues were noted, such as noise and over-crowding in the corridors and canteens and struggles with the mainstream classroom environment – "just too noisy…too many people"' (p.320)*<br>*'Sensory needs were identified as a constant battle' – "the corridors are evil…there's lots of people…it's very noisy and they touch you and I don't like it" (p. 333)* | Daily need to regulate sensory over-load | How can I manage sensory challenges? |
| *"The fire alarm is horrific…usually I get so annoyed I'd bite my fingers" – 'intense stress felt in response sensory anxieties…and potential sensory challenges if pupils were noisier than usual' (p. 331).*<br>*"If I'm very angry…I'll do something dangerous…I hit my head…I scratched myself" – 'combined impact of challenges was often so intense it was overwhelming and had resulted in self-injurious behaviours' (p. 330)* | Emotional wellbeing and stress from sensory challenges | |
| *"Whenever I feel anxious or anything, I can just sit out there and look at all the wildlife" – 'identified the school environment as enhancing her educational experience…she appreciated designated spaces for SEN pupils'…"it makes me feel really calm" (p. 330)*<br>*"Additional accommodations ranged from the provision of a safe space during unstructured times … and access to the school's well-being animals' – "We have tortoises which are great – they're very calming" (p. 333).* | Sensory-safe spaces help re-regulate | |
| *'Protective factors for her inclusion in the mainstream environment including support from staff with problem solving as well as the implementation of personalised accommodations tailored to her individual needs' – "I've got a wristband which is green on one side and red on the other…I can flip it and people know whether to talk to me or not" (p. 333).* | Co-production of personalised support | Where do I belong? |

# Appendix 2. Information supporting the Methods chapter

## Appendix 2.1 – Letter of approval from PEP in Local Authority

**People Directorate**
**Prevention & Early Intervention Service**
**CONFIDENTIAL**

**EDUCATIONAL PSYCHOLOGY SERVICE**
Applying psychology to promote positive outcomes for
**Children and young people**

**Luton**

**Luton Borough Council**
**The Leagrave Centre,**
**Strangers Way**
**Luton LU4 9ND**

17th November 2022

**Re: Trainee Educational Psychologist research**

To whom it may concern,

I am writing in regards to the research being undertaken by Kathryn Connolly, Trainee Educational Psychologist. I can confirm that I am aware of, and approve of the research study *'Harnessing the 'well' in being: An exploration of the wellbeing experiences of adolescent autistic girls and how these can be supported within mainstream schools'*, being undertaken within Luton schools, on behalf of the Luton Educational Psychology Service.

There are no additional ethics processes to go through in Luton, but we do value receiving a summary/briefing of Trainee's research once it has been completed so that it can be disseminated to promote good practice.

Kind regards

*Joanne Summers.*

**Dr Joanne Summers**
**Interim Head of Inclusion & Principal Educational Psychologist**

University of
East London

# School of Psychology Ethics Committee

# NOTICE OF ETHICS REVIEW DECISION LETTER

**For research involving human participants**

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**Reviewer:** Please complete sections in **blue** | **Student:** Please complete/read sections in **orange**

| Details | |
|---|---|
| **Reviewer:** | **Miles Thomas** |
| **Supervisor:** | **Helena Bunn** |
| **Student:** | **Kathryn Connolly** |
| **Course:** | **Prof Doc in Educational and Child Psychology** |
| **Title of proposed study:** | **Harnessing the 'well' in being: An exploration of the wellbeing experiences of adolescent autistic girls and how these can be supported within mainstream schools.** |

| Decision options | |
|---|---|
| **APPROVED** | Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment. |
| **APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES** | In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. |

| | Minor amendments guidance: typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials. |
|---|---|
| **NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** | In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.<br><br>**Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study. |

## Decision on the above-named proposed research study

| Please indicate the decision: | **APPROVED** |
|---|---|

## Assessment of risk to researcher

| Has an adequate risk assessment been offered in the application form? | YES ☒ | ☐ |
|---|---|---|
| | If no, please request resubmission with an **adequate risk assessment.** | |

**If the proposed research could expose the <u>researcher</u> to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:**

| **HIGH** | Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application is not approved on this basis. If unsure, please refer to the Chair of Ethics. | ☐ |
|---|---|---|
| **MEDIUM** | Approve but include appropriate recommendations in the below box. | ☐ |
| **LOW** | Approve and if necessary, include any recommendations in the below box. | ☒ |

| Reviewer recommendations in relation to risk (if any): | See below |
|---|---|

| Reviewer's signature | |
|---|---|

| **Reviewer:**<br>(Typed name to act as signature) | Dr Miles Thomas |
|---|---|
| **Date:** | **21/02/2023** |

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee*

**RESEARCHER PLEASE NOTE**

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

**Appendix 2.3 – Young Person's Information Sheet**



## INFORMATION SHEET for Young People

<u>Harnessing the 'well' in being – An exploration of the wellbeing experiences of adolescent autistic girls and how these can be supported within mainstream schools</u>*.*

**Contact person: Kathy Connolly**

**Email: u2190375@uel.ac.uk**

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

**Who am I?**

My name is Kathy Connolly.  I am a doctorate student in the School of Psychology at the University of East London (UEL) and am studying for a Professional Doctorate in Educational and Child Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

I am passionate about representing neurodiverse voices and transforming school provision to support all autistic pupils.

**What is the aim of the research?**

I want to explore the views of secondary-aged female autistic students on their wellbeing and how this is supported at school. Typically, school provision for wellbeing is designed and delivered with neurotypical pupils in mind and the voice of autistic female students is under-represented.

This research will be shared with English school, local authorities and the autistic community, at research conferences, academic journals and via professional social media.  I hope that this will promote a neurodiverse understanding of school wellbeing and promote good practice in schools. It is also hoped that future research may extend this understanding and support around wellbeing experiences into primary and specialist schools' environments to create a more holistic overview of what wellbeing means and how it can be supported for <u>all</u> autistic girls.


**Why have you been invited to take part?**

To address the study aims, I am inviting young people from the autistic community to take part in my research. You are eligible to take part in this study if you:

- Have a diagnosis of autism.
- Identify as female.
- Are 12-15 years old.
- Attending a mainstream secondary school in England.
- Can speak English at a conversational level.
- You are happy to talk about your wellbeing.


It is entirely up to you whether you take part or not, participation is voluntary.

**What will I be asked to do if I agree to take part?**

If you agree to take part, you will be invited to decide to what extent you wish to participate as a co-researcher. Activities you may choose include:

- You may also like to share your views on wellbeing and school support via an online interview (for up to one hour). Every online meeting will be recorded (audio and video) using Microsoft Teams and is expected to last up to 1 hour.
- You may like to join our end of study celebration to hear how the views of all girls are being celebrated and shared with schools.
- At the end of the research study, a lay summary and academic record of findings will be created and shared with the autistic community, schools and other professionals.
- They may wish to take a lay summary back to their own school and to share their experiences with teachers.


Every online meeting will be recorded (audio and video) using Microsoft Teams and is expected to last up to 1 hour. I will facilitate the research process.

There is no payment for participating in this study.

When you return the attached consent form I will email you a Microsoft Teams invitation link.

**Can I change my mind?**

Yes, you can change your mind and withdraw without explanation, disadvantage or consequence. If you are a co-researcher and would like to withdraw from the study, you may leave the research group at any point before, during and after. If you decide to share your views in an interview and would like to withdraw from the study, you can do so on the day of your allocated interview session. If you decide to withdraw, your data will not be used as part of the research.

Separately, you can also request to withdraw your data from being used even after you have taken part in the study. This request needs to be made within 3 weeks of the data being collected.

**Are there any disadvantages to taking part?**

As this study focuses on issues around wellbeing, you may wish to consider the following:

- **Your emotional wellbeing:** you might talk about past times when you were stressed, sad or angry. This may impact how you feel now.

- **Available support:** I will do regular check-ins with you during our time together to ensure you are feeling OK. I will also ask you to nominate a trusted adult that you feel you can speak to outside of our time together. Additional information about available support will be provided. This can also be found below:

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**NHS Live Well**

Further advice on how to manage your wellbeing can be found on https://www.nhs.uk/livewell

**ChatHealth**

For young people aged 11-19 (25 with SEND)
A service for young people to confidentially ask for help about a range of issues or make an appointment with a school nurse. They can also find out how to access other local services including emotional support or sexual health services.

Call 07520 616070

**Young Minds Textline**

Free, 24/7 and confidential support available for young people. Text YP to 85258.

**Young Minds**

Information on child and adolescent mental health. Services for parents and professionals.

Phone: Parents' helpline 0808 802 5544 (Monday to Friday, 9.30am to 4pm)

Website: **www.youngminds.org.uk**

**KOOTH**

Kooth is an online counselling and emotional well-being service for children and young people aged 11 -25.

The service is anonymous and free at the point of use. On www.Kooth.com children and young people can chat online to professional counsellors, read articles written by young people, join forums to receive peer-to-peer support, access self-help materials and keep a daily journal. The regular forums cover topics ranging from exam stress and anxiety to eating disorders and grief. Young people can also log on to access one-to-one online counselling sessions with a qualified counsellor from 12pm until 10pm on weekdays, and from 6pm until 10pm on weekends.

**Papyrus**

Young suicide prevention society.

Phone: HOPELINEUK 0800 068 4141 (Monday to Friday, 10am to 10pm, and 2pm to 10pm on weekends and bank holidays)

Website: **www.papyrus-uk.org**

**Anxiety UK**

Charity providing support if you have been diagnosed with an anxiety condition.

Phone: 03444 775 774 (Monday to Friday, 9.30am to 10pm; Saturday to Sunday, 10am to 8pm)

Website: www.anxietyuk.org.uk

**ChildLine**

Free, confidential support for children and young people in the UK, including a helpline and 1:1 online chat with counsellors. Call 0800 1111 or visit childline.org.uk

**How will the information I provide be kept secure and confidential?**

- You will not be identified by the data collected, or any material that comes from the data. Instead, pseudonyms will be used to protect your identity. Confidentiality will only be broken if you or another person is at risk of harm.

- All information that can identify you, your school, or any other person will be removed or replaced (e.g., School One).

- You will not be asked to share any private information.

- Your details will be securely saved on a password-protected file until the study ends. These will be stored securely on the researcher's OneDrive for Business account, which is also password-protected.

- All information will be shared securely by using University of East London emails.

- Only the researcher will have access to your confidential information. This will be deleted at the end of the study.

- The anonymised data will be kept securely on the researcher's OneDrive for Business account.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018.  For more information about how the University processes personal data please see [www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection](www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection).


**What will happen to the results of the research?**

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online repository. Findings will be shared with a range of audiences (e.g., autistic community, academics, school staff, educational psychologists etc.) through journal articles, conferences presentations, talks and blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally (all personally identifying information will either be removed or replaced).

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by the researcher for a maximum of 3 years, following which the data will be deleted.


**Who has reviewed the research?**

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

**Who can I contact if I have any questions/concerns?**

If you would like further information about this research or have any questions or concerns, please do not hesitate to contact me.


**Kathryn Connolly**: u2190375@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor **Dr Helena Bunn**. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: H.bunn@uel.ac.uk

**or**

Chair of School Research Ethics Committee: **Dr Trishna Patel**, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)


**Thank you for taking the time to read this information sheet**

**Appendix 2.4 – Young Person's Consent Form**



## YOUNG PERSON'S CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Harnessing the 'well' in being – An exploration of the wellbeing experiences of adolescent autistic girls and how these can be supported within mainstream schools.

**Contact person: Kathy Connolly**

**Email: u2190375@uel.ac.uk**

| | Please initial |
|---|---|
| I confirm that I have read the participant information sheet dated xxx for the above study and that I have been given a copy to keep. | |
| I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| I understand that anything discussed in the study should be kept confidential including any identifiable information of participants, their attendance and content of discussions. | |
| I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage. | |
| I understand that if I withdraw during the study, my data will not be used. | |
| I understand that I can withdraw my data from the study up to 3 weeks after my individual research interview. | |
| I understand that all research sessions will be recorded using Microsoft Teams. | |
| I understand that my personal information and data, including audio and video recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information. | |
| I understand that my data will be deleted once the research has been completed and graded. Pseudonymisation transcripts of my data and any analysis will be kept securely until the completion of the study. | |

| | |
|---|---|
| I understand that anonymised quotes from my data may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me. | |
| I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to. | |
| I agree to take part in the above study: | YES/NO |

Participant's Name (BLOCK CAPITALS):

Participant's Signature:

Date:

**I am nominating this adult as a person I can talk to about my wellbeing during the study:**

*(this may the same as your parent/carer or another adult that you trust)*

Adult's Name (BLOCK CAPITALS) :

Supporting Adult's Signature:

Date:

Researcher's Name (BLOCK CAPITALS) : KATHY CONNOLLY

Researcher's Signature:

Date:

**Please return via email to u2190375@uel.ac.uk**

**Appendix 2.5 – Planned adaptive actions taken to maximise participation of autistic co-researchers**

| Considerations for participation: | Adaptive actions taken: |
|---|---|
| Entrenched power dynamics reduce transformative and participatory purpose. *(Carlsson, 2001; Clark-Ibáñez, 2004; den Houting et al., 2021; Fletcher-Watson et al., 2019)* | Clear outline of proposed research process and participatory options provided during the recruitment process. Co-researchers invited to co-construct all aspects of the research design (post recruitment phase). Clear terms of reference for each work-shop session sent a week in advance. Joint decision making at key stages. Close attention to research hermeneutics-in-action (see below). Remove pressure from the girls as the central point of attention during data collection using a range of child-centered creative methods as tangible prompts alongside verbal question and answers. |
| Quality of relationship between lead researcher and co-researcher. *(Spiel et al., 2020)* | Time spent getting to know participants through exploratory pre-recruitment conversations and throughout the Workshop programme. Rapport building session to 'meet and greet' and establish a zone of psychological safety (including ground rules for engagement). <br> Reflexive diary kept and utilised during researcher's supervision to ensure transparency and accountability for all decision making. Constant reflections on the researcher's outsider role on peer interactions as well as in-action reflexivity. <br> Check in and out to monitor participant wellbeing. |
| Quality of relationship between co-researchers (e.g., power imbalance of stronger voices heard) *(Holland et al., 2010; Newman et al., 2021; Spiel et al., 2020)* | Active listening, arbitration and attention sharing from lead researcher. Invitation to use a range of communication methods (e.g., 'chat' function to text answers, emoticons and verbal responses). Setting safe boundaries with a reminder of ground rules during all online meetings to proactively manage behaviour and engagement. <br> Attunement of lead researcher to relinquish control of the research context to allow for free dialogue and creative expression – see extracts from reflecting diary in Appendix 3.1. |

| Considerations for participation: | Adaptive actions taken: |
|---|---|
| Agency of co-researchers to participate or not. Including choice of physical absence *(e.g., Hennessey et al., 2022; Hill, 2012; Skelton, 2013; Tisdall, 2012)* | Information sheets and consent forms distributed digitally to parents. Workshop flyers emailed a week in advance detailing activities for the session (See Appendix 2.6). Invitation to name and use preferred communication methods during all online participation phases. No pressure policy in all MS Teams invites to workshop sessions. Option to 'pass' on specific elements of the process, including not attending a workshop. |
| Skills of co-researchers to participate in research process *(e.g., den Houting et al., 2021; Newman et al., 2021)* | Digital literacy and technological access of participants pre-checked with parents. Brief description of the research process during workshops. Training of co-researcher during data analysis phase. |
| Adequate time to fully explore emerging constructs of phenomena or to teach research skills *(e.g., Wallace & Pandora, 2019)* | Successive workshops planned with clear agendas but 'in the moment' flexibility, allowing for exploratory discussion and adaptation, as needed. Summer holidays as data collection and initial data analysis phases maximised flexibility for research team. |
| Reduce ambiguity of interpreting children's voice *(e.g., Hennessey et al., 2022; Spiel et al., 2020)* | Member checking of language used throughout all research phases. Reflexive diary kept and utilised during supervision to ensure transparency and accountability for all decision making. Valuing participatory contributions in an accessible and engaging manner through member check processes. |

**Appendix 2.6 – Recruitment flyer**

## We need YOUR HELP and VOICE for a RESEARCH STUDY on WELLBEING...

Harnessing the 'well' in being: An exploration of the wellbeing experiences of adolescent autistic girls and how these can be supported in school.

Are you a girl (aged 12-15 years old) who is also autistic?

Do you want to take part in a research project that will find out what wellbeing means for neurodiverse girls and help support best practice in school wellbeing provision?

Are you interested in being part of a research team?

*For more information, please email me: U2190375@uel.ac.uk*

### ADDITIONAL INFORMATION:

**Who am I?** I am a trainee educational psychologist - interested in your views around wellbeing and the support you receive at school. I believe it is important to champion neurodiverse views about wellbeing and help schools better support your wellbeing.

**How would it work?** You can learn some valuable research skills by joining me and other autistic girls as a co-researcher in the research study. **You can choose how much or little you want to contribute.** We will work together as a team to decide what it is about wellbeing that you are all interested in exploring, design some interview questions, share your own views with me in an online chat or help analyse the data and create a summary. All our meetings will be online for about an hour. I will anonymise everything that happens in the research group. I will also store all your personal information securely and delete it at the end of the project.

# Appendix 2.7 - Examples of research resources for participatory workshops

## Planning for Session 3: How do we research?

In Session Two we talked some more about wellbeing and thought about what a good day and bad day for wellbeing felt like and what was happening at these times to make us feel that way – see below.

To help us decide whether we should continue to talk about wellbeing as one topic or if there is a specific area of wellbeing you'd like to explore further in our project, please look at your suggestions below and rank them from 1–10 (with 1 being the most interesting to explore and 10 being the area you are least interested in).

**Please ask your parent to email this back to me before Sunday**

☐ Wellbeing – the whole topic

☐ Feeling emotionally stable / not angry / not sad / not stressed / no fights / not anxious

☐ Allowed to be myself / not feeling pressured to speak to anyone

☐ Being understood and accepted – by teachers, my friends or others at school

☐ Playing sports / dancing – looking after my physical and emotional health

☐ Relationships and belonging – being with my friends / positive not negative interactions

☐ Able to do my learning / feeling successful at school / staying in lessons

☐ Able to use the things (cards/passes) that support me without judgement

☐ Creative activities – making / drawing / writing to support my wellbeing

☐ Quiet time on my own / allowed to move around school when it's quieter

### In our next session we will:

Choose our topic – think of some questions to ask about the topic – choose some different ways to represent our thinking for the interviews (where we will share our views individually before coming back together to analyse the data together).

*If you have any questions or simply want to chat before we meet, please get in touch via email:*
*U2190375@uel.ac.uk*

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### How would I like to share my views?

These are some of the ways you might like to share your thoughts with me when we start to collect data through the interviews. Can you think of any others?

### Our rules for keeping ourselves safe...

Don't share where we live or the name of the schools we go to / work in.

Don't share what we talk about outside of this group*.

It's up to us if we want to have our camera on or off and how we share our ideas (or whether we want to pass).

No surprises – we will have some time to think before the session so that we don't feel put on the spot.

No laughing or judgement.

*If you have any questions or simply want to chat before we meet, please get in touch via email:*
*U2190375@uel.ac.uk*

*Only exception to this is if a genuine safeguarding concern is raised.*

---

### Interview schedule

You have kindly agreed to share your views about your wellbeing and how schools can support this. The interview will be with me, using MS Teams and should take around an hour.

Co-researchers in this project have designed the questions below, based on working together to think about what is it important to share with schools about autistic girls' school wellbeing. All the co-researchers are autistic girls aged between 12–15 years old and attend secondary schools in the UK. Across three group workshops, they designed the focus of these questions, by sharing their own experiences of school wellbeing and what they find helpful.

One of our rules for keeping ourselves feeling safe in the group is 'no surprises' and so we are sharing the group's four main questions with you now:

☐ **Can you describe your wellbeing at school?**

Think about the difference in your wellbeing on a good day and bad day at school. You may like to reflect on this before the interview and perhaps organise your thoughts before we speak. This can be helpful as a prompt when we are exploring your answer to the question – See more ideas for organising your thinking over the page.

☐ **Can you describe what positive wellbeing feels/looks like for you?**

The co-researchers have been clear that their goal is to experience positive wellbeing* and they were curious as to how this might look and feel different for each girl. Prompt questions here might include:

- Who are you with when you are experiencing positive wellbeing (that makes you feel happy and calm? (adults/children/friends/pets)
- What are you doing ?
- Where are you? (think about the physical environment/places you like to be)
- What thoughts might you be having – what pops into your mind?
- How does this make you feel?
- At school, what experiences make you feel happy and calm?
- What else do you have planned for that day (perhaps something you are looking forward to in/at the end of the school day?

☐ **What do you already do to improve / protect / maintain your wellbeing?**

☐ **What should school be doing to support your wellbeing?**

Prompt questions may include:
- Do you feel listened to and included in decisions about your wellbeing?
- What would it be important for your teachers to know about you and your wellbeing?
- If you could give advice to people at your school about you, your wellbeing and autism, what would it be?

* See more ideas for organising your thinking over the page

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## Planning for Session 4: What we learnt about your wellbeing?

Welcome back after the long summer break ! I hope you all had a good rest and were able to boost your wellbeing.

I wanted to say:

AND....

**A MASSIVE THANK YOU**

for all your help in sharing your own experiences of wellbeing at school in the interviews you did with me.

for reading through your words to check the meaning was right for you.

### Next steps....

We are now ready to come back together to find out what we learnt about your wellbeing. We can meet on these dates, via MS Teams (for one hour).

| When we will meet | What we will talk about |
|---|---|
| Sunday 20th October at 6pm | Say hi (again) and begin to look at the key themes emerging from the research |
| Sunday 12th November at 6pm | Agree the final themes that summarise the research project |
| Sunday 19th November at 6pm | Think about what it was like to take part in this group and plan next steps for the project – who shall we tell about this work? |
| Sunday 3rd December at 6pm | Final celebration of all our hard work! |

*If you have any questions or simply want to chat before we meet, please get in touch via email:*
*U2190375@uel.ac.uk*

## Planning for Session 6:
## What we learnt about
## your wellbeing?

Welcome to our final workshop looking at the group's views on School wellbeing and thinking about how this group has worked for you.

In this session, we will be looking together at the views shared during the interviews and making sure that they make sense.

**Next steps....**

| When we will meet: | What we will talk about: |
|---|---|
| Sunday 19th November at 6pm | Finish looking at the group themes from the research and think about what it was like to take part in this group and plan next steps for this project – who shall we tell about this work? |
| Sunday 3rd December at 6pm | Final celebration of all our hard work! |

**REMINDER: Our rules for keeping ourselves safe...**

Don't share where we live or the name of the schools we go to / work in.

Don't share what we talk about outside of this group*.

It's up to us if we want to have our camera on or off and how we share our ideas (or whether we want to pass).

No surprises – we will have some time to think before the session so that we don't feel put on the spot.

We listen carefully. No laughing.

All views shared from the research will remain anonymous through use of the interviewee's chosen pseudonym.

*If you have any questions or simply want to chat before we meet, please get in touch via email:*
*U2190375@uel.ac.uk*

*Only exception to this is if a genuine safeguarding concern is raised.

---



**University of East London**
Pioneering Futures Since 1898

**CERTIFICATE OF PARTICIPATION**

In recognition of

**X**

for participating as a co-researcher in the

**Autistic Girls Wellbeing Research Group**

from April – December 2023.

Research skills included study design, data collection, data analysis and dissemination.

x
Educational Psychologist        December 9th, 2023

**Appendix 2.8 - Research aims**

## Aims of our research:

**CO-RESEARCHERS**

- For school to understand how to support me in class

- For teachers to understand that I am not going to be the same as everyone else in class. For them to support my differences.

- For school to listen to what I need and work with me to meet my needs.

- To meet other girls who are having the same experiences as me.

- To have a safe space to share my story.

**LEAD RESEARCHER**

- To develop a community-led research project that explored the girls' lived experiences of school wellbeing.

- To emancipate the voices of autistic adolescent girls.

- To promote the value of qualitative and participatory research methodology for collaboratively making sense of autistic experiences.

- To provide guidance for schools and other professionals in supporting wellbeing.

*The Autistic Girls Wellbeing Group*
*July 2023*

## Appendix 2.9 - Final interview schedule

**1. Can you describe a day at school when you had good wellbeing?**

*Prompts:*
a. Can you tell me what happens on a day when you are experiencing good wellbeing at school?
b. How does it feel when you have a good day at school?

*If showing a picture/drawing/piece of written work, ask:*

c. *Can you tell me what I am looking at?*
d. *What does this [behaviour described] do for you?*
e. *Why did you draw this – why is it important to share this?*
f. *How does this experience relate to other areas of your life?*
g. *Why do you think this has become a helpful behaviour?*
h. *How do you think we could use this drawing/picture/writing to help others understand about your wellbeing experiences as an autistic girl?*
i. *What could schools do to help you maintain your wellbeing on a good day?*

**2. Can you describe a day at school when you are experiencing poor wellbeing?**

*Prompts:*
a. Can you tell me what happens on a day when you are experiencing poor wellbeing at school?
b. How does it feel when you have a bad day at school?

*If showing a picture/drawing/piece of written work, ask:*

c. *Can you tell me what I am looking at?*
d. *What does this [behaviour described] do for you?*
e. *Why did you draw this – why is it important to share this?*
f. *How does this experience relate to other areas of your life?*
g. *Why do you think this has become a helpful behaviour?*
h. *How do you think we could use this drawing/picture/writing to help others understand about your wellbeing experiences as an autistic girl?*
i. *What could schools do to help you maintain your wellbeing on a bad day?*

**3. Can you describe what positive wellbeing feels/looks like for you?**

*Prompts:*

a. Who are you with when you are experiencing positive wellbeing (that makes you feel happy and calm? (adults/children/friends/pets)

b. What are you doing ?

c. Where are you? (think about the physical environment/places you like to be)

d. What thoughts might you be having – what pops into your mind?

e. How does this make you feel? (*2-3 words to describe how you feel*)

f. At school, what experiences make you feel happy and calm?

g. What else do you have planned for that day (perhaps something you are looking forward to in/at the end of the school day)?

h. Who are you with when you are experiencing positive wellbeing (that makes you feel happy and calm? (adults/children/friends/pets)

i. What are you doing ?

j. Where are you? (think about the physical environment/places you like to be)

k. What thoughts might you be having – what pops into your mind?

l. How does this make you feel?

m. At school, what experiences make you feel happy and calm?

n. What else do you have planned for that day (perhaps something you are looking forward to in/at the end of the school day?


*If showing a picture/drawing/piece of written work, ask:*

> o. *Can you tell me what I am looking at?*
> p. *What does this [behaviour/place/people described] do for you?*
> q. *Why did you draw this – why is it important to share this?*
> r. *How does this experience relate to other areas of your life?*
> s. *How do you think we could use this drawing/picture/writing to help others understand about your wellbeing experiences as an autistic girl?*
> t. *What could schools do to help you maintain your wellbeing on a positive day?*


**4. What do <u>you</u> already to improve, protect or maintain your wellbeing?**

*Prompts:*

a. Which of these statements feels most true about your school wellbeing:

❑ My wellbeing at school is not good and needs to be improved

❑ My wellbeing at school is good and this needs to be protected

❑ My wellbeing at school is OK and needs to be maintained.


b. What strategies do you find helpful to [choose one – improve/protect, maintain – depending on previous response] your wellbeing at school?

c. Which of these strategies do you do by yourself?

d. Which of these strategies do you do with the help or support of other people?

e. How do they know to support you in this way?

f. How did you learn that this strategy worked for you?

## 5. What should schools be doing to support your wellbeing?

*Prompts:*

    a. Do you feel that your school understands how to support your wellbeing?

        ❑ Yes

        ❑ No

        ❑ Some of the time

    b. Why is that? Why do you say that?

    c. What is it important for your teachers to know about you and your wellbeing?

    d. Do you think autism impacts your wellbeing experiences?

        ❑ Yes

        ❑ No

        ❑ Some of the time

    e. Why is that? Why do you say that?

    f. Do you feel listened to and included in decisions about your wellbeing?

        ❑ Yes

        ❑ No

        ❑ Some of the time

    g. What impact does being listened to and included have on your wellbeing at school?

    h. If you could give advice to people at your school about you, your wellbeing and autism, what would it be?

**Appendix 2.10 – Extract from a transcribed interview with exploratory notes**

Exploratory notes about WELLBEING: Key objects of concern (e.g., relationships, processes, people, events, values and principles), meaning (e.g., what are these like) and interpretative (e.g., how and why do they have these concerns – how do they relate to wellbeing? Language used, context given?) {Researcher bias/assumptions}

| Question one: Can you describe a day at school when you had good wellbeing? | |
|---|---|
| *Hermione:* On a good day I'm usually happy, chatty. I'm more able to cope throughout the day. I'm less stressed and anxious so I'm a much better person to be around on a good than on a bad day. | Difference between a good day and bad day based on her emotions – how she is feeling and how well she can communicate with others. Values feeling less negative emotions because it improves social interaction with/for other people. Able to manage/handle/survive for the whole day when experiencing good wellbeing. {Feeling less successful on a bad day?} |
| *Interviewer:* Okay. Alright. So how does that feel for you when you're having a good day? | |
| *Hermione:* It feels pretty good because I'm able to be free and not worry about everything else that's going on around, so yeah. | Sense of freedom when experiencing positive wellbeing. Opposite from restrictions on coping that worrying about everything brings. Good wellbeing is an enabler – locus of control/autonomy? |
| *Interviewer:* So, can you tell me a little bit more about what being free feels like for you? | |

**Appendix 2.11 – Example of member checking in individual case study analysis**

## Summary of Views for 'Hermione

This is a summary of the views you shared during your interview. Included in this document are:

- **Word cloud representing your actual words related to both positive and negative experiences of wellbeing**.

- **Key quotations (extracts) from what you told me + key themes which summarise these.**

    o Themes are colour coded to show positive wellbeing experiences (pink), negative wellbeing experiences (blue) and supporting factors such as context, supports, people, systems, policies (green).
    o There are two key themes emerging from your views.

**What happened:**

- You gave your informed consent after reading the information sheet.
- We spoke using Microsoft Teams. You were supported by your Mum who sat close by during the interview.
- The interview was recorded for the purpose of transcribing the data, and then deleted.
- The transcript (which includes all the words spoken by me and you during the interview) was then analysed to create this summary.

**What is this research about – what question are we trying to answer?**

*What are the lived experiences of wellbeing for autistic girls attending
mainstream secondary schools and what factors support this?*

## Visual representation of your experiences of wellbeing at school:

These are words or phrases you used when you described your wellbeing at school. This way of showing your words was chosen by the other girls in the research group who wanted to see their words represented in a visual way. The bigger the word, the more times it was said. This may mean that the word was more important to you. You chose the paintings to also represent good and bad wellbeing at school.

### Positive experiences of wellbeing at school:



### Negative experiences of wellbeing at school

**Key themes and quotations from your interview**

| | | | |
|---|---|---|---|
| Theme 1: Order please… | **Super Stress-Free Me:**<br><br>On a day with good wellbeing, I'm my very best self – socially, mentally and learning. | *"On a good day, I'm usually chatty and happy…I'm more able to cope throughout the day. I'm less stressed and anxious so I'm a much better person to be around on a good than on a bad day. It feels pretty good because I'm able to be free and not worry about everything else that's going on around. Being free is like not being stressed, not having to worry about being anxious or stressed".*<br><br>*"When I'm on a bad day, I feel quite down and I get quite angry, So when I'm on a good day, it's less. In the school it's very hard to learn around the people so coping [on a good day] is like being able to learn. I'm focused…I'm doing my work…I'm doing what I want to do".* | |
| | **A peaceful place :**<br><br>Away from the crazy chaos of people and emotions. | *[Describing the picture of the hummingbird which represents a day with good wellbeing] "I chose it because it's like a happy picture. It's colourful and it makes you smile. It's just peaceful like…not having people around me…like being crazy. Being with my friend. Somedays at school you feel quite angry and stressed and so the peace is good…Art is calming and quite relaxing to do".*<br><br>*"I wish I could learn alone and on my own where I can get on…I do not like being around others, especially big groups".* | |
| | **Chaos [in the classroom]:**<br><br>Lack of control over student behaviours triggers anger and frustration. | *"Yeah the students in the class, they're not that well-behaved and the noise of the children as well. That can just trigger me to be angry coz they don't really behave that well...it's not controlled. When I was in my old class it was manic. There were people throwing things. They were screaming. They were not doing their work. They were swearing and just being like a complete nuisance…like they weren't doing anything. I've changed bands so it's gone from manic…from crazy to less crazy but it's still there and it still irritating".*<br><br>*"I know it's hard but try and control the classroom more. It should be a peaceful environment and stop it [the students' bad behaviour] before it gets to that extreme".*<br><br>*"Put me in another room where it is more calm…a room where there's less people in and it's more calming to be in. They should not try and ask me questions and make me stay in the room where I am".* | |

| | | **Shifting seas…:**<br><br>The trouble with poor wellbeing is that it's a confusing jumble of emotions, thoughts and behaviours that wash over me in so many uncontrollable ways. | *[Describing a day at school with poor wellbeing] "I'm usually sad. I'm kinda angry. I'm less chatty and more quiet. I'm less able to cope. I'm more stressed out. I've got heightened anxiety and I've got headaches".*<br><br>*"I'll be getting quite fidgety; I'll be getting less focused, and I'll be just like having troubles. Probably shaking or doing something like…you'd clearly be able to see coz I'll be like fidgeting a lot or rubbing my hand…be red in the face…so I'll be quite stressed".*<br><br>*"I'm struggling with peers in general. I also struggle with the noise in the atrium at lunchtimes when I have to mix with the older years. When I go to the toilet, I get annoyed and anxious when I small vape as I feel like I'm not meant to be there. The behaviour of the students causes me to have extreme stress and confusion because I feel mad when this happens because I feel to go to school to not mess around and confusion because I can't understand this as I'm very different".*<br><br>*"In classes, I'm most angry because it's the hardest place to learn…being able to learn more without being angry or stressed".*<br><br>*[Describing a painting which represents poor wellbeing] "It's like a medley of colours. It looks confusing in a way and that could represent how I feel on some days. My brain's not working properly. I'm not right. It's also dark which represents sadness and anger…I feel on a bad day…it's dark and it's all busy and it's like jumbled up…the feelings are all jumbled up".* |
| | | **Solutions but no resolution:**<br><br>Frustrating that the system doesn't fundamentally change. It's all on me. | *"I can use that [the time out card]…leave the classroom for 5 minutes and come back in...which I cool down but then I'm still angry coz I'm going back into class where it's still the same…like they take the kids out and try and sort them out, but they just don't care…not really"*<br><br>*"I asked if I could sometimes go into the resource base coz I'm set one in all my lessons. That's a struggle for them coz in the resource base they do less difficult work … they're doing work which is like set three to four. So, it's like the work that I need to do to stay at this level, I can't get in the resource base…I can't get it"* |

| | | |
|---|---|---|
| | | *"Just trying to find a place which is quiet which is hard but try and go someplace which is quieter. Because at school there's a lot of people, like everywhere. Trying to find a place which is quiet is really difficult"*<br><br>*[describing the main problem at school "communication because we've sent in the evidence [a letter]…and I've told them how I'm feeling but they're not really doing anything about it. They still haven't had a meeting".* |
| **Theme 2: The sorting hat – finding my ' house' and a way to belong but on my own terms** | **Magical me:**<br><br>Developing my social identity through growing up with shared passions and interests | *"I've loved it [Harry Potter] ever since…I love the books…the characters...their stories…the events"*<br><br>*"There's an experience where I went to the Studio Tour...like I was actually in the stories in a way…so it was free from…just something that I loved…I was doing exactly what I wanted to do and in a place where everyone else is the same…everyone's likes the same thing…so you're not alone".*<br><br>*"It [Harry Potter] was such a good thing that I've got. I'm passionate about it. I don't know it's just…exciting, overwhelmed, magical".*<br><br>*[Associating with specific characters] "Hermione is smart, and she loves reading…I do read a lot and I love learning"*<br>*and Luna…she's more freeing and calmer…like the odd one out…because at school I'm not like everyone else but I'm still Ok with that. A bit like Luna, it's OK with not being like everyone else"* |
| | **Sympathetic sidekicks:**<br><br>When my magic fails…. they speak to me and up for me.<br><br>Helping me develop confidence in my self-advocacy skills. | *"On a bad day it's hard to explain how you are feeling...when you're in the moment, it's very difficult to calm yourself down and think. So, when you're trying to explain it to someone what's out there or how you feel...you don't actually know…you don't know what to do".*<br><br>*[Family is important because] "I can talk to them. They understand. They listen….If they understand they can help me...they'll be trying to give me ways to cope and help with the situation…My Mum and Dad could help and try and sort it out…I have spoken to my Mum and Dad and asked if they can speak to school about using the autism provision or to home school as I do not want to go on as things have been."* |

| | | |
|---|---|---|
| | | *[Friend support you by]* "She'll just try and help me right there and she'll just listen. She'll understand and she'll always be there.. Just trying to talk to me, like telling me to just breathe, trying to calm me, trying to stop me getting anxious, just trying to ignore them. She tells me to use my Time Out card and just tries to help me like not go crazy".<br><br>*[Having someone to talk to is]* "like a release…it makes me feel calmer. I didn't really struggle in Primary School. I always loved school and I did everything. But since I went to high school, I'm struggling so I find it helpful to talk".<br><br>"I've asked for support, and I've not really got any back so…I tried to tell them. My Mum went in for a meeting but because I wasn't there, they didn't really believe her. Like they said I had to ask her [the teacher] but I don't really like speaking up, so I wrote a letter to try and tell them". |
| | **The golden snitch:**<br><br>The ultimate goals to play for | "Find a way to learn without permanent distraction and when I'm in a state of stress, find a way to calm me down and out of that situation…comfort me and tell me to breathe and calm down and try and do stuff to make me feel OK"<br><br>"Try and find someone that you have something in common with and that you could talk to. Find quiet areas as much as possible and to avoid noise and conflict and speak out to Head of Years and other trustworthy people". |
| | **All on the same team:**<br><br>It's important for school adults to spend time getting to know you so they can | "I think it's important that they know how to…to know where…what to do…things to support"<br><br>"I have autism but because I don't really go around saying I have it, half the teachers didn't even know I had it. So that's why they didn't support me…but not in a way where it makes me feel different from everyone else bit in a way that they know if I do get stressed, like how and why in a way they can support"<br><br>"Do things that make you feel accepted when you're in school and about the autism, like in subtle ways help. Just them knowing can help" |

| | | |
|---|---|---|
| | provide highly attuned and inclusive support. | *"They can just like listen to their students…could help".* |
| | **Different but not less:**<br><br>On my terms. | *"I just feel like I don't want to be like, not like everyone else…so that it [the autism] doesn't define me. I'm top set in a lot of things and I do clubs and I do a lot of stuff. I'm not saying the autism defines me, but I don't want to go around telling people about the autism because I don't want them first judging me on that".*<br><br>*"I've got one friend and there's some Year 10s that I talk to. It's always been that way even in Primary School, I've always been with less friends. I don't really care about friends".* |
| | **Invisibility Cloak is not the answer:**<br><br>Masking is a way to cope but comes with consequences. | *"To manage my emotions and more, I hide how I feel even until recently with my Mum. I feel defeated by my autism...is not helped by me hiding or masking my struggles and feelings. From this my anxiety and stress levels are heightened. I hated becoming distant with my only two friends as I feel they couldn't understand, and I don't really trust anyone at school...I do mask all to try and not let anyone see how mad and sad I feel at school even though I love learning. I have been getting a lot of migraines and stomach aches and am tired all the time recently because of how I feel. I also keep crying at home too".* |

**Appendix 2.12 -** PowerPoint slides used to recap and brief co-researchers in Workshop Sessions 4 & 5

**Appendix 2.13** – Example of PowerPoint slides for Workshop Session 5 – GETs, sub themes and extracted quotations



## Working out who I am

**Different but not less**

**Misunderstood:**
*Difficult when no-one understands you*

"You're made fun of with horrible names because of your disability. It's not fair. You're treated differently and it really brings down your confidence" (Ron 4)

"I remember the first day she gave me a consequence point because I was looking out of the window but I was just a bit zoned out" (Libby 1)

"I heard the whole class talking about someone behind their back and I realised this is probably what happens to me. I know if anything happens, I'll really struggle to get over it" (Ivy 2)

**Constantly feeling judged:**
*No escape from the emotional fall out of being constantly evaluated by others*

"When she's at your desk trying to help…you just wanna get it over and done with cause everyone's looking at you" (Ron 3)
"Sometimes people assume I am stupid because I am autistic …they treat me five years younger than I actually am and I find that really hard to deal with" (Ivy 2)

"I kind of feel paranoid. Everyone's judging me all the time and everyone sees everything…everytime I fall on my sentences…everything that's wrong with me" (Ivy 2)

**OK to be me:**
*Freedom to be accepted and supported for who I am*

"I just feel like I don't want to be like everyone else …so the autism doesn't define me. I'm in top set and I do clubs and a lot of stuff. I don't go round telling people about the autism because I don't want them first judging me on that" (Hermione 2)

"When I get really nervous (and often I do get nervous), they're all really kind to me. I feel supported by my friends all the time. At lunch in school I sit with my friend and I really enjoy spending time with them. I'm kinda more of a listener than a talker" (Ivy 2)

"Hermione is smart and she loves reading…I do a lot of reading and I love learning. Luna she's more freeing and calm…like the odd one out…because at school I'm not like everyone else but I'm still OK with that. A bit like Luna, it's OK with not being like everyone else" (Hermione 2)

**Get educated:**
*Adults at school need to understand what it's like to be neurodiverse*

"I think teachers need to get more of an education on neurodiversity in general. Because if teachers understand what the children actually have to go through, maybe they'll be a bit more understanding, won't pick on me so much and have a different approach to getting back into the lesson " (Libby 1)

**Appendix 2.14** – Mapping potential influence from researcher's firsthand experiences

| Researcher's significant statements from fore-structure for phenomena | | | |
|---|---|---|---|
| *Social anxiety is real, frightening and disabling. Sometimes it's easier and safer to stay hidden.* | *It can feel difficult to know where one belongs at school, resulting in a sense of isolation, loss and loneliness but also sometimes freedom.* | *Bouncing back from the negative wellbeing experiences depends on having a safe space or person. Important to find what works for you.* | *Being academically able doesn't always equate to coping with school.* |

| Interviewer's (within – post encounter) interpretations | | | |
|---|---|---|---|
| Fear, zoning in/out, being aware of and noticing<br>Big words and emotions, desperate to get it all out, watched … judged, captive, more than unsafe…a prison, feeling emotions very intensely. | Helpless, anger at school staff for not doing more to help, trying to understand why school has felt so difficult, lonely, no-one to help, hyper alert to other people and her own feelings, | Control, tranquillity Lack of autonomy and advocacy. | Pressure |

Researcher's interpretation of Ron's encounter [34]
*(experiential statements and exploratory notes)*

| | | | |
|---|---|---|---|
| **Anxiety is a thief –** it steals your words, your energy, emotions and stops you learning. It traps you in a relentless cycle that you can't escape from.<br>**Eyes on me -** paralysed by the fear of being noticed and judged.<br>**Intimidated -** Always feeling scared and panicked. Difficult to speak your truth.<br>**Hiding behind the mask –** Masking is a | **A lonely life –** With few friends, there are limited options.<br>**Avoid making the same mistakes … again** – higher awareness in school staff needed to avoid re-traumatising.<br>**Who am I?** – it's difficult when no-one understands you and even worse when you don't understand yourself. | **Space to just be** – escaping and zoning into a different reality where I can just be me.<br>**Happiness is sharing** – sharing my time, energy and interests with my close people or animals makes me feel happy and safe.<br>**A little kindness goes a long way** – comfort knowing that I matter.<br>**Listen to my voice –** Help me feel heard, understood and my needs validated. | **Stop punishing me for the things that I find hard –** it's not my fault, autism means there are some things at school I just can't do.<br>**Suffocated by the system:** constant pressures of time limits, teacher expectations, threat of detention, fines and homework.<br>**My struggles aren't important to other people -** Un-noticed, de-prioritised and 'dealt' with. |

[34] PET 1: Imprisoned / confined  PET 2: Surface deep  PET 3: Silence(d) PET 4: Surviving in an uncertain world

| | | | |
|---|---|---|---|
| costly coping mechanism to stay hidden and survive the day. | | **Do what you love and love what you do** – getting lost and feeling safe in creativity. | **Keep control –** make it feel safe and more predictable for me. This about what I need. |
| **Actor without a script -** Sometimes you just don't have the right script to deal with the scene in front of you. | | | |
| **Unable to see the forest for the trees –** In the moment, it's impossible to unpick the intense jumble of emotions. | | | |

# Appendix 3. Information supporting the Discussion Chapter

**Appendix 3.1** – Extracts on the journey of managing the participatory approach – from research diary

| Session one: | Session two: |
|---|---|
| Prior to the start of session one, I am feeling apprehensive about the perceived flexibility needed using this method. I am concerned about balancing the productivity of these early planning sessions with engaging the girls, so they start to feel some ownership of the project and want to come back next week!<br><br>They seemed to prefer to keep their cameras off and to type their answers in the chat function. This really slowed down the pace of the conversations as no-one wanted to go first. However, once they started to share ideas, they seemed almost surprised by home similar some of their experiences were. I will need to adjust my expectations of how much we can get through in each session I think and focus more on the depth of content.<br>(Kathy – Reflective diary: 02/07/2023) | Having introduced the co-researchers to the topic of wellbeing, it feels like it may be difficult to narrow the focus area of wellbeing down into a succinct research question. I enjoyed hearing them compare their thoughts about a 'good' and 'bad' day of wellbeing. It feels like they are starting to gel as a group.<br>(Kathy – Reflective diary: 9/07/2023)<br><br>**Session three:**<br><br>The girls are feeling more comfortable in the Teams sessions now. Their shared responses are more detailed and flowing more independently of each other than before. I've been genuinely impressed and humbled by how decisive and creative the co-researchers have been. They've thought carefully about what research questions and data collection methods will work best for them. I feel more confident now that we have a meaningful and accessible way forward to the interview stage.<br>(Kathy – Reflective diary: 16/07/2023) |
| **Data analysis:**<br><br>The member checking process went more smoothly than I thought it would. I've received email confirmation from all parents that the girls read and discussed their interview record. Several have asked if they can take it to school to share with their Head of Year. This already feels like we are empowering them to advocate for their needs and make local changes that can support their wellbeing!<br>(Kathy – Reflective diary: 15/08/2023) | **Session seven:**<br><br>Feedback from the co-researchers on their perceived level of participation in the project was initially disappointing as I tried so hard to make sure that at each stage they felt ownership of the process. But when we investigated further what the alternative types of participation could have been, it became clearer that their comfort level was at the collaborator stage. I think if I had been in their school and they knew me better, we may have been able to shift the participation dial further.<br>(Kathy – Reflective diary: 24/09/2023) |

**Appendix 3.2** – Reasonable adjustments most valued by participants – extracts from research diary



**Reasonable adjustments for effective research with autistic girls: what they thought worked well**
*(extracts from research diary).*

**Creating a psychological safe space – boundaries and agency:**
*"Feeling safe and unrushed so that she can share her story"*, parent.

*"Reminder of the ground rules each time…and being able to add to them"*, Ron.

*"Offering emotional check-ins at each session helped me keep the co-researchers' wellbeing top of mind throughout"*, Lead researcher.

*"Freedom from pressure - to not turn up, if I couldn't do it that day"*, M.

*"Opportunity to read again what I had said in the interview"*, Hermione.

**Improving accessibility – technological and creative flexibility:**
*"Choosing whether to have camera and microphone on or off, depending on how I feel at the time"*, Katniss.

*"Visuals to help me understand the analysis process"*, E.

*"Sharing my pictures, which are important to me, as a way of showing how I feel"*, Hermione.

**Thinking time:**
*"Time to think…and type my answers in the chat"*, Ivy.

*"Time to get my head in the space – seeing the de-brief a bit before we met online"*, Katniss.

*"Having the interview questions beforehand so I can have to think about what I really want to say"*, Lizzy.

*"Time in between workshops and the need to prepare and send a pre-brief helped clarify the purpose, if not the content, of each session"*, Lead researcher.

**Quality of relationships:**
*"Time to get to know each other a bit – helped me feel more 'normal', like I wasn't the only one feeling this way"*, Ivy.

*"Flexibility to adapt in the moment and run with their interests felt a richer and more relevant experience and partnership"*, Lead researcher.

**Appendix 3.3** – Applying the Framework for Critically Reflective EP Practice