University of Southampton

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Autism and well-being: Masking in autistic girls and the role of animal contact in well-being.

by

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Thesis for the degree of Doctorate in Clinical Psychology

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Abstract

This thesis seeks to explore and understand the experiences of autistic people in relation to animal contact and masking. Chapter One offers an introduction to key concepts, including use of language and participatory research. It also covers research motivations, key findings and a concluding summary of the interconnected nature of Chapter Two and Three.

Chapter Two is a systematic review of qualitative research exploring animal contact in relation to well-being for autistic individuals. Twenty-four papers were included in the final synthesis and were quality assessed using the Critical Appraisal Skills Programme (CASP, 2024). Thematic synthesis revealed six themes; individual well-being; bridging and connecting; freedom to grow; anchor for the family; challenges; and faithful friends. The findings demonstrated that animal contact may support the well-being of autistic individuals in a multi-faceted way and underscored the need for more rigorous research.

Chapter Three is a qualitative empirical study exploring how adolescent autistic females understand their masking behaviours. Ten participants took part in semi-structured interviews, analysed using Reflexive Thematic Analysis (Braun & Clarke, 2006; 2021; 2023) from a relativist-constructionist orientation. Four themes were identified; social dynamics; emotional well-being; masking is a safety net; and the (un)masking journey. Findings suggest that masking is inherently social and may serve as a key survival mechanism supporting autistic individuals navigate a non-autistic society. However, it was associated with several negative outcomes and some participants described seeking opportunities to unmask. These findings emphasise the need for masking autonomy and for professionals to support autistic individuals to develop coping mechanisms that do not rely on conforming to societal norms. Instead, authenticity should be facilitated through the development of more accommodating environments, thus reducing the pressure to mask.

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Research Thesis: Declaration of Authorship

Print name: Anna Norman

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I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
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3. Where I have consulted the published work of others, this is always clearly attributed;
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5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
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Date: October 2025

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Definitions and Abbreviations

Adolescence	A phase of human development between childhood and adulthood (aged 10-19).
Autism Spectrum Disorder	A neurodevelopmental condition with a diagnostic criterion including persistent difficulties in social communication and social interaction, and restricted, repetitive patterns of behaviour, interests or activities.
Masking	The conscious or unconscious practice of reducing, concealing or suppressing autistic traits and behaviours in a social setting, whether explicitly learned or implicitly developed.
Well-being	A positive state that encompasses physical, social, intellectual, emotional, occupational, and spiritual dimensions, and broader concepts such as quality of life, meaning and purpose.
ADHD	Attention-Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CASP	Critical Appraisal Skills Programme
CAT-Q	Camouflaging Autistic Traits Questionnaire
CORE-10	Clinical Outcomes in Routine Evaluation-10
EBE	Expert by Experience
ERGO II	Ethics and Research Governance Online II

FAP ..... Female Autism Phenotype

FPE..... Female Protective Effect

NHS..... National Health Service

PPI..... Patient and Public Involvement

PRISMA..... Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RTA..... Reflexive Thematic Analysis

SPIDER..... Sample, Phenomenon of Interest, Design, Evaluation, Research type

YP-CORE ..... Young Person-Clinical Outcomes in Routine Evaluation

Chapter 1: Bridging Chapter

This thesis seeks to explore and understand the experiences of autistic people in relation to animal contact and masking. The chapter begins by discussing language use and motivations for conducting this research. The benefits and importance of participatory research are also explored, in addition to outlining the key findings of Chapter Two and Three. Finally, a conclusion is presented that summarises the interconnected nature of both Chapters in relation to shaping the well-being of autistic individuals.

Language

There is much debate regarding appropriate language in the field of Autism Spectrum Disorder (ASD; henceforth 'autism'). Literature exploring the views of autistic communities highlights a disconnect between the research base and the views of autistic people and their network (Gowen et al., 2019). A key component of this is the concerning use of demeaning, ableist and stigmatising language when referring to autism, autistic people and associated concepts (Bottema-Beutel et al., 2021; Gowen et al., 2019).

Disability advocacy groups and communities encourage people to communicate about disabilities in a way that promotes a positive conceptualisation and understanding of individuals and disabilities that highlights autonomy and capacity (Kenny et al., 2016). The use of person-first language (e.g., people with disabilities) was proposed in the 1990's (Blaska, 1993) as an alternative to disability-first language (e.g., disabled people) and was subsequently incorporated into law in some countries (e.g., the Individuals with Disabilities Education Act, 1997). However, some communities regarded this as undermining a key part of their identity, perpetuating the notion that their diagnosis is fundamentally negative (Halmari, 2011). More recently, autistic communities have suggested identity-first language (e.g., autistic person) recognising their diagnosis is a pivotal part of their identity that they

accept and are proud of (Hurlbutt & Chalmers, 2002). Although there is no universally accepted language to describe autism, a large-scale online survey exploring the views of autistic communities in the UK identified the terms ‘autism’ and ‘autistic’ person as the most favoured (Kenny et al., 2016).

Similarly, the terms ‘masking’, ‘compensation’ and ‘camouflaging’ are often used interchangeably when referring to hiding or minimising autistic traits and/or appearing non-autistic to overcome the challenges of living in a predominantly non-autistic society (Sedgewick et al., 2021). Although there is no clear consensus, it seems that, compared to the other terms, ‘masking’ is most used by autistic people (Sedgewick et al., 2021).

The term ‘neurotypical’ is commonly used to refer to a person without a diagnosis of autism. However, as autism is not the only form of neurodiversity, some literature suggests using ‘non-autistic’ unless specifically referring to a person whose brain has developed in a neurotypical way (Bottini et al., 2024; Sedgewick et al., 2021).

In conclusion, although there are many nuances in the use of language when referring to autism and associated terms, after reviewing the current literature (Bury et al., 2023; Kenny et al., 2016; Sedgewick et al., 2021) and personal communications with an expert by experience (EBE), this review will use identity-first language (i.e., autistic or non-autistic) and the term ‘masking’, unless directly quoting or citing existing literature.

Motivations

Societal Experiences of Autistic Individuals

Autism is a highly heterogenous neurodevelopmental condition that is characterised by difficulties with communication and reciprocal social interaction and restricted, repetitive

patterns of behaviour, interests, or activities, as outlined in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2022).

Unfortunately, society predominantly holds a deficit-based view of autism which perpetuates stigma and negative self-perception. The deficit model of autism implies that autism is a disorder that should be fixed and that the problem lies within the individual (Dinishak, 2022). However, more recent discussions have suggested alternative lenses from which to understand autism. For example, the neurodiversity model conceptualises autism as one form of neurological variation within the typical diversity of human development (Jaarsma & Welin, 2012; Nicolaidis, 2012) and the double empathy problem (DEP) externalises issues by suggesting bi-directional miscommunication between autistic and non-autistic people (Milton, 2012; Milton et al., 2022). These models highlight the need for systemic interventions that support autistic people without reinforcing or perpetuating negative self-perception and stigma.

This may be particularly important for autistic females as research has predominantly been conducted in male populations, resulting in a male-biased understanding of autism (D'Mello et al., 2022; Lai et al., 2015). As such, screening tools, assessment processes and the diagnostic criteria for autism may lack sensitivity to female populations (D'Mello et al., 2022; Øien & Nordahl-Hansen, 2018). Furthermore, research suggests that compared to males, some females face greater societal pressures and from an earlier age including expectations to conform to particular social characteristics, such as empathy and reciprocity (Krahn & Fenton, 2012), compliance (Rudman & Glick, 2001) and being friendly and agreeable (Brescoll & Uhlmann, 2008). It is possible that this may increase the pressure to mask from an early age and contribute to the underdiagnosis of autistic females (Gould, 2017).

As modern societies remain largely patriarchal (Hill, 2009) and are developed by and for non-autistic people, autistic people (particularly autistic females) often face multifaceted systemic barriers that perpetuate societal power disparities (Singh & Bunyak, 2019), compounding and reinforcing daily challenges.

Personal Motivations

As a woman who received a late diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) during this research process, this topic is deeply personal to me. My husband is autistic and much of my working history has been with children and families who are neurodiverse. I have witnessed first-hand the impact of chronic masking and the lack of appropriate interventions for neurodiverse people. I also recognise many of the issues discussed during this thesis in my own life, such as diagnostic overshadowing, a male-biased conceptualisation of neurodiversity and the stigma associated with being neurodiverse. I have always felt pressured to conform to society's depiction of being a woman (e.g., gentle, compliant and quiet) spending much of my earlier life masking, or facing scrutiny (e.g., being told I am “too loud” or “boisterous”) when I was unable to do so effectively. I have spent several years learning to unmask and live more authentically (e.g., being energetic, assertive and expressive) without fear of judgement. However, I often reflect on what it might have been like to have understood masking during my adolescence.

One of the ways I have coped with this process is by connecting with nature. Throughout my life I have felt a deep connection to the natural world, and I spent much of my childhood on our family farm, surrounded by animals. I have observed the way animals have benefitted a range of people, including those who are neurodiverse. Personally, animals have provided me with an unconditional connection, allowing me to be myself, and

professionally, I have worked with numerous patients who regard their animals as key members of their attachment hierarchy.

As a result, I had a strong desire to pursue a meaningful research project exploring the lived experiences of autistic individuals in relation to animal contact and masking.

Patient and Public Involvement

Patient and public involvement (PPI) is widely recognised as beneficial (Brett et al., 2014) in improving research relevance, quality and accessibility (Carroll et al., 2022; Gillespie-Lynch et al., 2017) and the inclusion of autistic experts by experience (EBE) adds research rigour and value through inclusive working by acknowledging that autistic people are experts (Gillespie-Lynch et al., 2017; Grant & Kara, 2021; Hobson et al., 2023). Currently, there is a chronic lack of meaningful participatory research that includes EBEs in the field of autism (Keating, 2021; Pickard et al., 2022), potentially contributing to the dissonance between conducted research and the autistic community (den Houting & Pellicano, 2019). As per the National Institute for Health Research ([NIHR], 2000) co-production refers to the process of sharing power and responsibility between researchers, practitioners and the public at all time points during research.

To ensure the research was truly meaningful and relevant to the autistic community, I felt it was essential to conduct participatory research that included EBEs, while also being mindful of potential power imbalances between researcher and collaborator (Nelson & Wright, 1995). Arnstein's (1969) Ladder of Citizen Participation is a helpful way of conceptualising participatory research in this context. For this thesis, EBEs were involved at all levels of research development to avoid any form of tokenism to promote genuine collaboration and co-production.

For Chapter Two, one autistic female EBE (Jenny) offered valuable insights into the lived experiences of autistic people throughout the research process. Her inclusion offered nuances and reflections that non-autistic researchers may have otherwise overlooked and supported the co-creation and shaping of more accurate and relevant themes and sub-themes.

For Chapter Three, a meeting with two autistic parents with autistic children was held in the early design stage to identify areas of need and finalise the research questions and aims. For the remainder of the research, Jenny joined the research team shaping the research throughout and offering thoughtful and constructive reflections. Her contributions shaped the development of study materials, use of language, theme development, data analysis and future research directions.

To date Jenny has attended 6 research meetings and offered an additional 4 hours of input. Jenny also reviewed the final thesis and contributed meaningful feedback related to the research relevance, language use and accessibility. Furthermore, as the importance of participatory research extends beyond the creation and execution of research (Keating, 2021), Jenny's involvement will continue during the dissemination process, including participating with a research conference presentation.

Summary of Key Findings

By exploring the well-being of autistic people in relation to animal contact and masking, this thesis seeks to address one unified research question: How can we better understand, and ultimately improve, the well-being of autistic individuals?

Chapter Two explores autistic individuals' experiences of animal contact in relation to well-being. The findings highlight that although there may be some challenges, animal contact can provide multifaceted well-being benefits for some autistic people. These insights

emphasised how animals can support independence and act as familial anchors, social mediators, and faithful friends who offer unconditional love, thus reducing the pressure to mask for some individuals.

Chapter Three explores the experiences of autistic adolescent females and how they make sense of their masking behaviours. The analysis revealed the complex social dynamics underpinning masking, indicating that it is primarily socially driven and that a significant lack of masking awareness exists among the general population. The findings also illustrate the negative impact masking can have on an individual's emotional well-being and identity, including a bi-directional relationship between mental health and masking. For some, masking was also viewed as a "safety net" that they could use in times of need; however overall participants expressed a desire to feel less pressure to mask.

Conclusion

Fundamentally, both chapters focus on how autistic people experience their social world and offer insights into how animal contact and masking may influence the well-being of autistic individuals. The DEP (Milton, 2012; Milton et al., 2022) proposes that masking is more likely to occur in contexts where non-autistic people misunderstand and respond negatively to the interactions of autistic individuals, due to a limited understanding of neurodiversity. As such, animal contact may provide autistic individuals an opportunity to escape the demands of social situations that involve experiences relating to this. Although Chapter Two is not gender-specific, the themes of social connection and well-being may be particularly relevant to autistic females who face unique challenges, such as greater expectations to conform to societal gender norms from a young age and therefore feel a greater pressure to mask (Krahn & Fenton, 2012). Consequently, due to animals providing a nonjudgmental and safe source of social connection that alleviates social isolation, autistic

individuals may feel a reduced pressure to mask and therefore experience less associated emotional burden. Therefore, animal contact may represent a valuable avenue of support for all autistic individuals, including females.

Together, these studies explore different but complementary aspects of how social factors (animal contact and masking) can shape the well-being of autistic individuals. The findings contribute to a broader understanding of the challenges autistic individuals face and the social and emotional needs of autistic individuals. It highlights the need for the continued development of inclusive and accessible ways to reduce social isolation, increase meaningful social connections and support authentic self-expression for autistic individuals.

Future research would benefit from conducting participatory research exploring gender differences in autistic individuals' experiences of animal contact to ensure meaningful, relevant and accessible findings (den Houting & Pellicano, 2019; Gillespie-Lynch et al., 2017; Grant & Kara, 2021; Hobson et al., 2023).

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Chapter 2: Autistic people's experiences of animal interventions and companionship in relation to well-being: A systematic review of qualitative evidence.

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Note: This report is written and formatted in line with the Research in Autism journal's author guidelines (Appendix A).

Abstract

Contact with animals is purported to support the well-being of individuals with Autism Spectrum Disorder (ASD). This paper presents a systematic review of the qualitative evidence exploring animal contact in relation to well-being for autistic people. A literature search of qualitative evidence relating to this topic was conducted using five databases, three grey literature databases and hand searching.

A total of 1235 articles were screened, and 24 were included in the final synthesis. Quality assessment took place using the Critical Appraisal Skills Programme (CASP, 2024). A thematic synthesis (Thomas and Harden, 2008) revealed six main themes: 1) individual well-being, 2) bridging and connecting, 3) freedom to grow, 4) anchor for the family, 5) challenges and the superordinate theme 6) faithful friends. These findings corroborate claims that animal interactions may support the well-being of autistic individuals and substantiates the need for more rigorous research.

Key Words

Autism Spectrum Disorder, Well-being, Animal, Pet, Interventions, Thematic Synthesis.

Background

Theories of the Human-Animal Connection

Throughout history, there exists evidence of a human-animal bond (Hosey & Melfi, 2018; Maher et al., 2011). This bond can be conceptualised through theories including the biophilia hypothesis (Wilson, 1984), attachment theory (Ainsworth & Bowlby, 1991; Bowlby, 1969; 1979), social support theory and the model of thriving through relationships (Feeney & Collins, 2015).

The biophilia hypothesis suggests that humans are inherently attracted to the natural world. The theory proposes that this deep-rooted connection may be explained by our evolutionary history whereby the development and survival of humans closely depended on interactions with the environment, including animals, which were vital to the survival of the human species (Wilson, 1984). As such, humans are biologically predisposed to engage with nature. Wilson (1984) suggests that beyond this, nature also offers a source of psychological and social wellness and that a lack of exposure to the natural world can result in negative psychosocial outcomes. With increased urbanisation in the modern world, seeking opportunities to remain connected to the natural environment has become increasingly pressing, and may in part explain the commonality of companion animals in modern society (People's Dispensary for Sick Animals, 2024).

Another key theory that underpins the human-animal bond is attachment theory. Attachment theory proposes that a child and primary caregiver develop a social bond that is biologically driven to ensure children remain close to their caregivers, thus increasing survivability (Ainsworth & Bowlby, 1991; Bowlby, 1969; 1979). These bonds change beyond infancy, including from parent to peer or partner (Ainsworth, 1989; Bowlby, 1969; 1979), and the quality of these early relationships impact a person's development and informs the way they experience the world (Bowlby, 1998). Attachment hierarchies provide a framework to understand a person's various attachment bonds and how an individual organises the multiple relationships that exist throughout life (Bowlby, 1979; Doherty & Feeney, 2004). Companion animals have been recorded as important figures in some people's attachment hierarchy, with them ranking as fifth most important behind partners, mothers, best friends and fathers (Meehan et al., 2017). For many (14%), companion animals were ranked as their primary attachment figure, with evidence that they provided all four of the key

behavioural features of attachment (proximity seeking, secure base, separation distress, and safety) (Meehan et al., 2017).

Animals can also play an important role in social support, which can be defined as the emotional, instrumental, informational, and appraisal assistance provided by friends, family, and broader social networks (Langford et al., 1997). According to social support theory and the model of thriving through relationships (Feeney & Collins, 2015), social support is essential for coping with life's challenges and mitigating the negative effects of adverse experiences. Similarly, social connections and meaningful relationships may serve as a protective function against mortality and ill health, as comparable to many lifestyle behaviours (e.g., smoking and exercise status) (Holt-Lunstad et al., 2010). Therefore, individuals with strong social support systems are better equipped to cope with hardship, offering individuals a sense of belonging, validation, and encouragement (Calhoun et al., 2022). Research suggests that companion animals may be a unique source of identified or perceived social support across the lifespan (Bekker & Mallavarapu, 2019; Bodsworth & Coleman, 2001; Garrity & Stallones, 1998; Meehan et al., 2017; Reniers et al., 2023; Sable, 1995), and service animals may surpass their designated role of practical, physical and tangible support, entering the realm of close social connection (LaFollette et al., 2019; Sachs-Ericsson et al., 2022).

These theories begin to explain the profound connections humans form with animals, including enhanced social bonds and emotional and physical health, and improved ability to cope with adversity. Furthermore, they corroborate the importance of offering animal-contact as a holistic and non-traditional way of supporting the well-being of autistic people.

Lived Experiences of Autistic People

Autism is sometimes framed through a deficit-focused model which emphasises the challenges autistic people face in comparison to non-autistic people and often frames autism as a disorder that must be fixed (Dinishak, 2022). Being autistic has been associated with numerous strengths and enhanced abilities in areas such as music and pattern recognition (Baron-Cohen et al., 2009; Howlin et al., 2009), attention to detail and logical reasoning (Lorenz & Heinitz, 2014). However, the deficit-based view of autism overlooks these positive attributes (Dinishak, 2022) and locates problems as within the autistic individual, potentially perpetuating stigma and contributing to a negative self-perception (Dinishak, 2022).

Conversely, the neurodiversity model regards autism as one form of human neurological variation within the broader spectrum of typical neurological diversity (Jaarsma & Welin, 2012). Building on this, the double empathy problem (DEP) proposes that problems arise from a mutual communication breakdown between autistic and non-autistic people, rather than a one-sided deficit (Milton, 2012; Milton et al., 2022).

As modern society is largely dictated by non-autistic people, there are a multitude of societal structures and systemic barriers that often negatively affect autistic people (Singh & Bunyak, 2019). These include inequitable service provision and accessibility (Wallace-Watkin et al., 2023), socioeconomic disparities (Khougar et al., 2023) and barriers to educational, social and occupational participation (Barry et al., 2020; Harmuth et al., 2018; Vasilevska Petrovska et al., 2019). While autistic people are not explicitly impaired or less abled than non-autistic people, these inequities and barriers can perpetuate a power imbalance, making daily life more difficult for autistic people.

Six Dimensions of Wellness

Given these societal challenges, autistic individuals can face a range of well-being-related difficulties shaped by their daily experiences. To explore the potential role of animal contact in supporting well-being, the literature will be examined through the six dimensions of wellness framework (emotional, physical, intellectual, occupational, spiritual, and social; Hettler, 1980), in addition to broader aspects of well-being (e.g., quality of life; World Health Organisation [WHO], 2021).

Social/Spiritual. Autistic individuals appear to share the same social needs as non-autistic people, including a strong desire for relationships (Müller et al., 2008). However, their relational styles may differ from non-autistic people and differences in emotional experiences, social competencies and societal barriers may lead to missed social engagement opportunities (Bird & Cook, 2013; Burrows et al., 2008; Sasson et al., 2017). Self-report data indicates that autistic people may feel different or alone and experience a lack of companionship (Müller et al., 2008). Lived experiences of sensory sensitivities, impulsivity, and social communication difficulties (including processing social cues and social or emotional inferences) may potentially contribute to feelings of isolation (Burrows et al., 2008; Sasson et al., 2013) and social anxiety (Spain et al., 2018).

Research reveals that social stigma and difficulties related to social communication can contribute to the formation of a negative social and personal identity, existential anxiety and identity distress in autistic individuals (Ratner & Berman, 2015; Ratner & Burrow, 2018), alongside poor self-esteem, feelings of helplessness, low sense of power and increased mental health presentations (Cooper et al., 2017; Khan et al., 2024). Although autistic populations have spiritual needs, these may be less pronounced than in other cohorts (Cwik, 2021) and generally autistic individuals score lower in spirituality scales (Crespi et al., 2019). Despite

spiritual fulfilment being related to several measures of quality of life (Cwik, 2021), there are limited accessibility and inclusion measures for autistic individuals in such communities (Hills et al., 2016).

Research is increasingly considering how autistic people may meet their social and spiritual needs through alternative means, including bonding with animals, and why this may be preferred. Studies have shown that the social attention of autistic individuals was higher in response to animals than human faces (Valiyamattam et al., 2020), and autistic children displayed particularly focused attention towards animals (Toutain et al., 2024). Additional evidence highlights improved performance in tasks involving social cognition when involving animals (Atherton & Cross, 2019; Valiyamattam et al., 2020) and that autistic children tend to prefer interaction with dogs over humans (Prothmann et al., 2009). Likewise, social skills training effectiveness increased when integrating dogs, as evidenced by a decrease in restricted and repetitive behaviours and fewer difficulties with social skills and communication (Becker et al., 2017). However, these findings should be interpreted with caution due to relatively modest and/or disproportionate gender samples.

Cross et al., (2019) found that autistic adolescents with an intellectual disability performed significantly better on the Karolinska-directed emotional faces test when detecting emotions from lion and gorilla filters when compared to the human version. This may be partly explained by animals being inherently calming and non-judgemental (Kruger and Serpell 2010). Animals can offer a safe space for someone to be themselves without fear of rejection or the need to engage in complex social rules, and this acceptance may be powerful for autistic people (Ward et al., 2017). Additionally, two personal accounts from a parent perspective have shown that strong, unique bonds can develop between autistic children and animals, ultimately leading to improved outcomes, including increased favourable emotions

(e.g., calm and joy), communication and participation in daily activities (Gardner, 2008; Isaacson, 2009).

Animal contact has also been found to enhance social cognition and functioning in autistic individuals, including increased social engagement, attentiveness, playfulness, communication and other positive social behaviours (Ben-Itzchak et al., 2021; Funahashi et al., 2014; Martin & Farnum, 2002; Sams et al., 2006; Silva et al., 2011; Sissons et al., 2022). Overall, findings suggest autistic individuals may gain deeper satisfaction and comfort from interactions with animals as a "compensatory mechanism for social contact" (Atherton et al., 2023, p. 3280).

Emotion. In addition to possible difficulties in social and spiritual domains, emotional difficulties, including emotion dysregulation (Samson et al., 2014) and alexithymia (Kinnaird et al., 2019), are more prominent in autistic individuals, and are associated with emotional regulation, expression and reactivity difficulties (Connelly & Denney, 2007; Samson et al., 2012).

The literature exploring human-animal connections suggests animal contact can result in increased emotional awareness and the development of certain characteristics including empathy, trust and compassion (Lin, 2024). Similarly, research investigating the impact of animal contact in autistic individuals found increased prosocial (e.g., smiling, laughing) and adaptive behaviours (e.g., coping and receptive communication) and decreased undesirable emotions or behaviours (Ajzenman et al., 2013; Funahashi et al., 2014; O'Haire et al., 2013). This may partially be explained by the physiological changes seen in some autistic people in the presence of animals, including decreased heart rate, skin conductance responses and cortisol levels, suggesting an acute stress and anxiety reduction effect (Polheber & Matchock, 2014; Wijker et al., 2021; O'Haire et al., 2015; Viau et al., 2010).

Behaviours that challenge, including self-injury and aggression, may also impact engagement in school, work or in the community affecting both the individual and their family (Carr, 2016; Sigafoos et al., 2003). For example, families may report increased stress, anxiety, interpersonal difficulties, and perceived burden due to the need for extensive planning and safety concerns (Pisula & Kossakowska, 2010; Rao & Beidel, 2009), which may contribute to a change or disruption in family dynamics (Sánchez Amate & Luque de la Rosa, 2024). However, research suggests that companion animals may reduce parental stress and improve family functioning in families with autistic children (Carlisle et al., 2020; Hall et al., 2016; Wright et al., 2015). Likewise, autism assistance dogs may increase safety and a family's self-reported ability to cope, and improve public perceptions and understanding, leading to reduced stigma and discrimination (Burgoyne et al., 2014; Burrows et al., 2008).

Intellectual/Occupational. Autistic individuals can experience challenges related to occupational and intellectual dimensions. For example, research evidence highlights a discrepancy in educational attainment between autistic and non-autistic children, where fewer autistic children qualify for further education despite no differences in educational ability (Stark et al., 2021). Furthermore, those who do attend and graduate from further education may experience persistent difficulties with accessing and maintaining full-time employment (Vincent & Ralston, 2024). Hence, a substantial number of autistic people may struggle to achieve independence and may continue to rely on familial support for education and employment well into adulthood (Billstedt et al., 2011; Howlin et al., 2004; Lord et al., 2020). For those individuals that do acquire employment, job satisfaction is reportedly low, with many reporting experiences of bullying and social isolation in the workplace (Hayward et al., 2018). These challenges may be partly linked to an individual's difficulties (e.g., social-communication challenges) in addition to societal barriers and the stigma associated

with autism, which can make job acquisition, retention and satisfaction difficult (Wei et al., 2018).

Some studies have emphasised the potential benefits of animal assistance/interventions in educational and workplace settings in autistic and non-autistic populations, including increased attendance, engagement, participation and focus (O'Haire et al., 2013; Smith & Dale, 2016) and increased employee psychological health and productivity (Hunter et al., 2019). More broadly, animal research suggests the responsibility of owning and caring for an animal not only increases independence but also increases autonomy, self-esteem, and self-efficacy, and provides a sense of purpose and meaning (Hill et al., 2020; Maresca et al., 2022; Triebenbacher et al., 1998).

Physical. In addition to intellectual and occupational difficulties, some autistic individuals present with motor and coordination difficulties (Lloyd et al., 2013) and are at greater risk for several negative physical health outcomes, including cardiovascular conditions and metabolic conditions (Chen et al., 2009; Croen et al., 2015). This may partly be explained by sensory sensitivities leading to a restricted diet and/or poor nutrition and reduced engagement with physical activity due to physical, communication or social barriers (Fecteau et al., 2017; Kral et al., 2013; Pan & Frey, 2006; Sala et al., 2020). Furthermore, autistic people experience sensory processing differences (Sala et al., 2020), which can significantly impact daily life as these skills constitute a key component of superordinate cognitive abilities (Baum et al., 2015).

Animals may offer relief relating to some of these difficulties. For example, both companion and assistance/intervention animals can increase physical activity and decrease sedentary times (Abadi et al., 2022), increase daily structure and routine (Brooks & Greenberg, 2023) and support executive functioning (Rezapour-Nasrabad & Tayyar-

Iravanlou, 2022). Furthermore, certain animal interventions, such as hippotherapy, are designed to "improve the engagement of the sensory, neuromotor, and cognitive systems to improve the functional outcomes" (Xiao et al., 2023, p.3). While some research has found that hippotherapy supported neuromuscular, motor function and balance goals (Heine, 1997; McGibbon et al., 1998) and reduced postural sway (Ajzenman et al., 2013), more research is needed as the evidence appears mixed at present (Xiao et al., 2023).

This Review

Modern society can be harsh and unforgiving for people that do not fit societal norms. As such, autistic people often face entrenched and multi-faceted challenges. To reduce and hopefully eliminate existing barriers and promote structures that benefit autistic people, it is important to uncover and understand alternative ways to promote their well-being.

Social support theory and the model of thriving through relationships suggests that social support plays a vital role in well-being (Feeney & Collins, 2015). Considering our inherent drive to connect with nature (Wilson, 1984), it stands to reason that animals can be important attachment figures and forms of social support for some individuals (Bekker & Mallavarapu, 2019; Meehan et al., 2017; Reniers et al., 2023). Hence, it is important to consider how and in what ways, animals may promote the well-being of autistic people.

While there exists a multitude of research exploring the link between animal contact and well-being for autistic individuals, this novel study seeks to systematically review the qualitative literature exploring autistic people's experiences of animal interventions and companionship relating to well-being and determine key themes using thematic synthesis (Thomas & Harden, 2008).

Methods

This systematic review was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, Page et al., 2021) guidance, including registering the protocol with the International Prospective Register of Systematic Reviews (PROSPERO; ID: CRD42024564234).

Participatory Research

To ensure research was meaningful, applicable and accessible (den Houting & Pellicano, 2019; Gillespie-Lynch et al., 2017; Grant & Kara, 2021; Hobson et al., 2023) the study included patient and public involvement (PPI) via an autistic female expert by experience (EBE) through co-production (National Institute for Health Research, 2000). Due to the embedded nature of the co-production the EBE shaped all aspects of the research. Some of the most significant influences included, offering valuable insights into the lived experiences of autistic people throughout the research process, supporting with the development of themes, influencing the use of language (e.g., re-wording the title of the thesis to be more autism and lay person-accessible) and changing the colour and layout of the thematic map.

Search Strategy

The 'SPIDER' (Sample, Phenomenon of Interest, Design, Evaluation, Research type) search strategy tool is specifically designed for standardised qualitative systematic searching (Cooke et al., 2012). Using the 'SPIDER' tool when developing the research questions and search strategy, allowed for the identification of terminology that is more suited to qualitative research questions (Cooke et al., 2012) (Table 1.1).

Table 1.1

'SPIDER' tool

'SPIDER' Tool	Key Words
S – Sample	Autistic populations
PI – Phenomenon of Interest	Animal contact, well-being
D – Design	Qualitative data (interviews, focus groups, etc)
E – Evaluation	Experiences
R – Research Type	Qualitative

Five electronic databases identified as relevant to the topic (Pubmed, PsycINFO, MEDLINE, AMED and CINAHL Ultimate) were searched in November 2024 to retrieve published and unpublished literature (no defined dates). To reduce publication bias three databases (ProQuest, Kings Fund and BASE) were searched to identify 'grey literature'. Scholarly journals were not included in this search as an excessive number of results were found when including this as an option (over 1.5 million results combined). To ensure a comprehensive review of the literature, backwards hand searching also took place, which consisted of reviewing the reference lists of the research papers that were full text screened.

Search Terms

Search terms were devised in collaboration with a librarian and were amended as needed across databases. It was identified in preliminary searches that several papers used mixed-methods and non-traditional qualitative methods. To gather a more comprehensive initial search, searches were kept broad and were not narrowed down by the 'Design' and

'Research Type'. However, the qualitative 'Design' and 'Research Type' elements were applied when screening papers. The search terms used in PsycINFO are shown in (Table 1.2).

Table 1.2

Search Terms Used for PsycINFO Database

'SPIDER' Tool	Key Words	Search Terms
Sample	Autistic populations	Autism OR "Autism Spectrum Disorder*" OR "Autism Spectrum Condition*" OR ASC OR ASD OR Asperger* OR Autistic
Phenomenon of Interest	Animal contact	Animal* OR pet* or animal-assisted intervention* OR animal assisted intervention* OR AAI* OR animal therapy or animal assisted therapy or animal intervention* OR Animal-assisted activit* or dog* or canine
Phenomenon of Interest	Well-being	Wellbeing OR well-being OR "well being" OR coping OR mental health OR quality of life OR life satisfaction
Evaluation	Experiences	Perception* OR attitude* OR opinion* OR belief* OR experience* OR view* OR thought*

Note. *= truncation

Inclusion and Exclusion Criteria

Table 1.3 outlines the inclusion and exclusion criteria used during the selection process.

Table 1.3

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Research explores the first-hand experiences of autistic individuals, or of those in their immediate support system (e.g., parents), where the data pertains to the autistic individual.	Research that refers to the experience of autistic individuals who have co-morbid disorders, presentations or disabilities without indicating which themes are specific to autism.
Research includes exploration of animal contact (of any kind, e.g., companion, pet, therapy, assistance, intervention).	Research explores the experiences of therapists, clinicians of service providers of autistic individuals.
Research includes exploration of well-being of any kind.	Participants who are not autistic.
Research includes qualitative analysis of qualitative data.	Single case studies.
Research includes a mixed methods research design, with qualitative analysis of qualitative data.	Research includes only quantitative analysis of data with no qualitative analysis.
Published research and grey literature.	Research with no clear or defined form of data analysis.
Research is published in English.	Secondary data reviews.
Full text must be available.	Books, audio files and conference proceedings.
	Full text not available.
	No English version available.

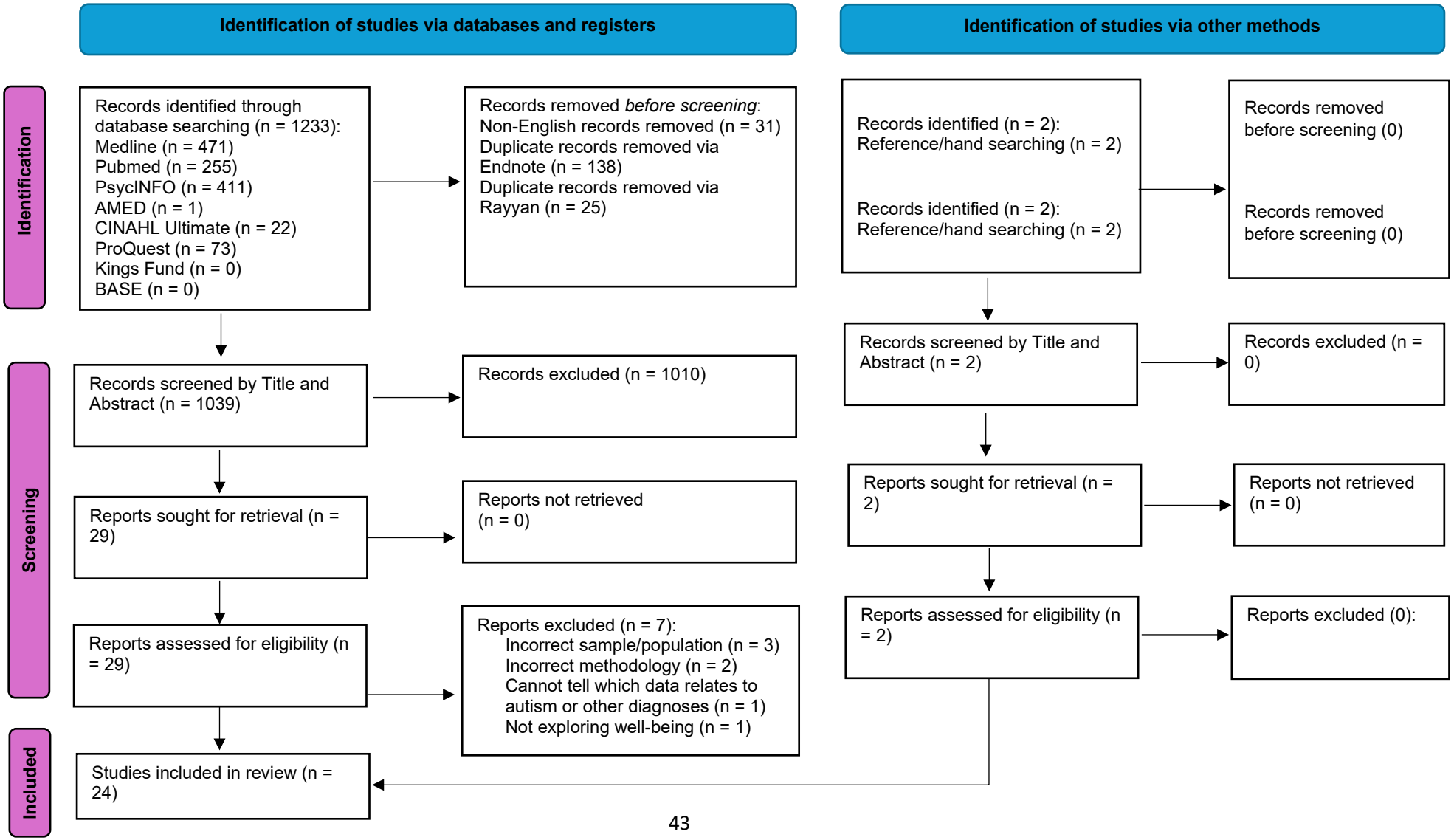
Screening Process

Figure 1.1 summarises the screening process of this systematic review, using a PRISMA flowchart (Page et al., 2021). 1233 research papers were identified through the initial database searches. After duplicates and non-English records were removed, the title and abstract of 1039 research papers were screened independently by the first researcher. Considering the importance of multiple reviewers to improve reliability (Stoll et al., 2019), a secondary reviewer, who was blind to the primary researcher's search decisions, screened a randomly selected 10% (n = 105) of the total search results. For title and abstract screening, inter-rater agreement was 94.3% (k = 0.89). Three papers were incorrectly excluded based on incorrect method (quantitative), a determination that could only be accurately made after full text review. One paper was mistakenly excluded under the assumption that it was not peer-reviewed, and another was incorrectly included despite being a case report, which falls under the exclusion criteria. Finally, one paper was incorrectly included despite not exploring wellbeing. The six discrepancies were reviewed by the supervisory team who decided that four of the papers were eligible for full-text screening. In total, 1010 papers were excluded through the process of title and abstract screening.

The full text of 29 papers were retrieved and reviewed independently by the primary researcher and a secondary reviewer, who were blind to each other's decisions. For full-text screening, inter-rater agreement was 100% (k = 1). From these papers, 22 research papers were identified as appropriate for the final review. Hand searching of the reference lists of these 22 papers revealed an additional two papers, resulting in 24 papers that were included in the final synthesis.

Figure 1.1

PRISMA Flowchart



Quality Assessment

The Critical Appraisal Skills Programme (CASP, 2024; Appendix B) is a ten-item qualitative checklist tool, widely used for assessing the strengths and limitations of research employing any qualitative methodology. The CASP was selected as it was devised for use in health-related research and is user-friendly (Long et al., 2020). It is divided into three sections: validity of results, rigorousness of results and importance of the research. For each question, there are additional prompts to consider whether the study meets a "yes", "no", or "can't tell" option. Due to lack of formal guidance on definition of each option, the research team decided the "can't tell" option would be used when there was insufficient information to make a "yes" or "no" judgement. To rate study quality, a criterion was adopted akin to those from previous systematic reviews (e.g., Chatfield et al., 2017), categorising studies as low, medium or high quality depending on the number of "yes" answers (0-4, 5-7, and 8-10 respectively).

To avoid unnecessary exclusion of potentially valuable findings, no studies were omitted based on quality assessment. Instead, the quality assessment process was used to highlight and consider strengths and weaknesses to allow a more effective interpretation of findings.

Data Extraction

The primary researcher extracted relevant data from the 24 final research papers: author, year, country, aims, recruitment method, sample, data collection and analysis method and key findings (Table 1.4). If the study consisted of multiple parts, phases or populations, only the data relevant to this qualitative systematic review were extracted. For example, data related to quantitative methods, or data from participants who were not included in this review (e.g., therapists' perceptions) were excluded. Likewise, only data where it was clear

Table 1.4

Characteristics of Studies Included in the Systematic Review (n=24)

#	Author, Year, Country and Title	Aim(s)	Recruitment Method	Sample	Data Collection and Analysis Method	Key Findings
1	Guay et al., 2023, Canada Acceptability and effects of acquiring an assistance or companion dog for families of children on the autism spectrum.	To summarise the acceptability and effects of assistance and companion dogs by documenting parents' perceptions.	Recruitment for phase one took place via social media and autism assistance dog organisations. 50 families who had participated in the first phase (and consented for further contact) were invited to take part in phase 2.	Seventeen mothers to 17 autistic children (aged 6-16, 15 males, two females,) agreed to participate in phase two. Most families had an assistance dog (n = 14).	Semi-structured interviews. Qualitative data from interviews analysed with NVivo using a mixed qualitative approach, conducted in two steps.	Three main categories were identified: effects on the child; effects on other family; and general perceived burdens
2	Ang & MacDougall, 2022, Singapore/UK	To explore the views of parents and on the effects of Animal-	Purposeful sampling (participants recruited from the AAT	Four mothers with autistic children (aged 3-21, three male and one female) who were	Semi-structured interviews.	Three main themes were identified: perceived benefits of AAT; the way AAT

	An evaluation of animal-assisted therapy for autism spectrum disorders: therapist and parent perspectives.	Assisted Therapy (AAT) for autistic individuals and the process by which it works.	community and autism support groups).	currently undergoing AAT.	Qualitative phenomenological design, using thematic analysis via NVIVO.	works; potential limitations of AAT.
3	Appleby et al., 2022, Australia Australian parents' experiences of owning an autism assistance dog.	To produce a rich understanding of parents' experiences and the perceived benefits of owning Autism Assistance Dogs (AAD).	Purposeful sampling, specifically criterion sampling. All eighteen families who had received a dog from the AAD Programme and met the eligibility criteria were contacted via letter.	Eight families (including mothers and fathers) of autistic children (aged 7-12) with dogs from the AAD programme. Further information regarding participants was omitted to maintain anonymity.	Semi-structured interview, within the participant's home or workplace (digitally recorded and lasting between 30 and 90 minutes). A qualitative descriptive approach, with recordings that were transcribed verbatim	Four main themes were identified: Freedom through restraint; expanding our world; a calming/ sensory tool (AAD); "at the end of the day they're dogs"; friendship and personal growth.

					and analysed thematically.	
4	Gunnarsson et al., 2024, Sweden Being in a meaningful context. Nature and animal-assisted activities as perceived by adults with autism.	To explore the feasibility and experiences of animal-assisted and nature-based activities as a complementary intervention for young adults with autism and social withdrawal.	Convenience/purposeful sampling: Recruitment via staff working with the target group.	Thirteen young adults with autism (aged 21-30, six male and seven female) who are socially withdrawn, with no organised occupation during the previous year. A total of 11 participants completed the intervention.	Pre- and post-intervention interviews took place (lasting between 14 and 53 minutes) at a place preferred by the participant or as a digital meeting. Qualitative content analyses (Graneheim & Lundman, 2004) were used to analyse data.	Three key categories, each with subthemes, were identified: Being in a meaningful context; Creating a comfort zone; Developing structure in everyday life. Only the subtheme “interacting with horses and peers” was included as it was not possible to identify which data related to animals specifically, or nature.

5	Hellings et al., 2022, Australia Benefits and challenges of assistance dogs for families of children on the autism spectrum: mothers' perspectives.	To explore the lived experience of assistance dog ownership for autistic children and their families, including the expectations, benefits, challenges, and the impact on activity participation.	Convenience sampling (through organisation providing assistance dogs for autistic children).	Four mothers of autistic children (aged 5–13, all male); all were participating in the autism assistance dog placement and training program.	Data were collected through semi-structured interviews (pre- and post-dog ownership) and photovoice (post-dog ownership). Analysed using interpretive phenomenological analysis (IPA).	Four themes were developed: Benefits to the child and the family/caregiver; Dog ownership required adjustment and was not always as expected; Community attention was sometimes but not always beneficial; Community education about the role of assistance dogs is needed.
6	Hill et al., 2020, Australia Canine-assisted occupational therapy for children	To explore the impact of canine-assisted occupational therapy on the	Purposeful sampling: Parents of autistic children participating in the pilot randomised controlled trial (RCT)	Ten parents (nine mothers, one father) of autistic children (aged 4–6, seven male and three female) who had a	Semi-structured telephone interviews were conducted with parents after seven weekly sessions of	Four main themes were identified: therapist qualities; goal-directed (canine-assisted) therapy;

	on the autism spectrum: parents' perspectives.	therapy engagement of autistic children from the parents' perspectives.	who were available for telephone interview were included.	previous positive experience interacting with dogs.	canine-assisted occupational therapy. The data were transcribed and analysed using an inductive thematic analysis approach guided by interpretive description design.	emotional safety; therapy engagement.
7	Scotland-Coogan et al., 2021, U.S. Caregiver perceptions of the benefits of hippotherapy for children with various disorders	To explore caregiver perceptions of the benefits of hippotherapy for children with various disabilities and/or conditions.	Purposeful sampling of caregivers whose children were participating in hippotherapy at a therapeutic riding centre in Central Florida. Participants	Eleven caregivers to 12 children (aged 1–20) with various conditions. The two parents to autistic children were included in this review (demographic information for these two specific	Semi-structured interviews transcribed verbatim. Thematic analysis was employed following Stake's (2006) multi-case analysis procedure.	Four themes were identified: caregiver life concerns for their children; benefits of hippotherapy; quality of life improvements; use of other therapies.

	disabilities and medical conditions.		were recruited based on their willingness.	participants is not known).		
8	Chadwick, et al., 2022, UK Engaging with animal-assisted interventions (AAIs): exploring the experiences of young people with ASD/ADHD diagnoses.	To explore the experiences of young people with ASD/ADHD engaging with Animal-Assisted Interventions (AAIs).	Purposeful sampling: Participants were selected by Alternative Education Provision (AEP) directors based on diagnoses and suitability for research participation.	Three students. Only the two autistic students (one female age 13, one male age 15) attending an AEP for therapeutic and educational support, were included in the review.	Semi-structured interviews lasting ~20 minutes, conducted in a quiet area of the farm. Data were transcribed verbatim and analysed using constructivist thematic analysis.	Three main themes were identified: self-esteem, emotional benefits and identification.
9	Smyth & Slevin, 2010, Ireland Experiences of family life with an autism assistance dog	To explore the experiences of families living with an autism assistance dog, focusing on family life.	Purposeful sampling: Agreement that parents could be asked to participate was granted by the Irish Guide Dogs Association, based on diagnoses and	Five mothers and two fathers to autistic children (aged 5-12, six males, one female) who had an assistance dog.	Data were collected through semi-structured interviews with the parents, in a location of their choosing (home/workplace).	Seven key themes were identified: safety, freedom, skills acquirement, family cohesion, social acknowledgement,

			suitability for research participation.		Qualitative phenomenological design, using Colaizzi's (1978) procedure to analyse data.	companionship and concerns.
10	Adkins et al., 2023, U.S. Exploring health behaviors and the role of pet dogs in households with autistic children: The DANE study.	To gain insights into autistic children's relationships with their pet dog to assess the potential for Animal-Assisted Interventions (AAI) focused on health behaviours; to evaluate how dogs integrate into autistic	Purposeful sampling: participants were recruited via emails to veterinary school and therapy dog organisation listservs, social media, and targeted clinics, based on diagnoses and suitability for research participation.	Ten parent-child dyads that had been living with a pet dog for at least one year. All parents were females, and the children were diagnosed with autism spectrum disorder (aged 8–18, eight male, one female, and one 'other').	Semi-structured interviews conducted via Zoom. Qualitative content analysis using NVivo, with thematic coding.	Three major domains arose: child's relationship with the family dog; the role of the dog in families with an autistic child; and eating and physical activity.

		households; to explore the parents' perceptions of this intervention.				
11	Agnew et al., 2023, Australia 'Having the dog as part of our family gives us hope': Experiences of the impact of assistance dogs on the occupational engagement of children with autism and their families.	To explore the perspectives of caregivers of autistic children, with assistance dogs to understand the impact of the assistance dog on the occupational participation and engagement of both the child and their family.	Purposeful sampling: recruited through Australian assistance animal organisations and social media based on diagnoses and suitability for research participation.	Six mothers aged 25–50 to seven autistic children (age 4-11, six males, one female), each partnered with an assistance dog that has been professionally trained by an accredited organisation.	Semi-structured interviews (lasting 45-60 minutes) were conducted over the telephone or via video. Data were digitally recorded, transcribed verbatim and then analysed using thematic analysis.	Three themes were identified: participation in everyday occupations prior to and after partnering with an assistance dog; increased engagement in everyday occupations; impact of the assistance dog on the family unit.

12	Morgan & O'Byrne, 2023, Ireland How Autism Assistance Canines Enhance the Lives of Autistic Children.	To explore autism assistance canines, influence the life experiences of an autistic child from a parent, canine handler and teacher perspective in Ireland	A combination of purposeful and snowball sampling was used to recruit parents, canine handlers, and teachers, based on diagnoses and suitability for research participation.	Teachers, canine-handlers and parents participated. Only the four parents of autistic children were included within the review (demographic information for these four specific participants is not presented).	Semi-structured telephone interviews lasting 45–60 minutes. Data were transcribed verbatim and analysed using Braun and Clarke's (2006) thematic analysis.	Four primary themes were identified: child canine bond; social development; family; animal assisted education.
13	Chapman, 2024, no defined country. "I am not a bad person [or] evil for being distressed": An exploratory study of autistic adults' experiences	To understand autistic adults' experiences and strategies used in emotion regulation; to examine factors influencing camouflaging	Purposeful sampling: Participants were recruited via email, social media and autism organisations' websites, based on diagnoses and suitability for research participation.	Three hundred and eighty participants completed the survey after data cleaning (mean age 36.67, 49 male, 163 female, 76 gender diverse).	Three open-ended questions through Qualtrics (online survey platform). Qualitative data were analysed using reflective thematic analysis (via NVivo).	Seven themes, and additional subthemes were identified: autistic emotional experiences; emotion regulation strategies; interpersonal rejection; desired support; animal

	of camouflaging, resiliency, emotion regulation, and human-animal interaction.	behaviours; to investigate human-animal interaction as an emotion regulation strategy.		NB: Demographic data not available for all participants.		agency; transcendental interconnectedness; and defining the interaction.
14	Tan & Simmonds, 2018, Australia. Parent perceptions of psychosocial outcomes of equine-assisted interventions for children with autism spectrum disorder.	To explore parents' perceptions of the psychosocial outcomes of equine-assisted interventions for autistic children.	Purposive sampling: Recruitment consisted of emailing advertisements to EAI organisations working with autistic children, based on diagnoses and suitability for research participation.	Six parents (five mothers and one father) of six autistic children (aged 3–14, all female) all of whom had received equine-assisted intervention for at least one month on a weekly basis.	Semi-structured interviews lasting 38–67 minutes. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA).	Four themes emerged: child's improved self-concept and enhanced emotional well-being; child's improved self-regulatory ability; social benefits for child; and unexpected outcomes.

15	Harwood et al., 2019, Australia. Parental perceptions of the nature of the relationship children with autism spectrum disorders share with their canine companion.	To explore parents' perceptions of the nature of the relationship between autistic children and their canine companions.	Purposive sampling: Recruitment occurred via agencies and support groups for families of autistic children, based on diagnoses and suitability for research participation.	Eleven mothers of 13 autistic children (aged 5–12, seven males, six females) with companion canines and in some cases, other companion animals.	Semi-structured interviews (20–50 minutes). Thematic analysis.	Five key themes were identified: love and companionship; perception of ownership, provision of comfort and calming influence; education and understanding about the world; challenging experiences.
16	Kalmbach et al., 2020, U.S. Parental perspectives of occupational therapy in an equine environment for children with	To describe parental perspectives on children's experiences of occupational therapy in an equine environment and	Purposive sampling: Parents of autistic children from the quantitative phase of the study were emailed and invited to participate in the qualitative phase, based on diagnoses and	Five parents (four mothers, one father) of four autistic children (aged 8-13, all males).	Two rounds of semi-structured interviews, lasting 30-60 minutes, post-intervention. Qualitative content analysis (Schreirer, 2012), using Percy and colleagues	Three major themes were identified; parental perspectives on the child's experiences of the intervention; parental perspectives on the intervention's influences on

	Autism Spectrum Disorder.	its influences on everyday life.	suitability for research participation.		(2015) thematic analysis procedure.	everyday life; and concerns and dissatisfaction.
17	Starkweather et al., 2024, U.S. Pawsitive purpose: the impact of autism assistance dogs on the occupations of autistic children.	To illustrate the role and value of autism AADs in facilitating participation and engagement in activities of daily living for autistic children.	Purposive sampling: families contacted via the president of an AAD training programme, based on diagnoses and suitability for research participation.	Four mothers of four autistic children (aged 9-13, three males, one female) who had AADs for at least one year.	Two semi-structured, narratively focused interviews. Data was transcribed via ©Temi (an electronic speech-to-text translation software) and analysed using IPA and thematic coding (Creswell & Creswell, 2017; Smith & Osborn, 2015).	A single overarching theme (The multi-factored role of autism assistance dogs), and four subthemes were identified; occupational facilitators; symbols of awareness; age-appropriate security blankets; and generators of familial experiences.

18	Carlisle, 2014, U.S. Pet dog ownership decisions for parents of children with autism spectrum disorder.	To examine pet dog ownership decision-making by parents of autistic children, including perceived benefits, burdens, and child-dog interactions.	Purposive sampling: Recruitment through an ASD diagnostic and treatment centre, based on diagnoses and suitability for research participation.	Seventy parents (mean age 42 years, 61 females and 9 males) of autistic children (aged 8–18, 65 males, five females).	Data collected via telephone interviews using a demographic questionnaire and structured open-ended questions. Qualitative content analysis (Corbin et al., 2008).	Several key findings were reported: • Children engaged with dogs through play and shared personal space. • Sensory issues affected children's interactions with dogs. • Benefits included learning responsibility and companionship. • Challenges included time and cost.
19	Burrows et al., 2008, Canada.	To assess the effect of service dogs in the family	Purposive sampling: Recruitment through National Service Dogs,	Ten parents (nine mothers and one father) of ten autistic children	Qualitative ethology, including multiple semi structured	Three key themes emerged: the dog as a sentinel of safety;

	Sentinels of safety: service dogs ensure safety and enhance freedom and well-being for families with autistic children.	through; identifying patterns of behaviour in the relationship between service dog, child and family members, and by concluding the organisation, and functional significant of, this behaviour.	based on diagnoses and suitability for research participation.	(aged 4-14, seven males, one female).	interviews (lasting 35-120 minutes). Content analysis.	gaining freedom through enhanced safety, facilitating public outings and family activities; improving social recognition and status.
20	Cleary et al., 2024, Australia. 'The horse weaves magic': parents and	To explore parents' and service providers' experiences of horse-based	Purposive sampling: Parents recruited via autism-related social media, based on diagnoses and	Six parents (four mothers, two fathers) to four autistic children (aged 9-17, three females, one male) who	Semi-structured interviews conducted via video/phone.	Three main themes emerged: physical and social benefits; protecting mental health;

	service providers on the benefits of horse-based therapies for autistic children—an Australian qualitative study.	therapies for autistic children.	suitability for research participation.	were engaged with horse-based therapy.	Thematic analysis (Braun & Clarke, 2021).	recommendations for improvements and accessibility of horse-based therapies.
21	Byström & Persson, 2015, Sweden. The meaning of companion animals for children and adolescents with autism: the parents' perspective.	To understand parents' perspectives on how autistic children and adolescents benefit from companion animals.	Purposive sampling: Parents recruited through written invitations via the Habilitation Services Program in southwest Sweden.	Thirteen parents of 12 children with autism (aged 8–20). Further demographic information for parents was not provided.	Focus-group discussions including open-ended questions. Inductive thematic analysis (Braun & Clarke 2006).	Three themes were identified: quality of the relationship with the companion animals; increased interaction with people; the companion animal as an optimizer (facilitator) of function and development.

22	Atherton et al., 2023, UK/Canada/ Czech Republic/ Sweden/Germany/ Denmark 'They ask no questions and pass no criticism': A mixed-methods study exploring pet ownership in autism.	To explore the impact of pets on autistic individuals and how the human-animal bond supports their social needs.	Purposeful sampling: Based on suitability for research participation, participants who met criteria from the quantitative phase of the study were emailed and invited to participate in the qualitative phase.	Sixteen autistic adults (aged 18–63, seven females, seven males, 2 non-binary/other) who had ever owned a pet.	Semi-structured interviews (lasting ~50 minutes) using online platform. Interpretive Phenomenological Analysis (IPA).	Four main themes were identified: pets with benefits; pets as a social alternative. pets as a social lubricant; and barriers and breakthroughs to pet ownership.
23	Barcelos et al., 2021, UK. Understanding the impact of dog ownership on	To develop a framework of wellbeing outcomes associated with dog-related	Purposive sampling: Participants recruited via national/regional autism organisations, social media and media reports, based on	Thirty-six autistic dog owners (aged 18–74, 18 females, 18 males)	Semi-structured interviews (lasting 15-49 minutes) were conducted via video.	Eight themes were identified: inevitable features of dog ownership; dogs' health; shared interactions with dog;

	autistic adults: implications for mental health and suicide prevention.	activities in autistic adults and compare it with the framework established for the general adult population.	diagnoses and suitability for research participation.		Data were digitally recorded, transcribed verbatim and then analysed using thematic analysis and heat maps.	educational impacts; looking after the dog; play related; social interactions with others; dog unwanted behaviours/situations.
24	Burgoyne et al., 2014, Ireland. Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross-sectional study	To explore parents/ guardians' perspectives of having an assistance dog.	Purposive sampling: Participants recruited via national assistance dog intervention (N=205) and parents/guardians on the waiting list for an assistance dog (N=107) were eligible to take part in the study	Two hundred and twenty-one parents/ guardians of an autistic child; 134 parents/guardians with an assistance dog, and 87 parents/guardians from the waiting list. Further demographic information for parents was not provided.	Questionnaire: Qualitative data from open-ended questions were analysed using open coding and categorisation to identify themes.	Three themes were identified under 'benefits'; physical factors, relationship factors and family factors, and four themes were identified under 'constraints'; change factors, relationship factors, limiting factors and no constraints.

that the first-hand narratives were relevant to the well-being of the autistic individual were included in the data extraction.

Data Synthesis

Several quantitative systematic reviews exploring similar concepts already exist (e.g., Davis et al., 2015; Rehn et al., 2023; and Xiao et al., 2024). While quantitative studies ascertain whether interventions can be effective, this research aims to understand how individuals make sense of the experiences, the meaning derived from it and why they might be helpful. These insights can then inform theory development and more nuanced interventions. Furthermore, the Centre for Reviews and Dissemination (CRD, 2008) guidance on undertaking reviews in health care emphasise the importance of qualitative research in understanding why and how an intervention works, and to build on theory established by quantitative studies. As such, a qualitative approach was undertaken so maintain a clear focus on the perspectives of autistic individuals regarding animal contact and their lived experiences of wellbeing.

With the aim of exploring broad themes and patterns across multiple studies, thematic synthesis was chosen because it provides a structured approach to systematically reviewing qualitative data. By identifying codes and developing themes, it establishes a clear audit trail that enables readers to trace the conclusions drawn from the synthesis (Thomas & Harden, 2008). This method is one of the most accessible qualitative synthesis approaches that accommodates both ‘thin’ and ‘thick’ data (Thomas & Harden, 2008), allowing for descriptive analysis of study data and the generation of new insights, interpretations and theory (Flemming & Noyes, 2021).

This review followed the thematic synthesis approach outlined by Thomas and Harden (2008). As it can be difficult to identify what constitutes “findings” when analysing

qualitative information (Thomas & Harden, 2008), different papers approach this in different ways (e.g., Campbell et al., 2003; Sandelowski & Barroso, 2002). For the present review, and like Graham and colleagues (2022) methodology, results and findings constituted participant accounts and author interpretations contained within the study findings, outcomes or equivalent sections of the included studies. Any findings not relevant to the review, such as those related to quantitative methods, or participants who were irrelevant to this review (e.g., therapists' perceptions) were not included in the analysis.

As per Thomas and Harden's (2008) three step process, the final studies were read multiple times to familiarise the researcher with thefindings. Next, the relevant results and findings sections were coded line-by-line using NVivo software (Lumivero, 2023). To increase rigour, two of the studies were coded independently by both the primary researcher and a secondary reviewer (Krefting, 1991). The codes for all studies were then reviewed and compared, with similar codes being amalgamated where appropriate. A codebook (Supplementary Material A) was created with the generated codes, which were organised into descriptive themes. These were discussed with the research team resulting in the final analytical themes and sub-themes.

Philosophical Positioning

Thematic synthesis can be employed under many different philosophical standpoints (Barnett-Page & Thomas, 2009). For this review, a relativist-constructionist orientation was taken. Ontologically relativism conceives that there is no absolute reality. Instead, multiple realities exist and depend on the individual that perceives it, conditional to their life and social experiences (Denzin & Lincoln, 2005). Social constructionist epistemology posits that knowledge acquisition is an active process that is constructed through our language and social reality (Gergen, 2022).

Researcher Reflexivity

Reflexivity, the process of continual self-examination and self-evaluation of researcher positioning, and the consideration of how personal biases may affect the research process, should be practiced throughout the entire research procedure (Berger, 2015). The research team are all white British females who own companion animals. The EBE is autistic, and the primary researcher was diagnosed with attention-deficit hyperactivity disorder (ADHD) during the research process. All research team members know someone in their close network who is autistic and have worked clinically with autistic individuals.

The personal neurodiversity and clinical experience within the research team may allow for a potentially useful position as insider-researchers and/or possessing a prior level of awareness around the experiences of neurodiverse and autistic individuals, which may aid in the understanding and interpretation of the research. However, attention was continually paid to the possible influences of existing assumptions, biases and expectations throughout the research process. For this review, as a reflexive exercise, the primary researcher undertook reflexive journalling during all stages of the research (see Supplementary Material B for an excerpt) and the research team engaged in reflexive discourse to consider the biases held about the topic and regarding the research process.

Results

24 papers were included in the final review (Table 1.4). Each study will be referred to using its unique assigned reference number hereafter. All papers were published between 2008 and 2024. The countries of research varied; Australia (3, 5, 6, 11, 14, 15, and 20), U.S. (7, 10, 16, 17, and 18), Ireland (9, 12 and 24), Canada (1 and 19), UK (8 and 23), Sweden, (4 and 21), Singapore/UK (2), UK/Canada/Czech Republic/Sweden/Germany/Denmark (22), and no defined country (13). Most studies collected data through semi-structured interviews and

the remaining studies used open-ended questions on a questionnaire (13 and 24), structured interviews (18) and focus groups (21). Many studies employed thematic analysis (3, 6, 7, 8, 11, 12, 13, 15, 20, 21 and 23), and most explored parent/carer views, except those that sampled autistic adults (4, 13, 22 and 23), parent/child dyads (10), and autistic students (8). All studies exploring parent/carer perceptions focused on children as the index individual (aged 3-21 years). The studies included a range of animal contact types (Table 1.5). The most common were animal-based interventions/activities (2, 4, 6, 7, 8, 14, 16, and 20), assistance animals (3, 5, 9, 11, 12, 17, 19, and 24) and companion animals (10, 15, 18, 21, 22, and 23). One study investigated assistance and companion animals (1), and one explored human-animal interaction more broadly (13).

Table 1.5

Animal Contact Types Explored in Each Study

Study ID	Animal Contact Type	Study ID	Animal Contact Type
1	Assistance and companion animals	13	Human-animal interaction
2	Animal intervention/activity	14	Animal intervention/activity
3	Assistance animal	15	Companion animal
4	Animal intervention/activity	16	Animal intervention/activity
5	Assistance animal	17	Assistance animal
6	Animal intervention/activity	18	Companion animal
7	Animal intervention/activity	19	Assistance animal
8	Animal intervention/activity	20	Animal intervention/activity
9	Assistance animal	21	Companion animal
10	Companion animal	22	Companion animal
11	Assistance animal	23	Companion animal
12	Assistance animal	24	Assistance animal

Quality Assessment

All 24 papers were critically appraised using the CASP (CASP, 2024; Table 1.6) and all met criteria for medium (n = 14) or high (n = 10) quality. Most papers lacked information around recruitment strategy, except study 4 and 24. Several studies did not provide sufficient information around the researcher/participant relationship (1, 2, 4, 6, 7, 9, 13, 14, 15, 17-24), ethical information (1, 16, 19, 20, 21 and 22) and findings (3, 6, 7, 8, and 20). Most studies did not provide sufficient data analysis, except studies 2, 4, 5, 12, 16, 17 23, and 24. Generally, the papers included were of a very good quality.

Thematic Synthesis

Using thematic synthesis (Thomas & Harden, 2008), 340 initial codes were collapsed into 224 final codes. Table 1.7 summarises the six analytical themes and 14 subthemes identified through thematic synthesis. Due to the nature of the topic, each theme was intertwined with multiple aspects of the person's well-being, meaning the identified themes and subthemes were all deeply interconnected. However, due to individual differences and the unique experiences of each participant that shaped their engagement with animals, it was difficult to effectively visually depict this. Although a thematic map was created to illustrate these interrelationships (Supplementary Material C) it was agreed that this diminished the power of the subthemes. As such, only a simplified version was included in the final manuscript (Figure 1.2).

Theme 1: Individual Well-being.

This theme encapsulated the role of animals on an individual's well-being, including emotion regulation, sensory and physical outcomes and strengthening identity and confidence.

Table 1.6

Critical Appraisal Skills Programme (CASP, 2024) Ratings

Study number	Question number and topic										Total			Quality rating
	1. Aim	2. Methodology	3. Research design	4. Recruitment strategy	5. Data collection	6. Researcher/ participant relationship	7. Ethics	8. Data Analysis	9. Findings	10. Research importance	Yes	No	Can't tell	
1	Y	Y	Y	C	Y	C	C	C	Y	Y	6	0	4	Medium
2	Y	Y	Y	C	Y	C	Y	Y	Y	Y	8	0	2	High
3	Y	Y	Y	C	Y	Y	Y	C	C	Y	7	0	3	Medium
4	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9	0	1	High
5	Y	Y	Y	C	Y	Y	Y	Y	Y	Y	9	0	1	High
6	Y	Y	Y	C	Y	C	Y	C	C	Y	6	0	4	Medium
7	Y	Y	Y	C	Y	C	Y	C	C	Y	6	0	4	Medium
8	Y	Y	Y	C	Y	Y	Y	C	C	Y	7	0	3	Medium
9	Y	Y	Y	C	Y	C	Y	C	Y	Y	7	0	3	Medium
10	Y	Y	Y	C	Y	Y	Y	C	Y	Y	8	0	2	High
11	Y	Y	Y	C	Y	Y	Y	C	Y	Y	8	0	2	High
12	Y	Y	Y	C	Y	Y	Y	Y	Y	Y	9	0	1	High
13	Y	Y	Y	C	Y	C	Y	C	Y	Y	7	0	3	Medium
14	Y	Y	Y	C	Y	C	Y	C	Y	Y	7	0	3	Medium
15	Y	Y	Y	C	Y	C	Y	C	Y	Y	7	0	3	Medium
16	Y	Y	Y	C	Y	Y	C	Y	Y	Y	8	0	2	High
17	Y	Y	Y	C	Y	C	Y	Y	Y	Y	8	0	2	High
18	Y	Y	Y	C	Y	C	Y	C	Y	Y	7	0	3	Medium
19	Y	Y	Y	C	Y	C	C	C	Y	Y	6	0	4	Medium
20	Y	Y	Y	C	Y	C	C	C	C	Y	5	0	5	Medium
21	Y	Y	Y	C	Y	C	C	C	Y	Y	6	0	4	Medium
22	Y	Y	Y	C	Y	C	C	C	Y	Y	6	0	4	Medium
23	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9	0	1	High
24	Y	Y	Y	Y	Y	C	Y	C	Y	Y	9	0	1	High

Table 1.7

Description of Identified Themes and Subthemes.

Theme	Subtheme
Individual well-being	• Emotional co-regulation. • Sensory and physical benefits. • Confidence, identity & self-efficacy.
Bridging and connecting	• Facilitating social interaction. • Emotional awareness & perspective-taking. • From stigma to support.
Freedom to grow	• Facilitating learning. • Responsibility and independence.
Anchor for the family	• Strengthening the family. • Expanding opportunities.
Challenges	• Adjusting and implementation. • Loss and transitions.
Faithful friends	• Animals as companions. • Connection without expectations.

Figure 1.2

Thematic Map

Theme 1: Subtheme 1: Emotional Co-Regulation. Emotion regulation was commonly referred to across the studies. The presence of animals seemed to reduce emotional dysregulation, with many parents reporting a noticeable reduction in behaviours that challenge, including meltdowns, tantrums, outbursts, screaming and violent behaviours. For example, one parent commented, "having the dog at his side to help him calm down, it helps reduce aggression and tantrums end more rapidly!" (1). Another set of parents "attributed improvements in Ryan's abilities to handle disappointment, to transition to non- preferred activities with less resistance, and to control his violent reactions—in short, to remain calm—to the intervention" (16).

The mechanism behind animals' benefits as emotional co-regulators appeared multi-faceted. One study found that animals helped to ground autistic individuals through their presence and touch, encouraging a sense of awareness and mindfulness of the self or the needs of the animals; "my current dog can see when I am in distress and stays near. I calm myself out of desire to not scare the animal, and when I am more calm it approaches to express affection" (13). Many participants reported animals to generally have a calming effect on them, e.g., "I go see the animals cause the animals really help me calm down" (2). In many studies, animals provided a helpful distraction or method of redirection when individuals started to become dysregulated or anxious. One parent commented, "the dog distracts my daughter in a positive way so that things that would normally upset her don't now, where it would have been a major trauma and tantrum in the past." (9). Additionally, some parents felt more equipped to support their child when dysregulated, e.g., "[it] seems to have helped him regulate his behaviour and his emotional outbursts, which then helps me regulate his behaviour" (2).

Participants reported actively pursuing animals to self-regulate, in addition to the animals seeking out opportunities to support their humans. One parent shared "Charlie will visit and put his head in Dan's lap and that calms him down" (5). Some animals seemed able to register when their human was feeling dysregulated, which may have contributed to participants feelings of being loved and understood by the animals.

Theme 1: Subtheme 2: Sensory & Physical Benefits. Like emotional regulation, several studies included narratives on sensory regulation through animal contact, including movement and physical stimulation, deep pressure and touch. One study explained that "the child's parents would have to lay on top of him to provide the deep pressure required for him to remain in bed and fall asleep. Now, it is Dixon's job to provide that deep pressure" (17). Participants also reflected on the physical outcomes from animal contact, including improved motor skills and increased physical activity "Since we've had Max, he's been getting outdoors a lot more, he's been running with Max on the marsh, throwing sticks for him" (5).

The sensory and physical benefits appeared to be closely linked with emotion regulation. For example, the reduction in emotional dysregulation aligned with an increased ability to effectively regulate emotions, usually through contact with the animal, e.g., "as soon as he has an upsurge of anxiety, he will place himself on the side of the dog, petting it, and the dog welcomes him. […] Then, he quietly regains his senses" (1).

Theme 1: Subtheme 3: Confidence, Identity & Self-Efficacy. Another common thread amongst studies was increased self-confidence and self-esteem. For some, this related to developing social confidence when out in the community, or to return to school. One parent shared, "I didn't think I could get Ethan back to school but I think Max has actually given Ethan an element of confidence" (5). Further, many parents noticed increased confidence in

their child's general abilities and a willingness to try new things, e.g., "the intervention helped to increase Ryan's "confidence in his abilities" and helped him become "more willing to try" things that scared him" (16).

Several studies also summarised how participants felt a sense of pride, purpose, meaning and "personal fulfilment" (7). This typically stemmed from looking after and caring for the animal, compounded by a sense of responsibility and a strong bond. There was a general sense that "the animals give a sense of purpose and love" (2) to the participants. This was also seen when animals were used in a therapy setting, as it motivated them to engage and incentivised their participation, e.g., "He'll do the task that he needed to do in order to give [Therapy dog] a treat. It just gives him a different sense of purpose" (6).

One participant felt more able to assert boundaries, "He shows me it's okay to demand people respect my needs and boundaries, such as not touching me without my explicit permission, even to hug" (13). Two studies even contained narratives around an animal's role in giving someone a reason to live and preventing suicide, "He [the dog] is like a protective factor. I have attempted suicide before, and he has helped it stopped happening again" (23).

Overall, animal contact, whether through an intervention or a companion seemed to positively influence the social- and self-identity of autistic individuals, possibly through a sense of responsibility to, connection with, and unconditional love from the animal. The self-perception of many individuals reportedly improved as a result.

Theme 2: Bridging and Connecting.

This theme encapsulates participants' descriptions of animals as social mediators that facilitate connection and support the development of emotional awareness. It also summarises the role of the public.

Theme 2: Subtheme 1: Facilitating Social Interaction. Several studies commented on how the animals impacted participants' communication and interaction with others. Some reported an increase in their child's verbal and non-verbal communication, e.g., "[My child] is more verbal now … In the past, the verbal was really, really difficult for him" (10). Several studies described animals as a bridge between the autistic individual and the social world, or as an icebreaker that "softens the way" (9). It gave autistic people an anchor for conversations and a reason to engage with others. It also opened opportunities for non-known people to engage with the autistic people, who otherwise may not have approached, e.g., "when we've got Max, people are gravitating towards him and the dog" (5).

Overall, animals acted as a social mediator, facilitating new connections and strengthening existing ones: "The dog has made it easier for us to socialise and integrate our son more into everyday society … He is happy now to have people visit. This animal has made our lives a thousand times better" (9).

***Theme 2: Subtheme 2: Emotional Awareness and Perspective Taking*.** In addition to facilitating social interaction, another key theme was the development of emotional understanding and literacy. For example, some studies noted that engaging in animal contact allowed their child to talk about their emotions in a way that they had been unable to previously, e.g., "She's able to talk about some of the challenges that she's facing non-confrontationally" (2). Through engaging with the animals, many individuals endeavoured to understand and interpret the animals' behaviours, and as a result empathised with and related to them. Several studies reported on an increased understanding and awareness of others, alongside increased self-reflexivity. One parent reflected, "He's learning to analyze his dog's reactions so it's a good start to help him understand better that his actions have an impact on others" (1).

Participants seemed to develop their emotional awareness through observation and self-reflection through interaction. Those who may usually find social interaction and emotional expression difficult, were able to observe, develop skills and express their emotions more freely in a safe, non-judgemental environment.

Theme 2: Subtheme 3: From Stigma to Support. Both parents and individuals reported on the changing perceptions of the public. People felt less judged and more accepted by the community and found that they were more frequently approached or supported by the public:

> Before Frankie, if I took John to the shop and he had a meltdown … people used to look at you as if [to] say 'discipline your child'… Whereas when you've got Frankie … people walk up like 'is there anything I can do to help? (3)

It seemed that, overall, a person's behaviours was better understood in the context of their needs and the presence of assistance animals seemed to reduce judgement, increase "tolerance" and the stigma associated with autism, or behaviours related to autism, when out in the community by making the "invisible visible" (17). One parent shared, "Comparatively, now when people "pay us attention [it is] in a kind and thoughtful way instead of a judgmental way" (P1), so it is not as stressful for the family" (17).

Theme 3: Freedom to Grow.

This theme encompasses the role of animals in enabling learning and development of autonomy and independence through feeding, grooming, and care, facilitated by predictability routine, and increased safety.

Theme 3: Subtheme 1: Facilitating Learning. Some studies reported an increase in an individual's ability to generalise skills to new or alternative environments, "He really likes to groom and feed his dog, and this brought him towards wanting to do home related tasks as

well. The dog unconsciously motivated his desire to help others" (1). Other participants spoke about incidental learning enabled by the animal-child relationship, through indirect teaching or tasks that involved the animal, e.g., "it was empowering for them because they were bringing the dog along and it wasn't all about them doing things they didn't know had to do but showing the dog how to do things" (14).

Many studies noticed that motivation to engage increased when animals were involved, as they acted as a form of incentive. For some, the individual's curiosity and care towards the animal supported an active interest in learning and knowledge, e.g., "I think maybe [learning more about how to feed Bailey healthy foods] is something important. That actually sounds interesting. I'll go with that. I care about her as much as anyone else." (10). For some this seemed to be connected to "Theme 1: Subtheme 2: Confidence, Identity & Self-Efficacy", whereby increased confidence and identity, and a sense of purpose and fulfilment motivated their engagement and willingness to learn.

Overall, the individuals found learning more accessible, acceptable and applicable, and were motivated by animal integration, possibly mediated by increased confidence and a sense of purpose.

Theme 3: Subtheme 2: Responsibility and Independence. In addition to facilitating learning, many studies reflected on the individual's increased responsibility. This was typically related to the responsibilities of owning or caring for an animal (e.g., feeding, grooming and walking them), which was largely seen as enjoyable and a pleasure. For many the responsibility reinforced a sense of autonomy and independence, which ultimately supported their self-esteem, e.g., "She looks after her rabbit, clips its nails, and says when it's time to buy food. She sometimes brings the rabbit to me and asks whether it is hurt." (21).

For some, this sense of responsibility was generalised outwards, including caring for others, themselves and everyday tasks, and even increased some individual's willingness to try new things. For many, the responsibility of owning or caring for an animal gave their life meaning and purpose, e.g., "I think one that, generally speaking, I'd always put in the life satisfaction is taking her for walks … it adds a nice, almost weekend to the day" (23).

Routine appeared to be a key factor for the development of responsibility. For example, some reported that the discreet and structured set of steps of the animal intervention (e.g., grooming, mounting, riding a horse) was beneficial for the participants. Similarly, some described the animals themselves as predictable and related to them in this regard, e.g., one participant reflected on how they felt aligned with their cats, "They absolutely thrive off routine and don't like their environment changing" (22).

In addition to routine, safety was also a common component in this theme. This included physical safety (e.g., reduced absconding, improved road safety, animals alerting to physical health episodes, and preventing self or accidental harm), e.g., one parent recalled, "I mean he's literally saved Lucas' life … several times … you know I've gotten him out the car at school and he's taken off across the road with a car coming and Toffee's anchored" (3). Beyond this, some studies reflected on the emotional and social safety animals can provide by offering a calm, non-judgemental and reciprocal space for the individual. For example, one parent commented that animals offer "a safe, protected place where there's no judgment" (2).

Overall, studies found caring for animals promoted a sense of responsibility which fostered autonomy and independence in a variety of settings, where routine and safety seemed to play a central role in facilitating this.

Theme 4: Anchor for the Family.

This theme covers the role of animals in the development and consolidation of family bonds, reduced familial stress and increased inclusion and participation.

Theme 4: Subtheme 1: Strengthening the Family. Several of the family-perspective studies commented on how animals created an "anchor point" (1) and increased familial bonds. A common narrative was the improved relationships between parents, and between siblings, e.g., "There was no real interaction between Dan and Mitchell, as siblings, but since the dog's come into it, it's like this pack, there's three of them now" (5). One study reported envy from the siblings towards the child who was allocated the dog, however this was resolved with time, and the sibling's relationship improved overall, with more joint play and interaction (1). More broadly, the presence of animals also seemed to "improved familial atmosphere" (1) and make "the whole family gel" (9).

Considering that individuals are not an island, it is understandable that other family members also benefitted from the animal contact, including improved stress, isolation, sleep and physical health. For example, one parent shared that "Now [the child] goes to sleep right away … It improves his quality of sleep and [ours] … I'd be up all night with him, and I'd be exhausted trying to take care of him and his brother the next day" (17). Further, although the animal was introduced for one individual, some other family members reported a therapeutic benefit for themselves, e.g., "One parent stated that their autism assistance canine "was like a therapy dog for me."" (12).

***Theme 4: Subtheme 2: Expanding Opportunities*.** Several studies described increased access to everyday activities and social participation, much of which was previously difficult or impossible to undertake. This was primarily commented on by the parents/guardians, who

reported feeling able to take their family on outings including the beach, shopping centres and concerts. However, even more complex activities, such as trips away and holidays were described as accessible, e.g., "Even an airport now is a doddle" (9). Conversely, one study did not find that the level of access or enjoyment in family outings increased (5).

This enabling effect seemed to be explained by the individuals' and families' increased ability to cope, as well as the public's changed perceptions due to the presence of the animal.

Theme 5: Challenges.

This theme encompasses some of the challenges described by participants relating to animal ownership and interventions, changes in the responses from the public and difficulties around the future, including loss and transition.

***Theme 5: Subtheme 1: Adjusting and Implementation*.** Several studies summarised the difficulties that come with owning, caring for or interacting with animals. This included problematic behaviours (e.g., toileting issues, rough play, pulling and negative impact on sleep). Although many studies reflected on the sensory benefits of animal contact, this was also a challenge in some instances, including unwanted sensory-related situations (e.g., noise, smell, texture). While many individuals described the responsibility as a positive that facilitated independence and growth, the responsibility demands (e.g., feeding, walking, bathing) were also described as being a challenge, largely due to time constraints. For many, while animals were a big responsibility, it was worthwhile. 'It's definitely a big responsibility, so you've really got to weigh that up … But for us, obviously, the benefits outweigh the negatives" (11). Some individuals even found the learning curve challenging yet rewarding, and considered ways to make this easier:

> I think that when people choose to get an animal, I think they need to be patient with themselves and learn what is required and then how to do it step by step. It would be awesome if they could have sort of a pet mentor or a pet life coach to show them what to do and to get them onto that schedule (22).

Some parents/guardians reflected on the challenges associated with managing the child-animal relationship, finding it overwhelming to manage both simultaneously. Further, one parent shared that they had "struggled to develop a really strong bond between Michael and the dog" (5) as the dog had developed a strong connection with all family members. While this was not explicitly negative, it was not what they had hoped or expected.

Several studies also reflected on the associated risks for the animals, "Liam just got so impatient … he literally just kicked her … those moments really stand out for me because whenever she gets hurt I feel quite sick really" (3) and the potential impact of their own emotions on the animals, e.g., "I think [the animals] feel … quite cautious. I don't blame them … but it depends on the mood that the human is feeling because some animals can sense me feeling bad. Upset." (8). In one study, the risk to animals was a strong theme and included one incident of the death of a pet guinea pig (15).

Many participants reflecting on animal interventions had concerns around, and wanted more guidance for, appropriate implementation, e.g., "[I want] those step-by-step instructions so I can learn more information about it" (11). There were also some concerns around maintaining the positive effects of the intervention outside of sessions, e.g., "between Sunday, when he would wait for the therapy, on Monday, when he received it, and on Tuesday, with the memories of it … The rest of the days, he didn't have any motivation" (16).

While some individuals perceived the newfound community consideration helpful, one study (5) reported two parents that struggled with the increased attention. One parent described it as "overwhelming" or "interfering", and another found it difficult that the dog identified her son as having a disability. Some studies commented on the publics lack of understanding for animal interventions and support, and the need for increased awareness:

> I find it really frustrating that they turn around and say that an assistance dog is not a necessary support … do they understand how these dogs are helping these children that really need help to leave their house? And if so, why are they saying that it is not necessary (11)

Theme 5: Subtheme 2: Loss & Transitions. Another common theme was the impact of transition and loss. Most studies reflected on the challenges related to this, including associated distress and negative emotions:

> I really got caught up with one horse there that I've ridden basically from the start, so that I cried and embraced this horse on the last day because it was so hard to leave her. I thought I was tougher, but I wasn't so when we …. when I said goodbye, I broke down and cried. (4)

In one study where animals were a strong protective factor for some individuals, the death, or prospective death of their dog resulted in a loss of purpose in life and was associated with high self-reports of low moods and negative emotions (23). However, one study also highlighted the role animals play on learning about mortality and the circle of life, and opportunities to educate about such topics:

> Now whenever we have had a couple of family members pass since then and it's been an easier transition for Bec because she gets now that death does mean

> that we aren't going to see them again but we can still talk to them so we found it very valuable, that experience of a pet passing because Bec for a child that has such a significant language delay she was still able to absorb the concept. (15)

Theme 6: Faithful Friends.

This superordinate theme explores animals as faithful friends who offer non-demanding and non-judgmental companionship to many individuals, resulting in deep connections founded upon mutual understanding. The impact on masking is also discussed.

Theme 6: Subtheme 1: Animals as Companions. One theme that was present across all studies was animals as companions. Several studies described the animals as providing meaningful companionship, being a best friend or a member of the family, e.g., "I think that's the best way to put it, she really felt that [Therapy dog] was her friend, like her companion. And [Therapy dog] was just like her you know" (6). Participants spoke of strong bonds, deep connection and bi-directional affection, underpinned by the animals as providing unconditional love; "I think that's one of the reasons why she loves Chloe so much because Chloe is so interested in her and so affectionate with her, so she gives that mutual affection back" (10).

There was a strong narrative of animals being non-judgemental, non-demanding and patient allowing participants to express themselves without facing negative consequences, "they can't tell you to 'shut up, you're annoying me' … they can't tell you to go away and you can't really tell them to go away 'cause they can't understand you, so they will sit there and just listen" (8). For many, the animals seemed to understand and support an individual's internal emotional world, without the need for language, resulted in them feeling loved and understood.

Theme 6: Subtheme 2: Connection Without Expectations. Another pivotal narrative was that animals do not follow human social rules. Many individuals found it challenging to navigate social situations with other people, whereas with animals these difficulties do not exist. Consequently, the pressure or need to mask is reduced or eliminated, and individuals can be their true selves, without fear of judgement:

> With an animal, you don't need to wear a mask because they don't know the human social rules that you are breaking. There's something about the fact that they are not the same species which is helpful. Because an animal is not going 'doesn't she know that you have to hold eye contact?' A cat doesn't like eye contact. So, they're not watching you trip over the social rules. (22)

Many people spoke about deeply relating to and being feeling understood by the animals, all of which contributed to feeling safe and comfortable in their presence, "My dog knows what I'm feeling from the way I act. He knows to come lick me or act cute to make me feel better and when I'm alone with him I feel comfortable telling him things" (13). For some the bond transcended human-human relationships, "The friendship that they've formed is something that I don't think Dan will ever get with a human" (5).

Discussion

Key Findings

This systematic review synthesised the qualitative evidence exploring animal contact in relation to well-being for autistic individuals. The review process elicited six analytical themes: individual well-being, bridging and connecting, freedom to grow, anchor for the family, challenges, and faithful friends.

The presence of animals was found to support the well-being of autistic individuals in multiple ways. Firstly, participant experiences highlighted the impact on the self. A key mechanism for this was through emotional co-regulation, whereby animal contact improved emotional regulation and reduced emotional dysregulation, through providing comfort, distraction, and support. Animals were perceived as calming and comforted individuals during periods of dysregulation. This supported pre-existing evidence suggesting animal contact may increase prosocial and adaptive behaviours, decrease stress and reduce undesirable behaviours and emotions (Ajzenman et al., 2013; Funahashi et al., 2014; O'Haire et al., 2013; Tseng, 2023; Xiao et al., 2023).

Animals also provided physical benefits, including improved motor coordination and increased physical activity, and as a sensory regulatory tool. Animal contact also supported improved self-confidence, with many participants reporting improved self-esteem, increased willingness to try new things, and a greater sense of purpose through caring for their animals. This corroborates research highlighting improvements in physical outcomes such as motor skills, physical activity and self-regulation (Abadi et al., 2022; Ajzenman et al., 2013; Rezapour-Nasrabad & Tayyar-Iravanlou, 2022; O'Haire, 2013; Vakrinou & Tzonichaki, 2020; Viau et al., 2010).

This review also supports the evidence that animals can enhance social cognition and functioning in autistic populations (Ben-Itzchak et al., 2021; Funahashi et al., 2014; Martin & Farnum, 2002; Sams et al., 2006; Silva et al., 2011; Sissons et al., 2022). Animals were highlighted as social mediators that facilitated social communication and learning, bridging the communication gap for autistic individuals. They acted as icebreakers, encouraging verbal and non-verbal communication, while also providing a sense of connection and social acceptance. It seemed that through providing a safe and non-judgemental environment,

animals could offer opportunities for development of emotional awareness through observation and self-reflection via interaction (e.g., when an animal responds to a participant's behaviours). Animals also influenced the public and community's perceptions, reducing social stigma and increasing community access for families, and corroborated research that found animal contact increases characteristics such as empathy, trust and compassion (Lin, 2024).

The responsibility of caring for animals supported autistic individuals learning, knowledge acquisition and application and fostered a sense of independence and confidence. Animals were described as both protectors and sources of comfort who enabled autonomy via routine and structure, allowing participants to explore the world in a safe and secure way. This supported existing research which has found that animals may increase safety through biological, psychological, and social factors (Tseng, 2023) and lead to positive changes in adaptive functioning and independence (Leung et al., 2022).

The results also indicated a far-reaching and wide-spread impact on the family, with animals serving as a "social glue" that supported cohesion, developed relationships and reduced stress within the family. Like other studies that found a correlation between animals and decreased parental stress (Tseng, 2023) and increase community participation (Leung et al., 2022), the findings suggests that animals may contribute to reduced stress, increased joy and enhanced familial social participation, by making the inaccessible, accessible.

While the benefits were profound, there were challenges, including the responsibility of caring for animals, adjustment difficulties, issues with intervention implementation and maintenance, and the emotional demands of transition, loss and death. Despite these difficulties, many people felt that the positive effects of animal contact outweighed the

challenges, with animals playing a fundamental role in supporting the well-being of autistic individuals.

In line with the research exploring animals as social connections and attachment figures (LaFollette et al., 2019; Meehan et al., 2017; Sachs-Ericsson et al., 2022), animals were found to be close companions and best friends for many individuals. Animals often offered a non-demanding and non-judgemental source of social support, where they could be their true selves, without masking. Some individuals related to animals and felt there was a mutual-understanding, and some reported that their relationship surpassed other human relationships. This supported the existing research that found animals offer a calming, non-judgemental safe space (Kruger & Serpell 2010; Ward et al., 2017).

Implications

Theoretical Implications. In this review, one of the pivotal change mechanisms was the safety and security provided by animals to autistic individuals. Attachment theory posits that babies feel safe to venture out and explore the world, when they have been given a safe and secure base by their caregiver who will be available to offer comfort in times of distress (Ainsworth & Bowlby, 1991; Bowlby, 1969; 1979). As attachment bonds shift, attachment hierarchies help organise these evolving connections (Bowlby, 1979; Doherty & Feeney, 2004) and this review suggests that for some autistic individuals, animals may be a pivotal attachment figure, corroborating the work of Meehan and colleagues (2017).

As per social support theory and the model of thriving through relationships (Feeney & Collins, 2015), the results of this review highlight the powerful impact of companionship and social connection on an individual's well-being. Many individuals found intense benefit from

the social support offered to them by the animals, ranging from companionship, best friends, being a part of the family and unconditional love. In line with previous research, the results found that the social connection with animals was able to increase coping and relieve many negatives outcomes, including stress (Calhoun et al., 2022). This research strengthens the claims that animals may offer a unique source of social support for some individuals (Bekker & Mallavarapu, 2019; Bodsworth & Coleman, 2001; Garrity & Stallones, 1998; LaFollette et al., 2019; Meehan et al., 2017; Reniers et al., 2023; Sable, 1995; Sachs-Ericsson et al., 2022).

Clinical Implications. The findings from this review substantiate the benefits of animal contact in relation to well-being for some autistic individuals. Much of the perceived change and impact was underpinned by a lack of social expectations from animals and the interaction being non-judgemental. For some, this expanded their social and emotional world, developed a sense of self and identity, and increased self-esteem and self-confidence. Considering the research into masking, including its impact on self-identity and self-worth, this review highlights the importance of supporting individuals to "unmask", should they choose to. It also suggests that autistic individuals should be provided with discreet opportunities to comfortably and safely be themselves, outside of the home. One way could be to increase the opportunities for incorporation of animals into settings such as school, work and health settings.

By breaking down barriers that prevent such interventions from being routinely incorporated into service provision, we can increase the accessibility of more inclusive and diverse interventions. Some guidance for use of Animal Assisted Interventions already exists (e.g., Intensive Care Society, 2020; Royal College of Nursing, 2019; The Society for Companion Animal Studies, 2013) and the British Association for Counselling and Psychotherapy (BACP) have several reports on their website discussing animal interventions

(e.g., BACP, n.d.) however, to date no national guidance exists that standardises animal contact in health settings. This review supports the development of such guidance, with the aim of increasing the diversity and equitability of services by offering interventions that are more accessible for many patients.

Limitations

While this review was methodologically sound, there are some limitations, including an inherent risk of subjectivity and bias due to self-report data. It is also likely that the participants possessed a positive inclination towards animals, given their decision to own or interact with them, which may have influenced their responses. Similarly, thematic synthesis is inherently biased due to relying on the researcher's interpretation of results. However, the research team endeavoured to remain reflexive throughout, to mitigate bias where possible.

Most studies were from the parent/carer perspective. It is likely that parents/carers are more able to report on their child's external and/or visible behaviours and find it more difficult to attend to and understand a child's internal emotional states or thought processes, which are not as easily observed (Williams et al., 1989). Similarly, masking is common in autistic individuals (Petrolini et al., 2023) and by relying on second-hand experiences, some of the experiences or insights may have been overlooked. However, by including a range of perspectives the analysis captured multiple dimensions, providing a richer understanding of the topic. It also allowed for contextual and systemic depth, helping to develop an understanding of why first-hand experiences occur, by providing context that would otherwise be missed.

Almost all studies were conducted in Western countries, with the majority in Australia and the U.S. Across studies, only 41% of the total participant dataset has recorded ethnicity,

making it impossible to fully assess diversity or generalise the findings. Additionally, ideas about autism (Kim, 2012), well-being (Sollis et al., 2024) and animals (Gray & Young, 2011) can vary greatly across cultures, and so summarising studies from primarily Western countries may result in some cultural values, norms and experiences being overlooked. As such, these results may not reflect the experiences of autistic individuals from other ethnic or cultural backgrounds, many of whom are affected disproportionately by health vulnerabilities and inequalities and may face additional and different challenges (Ames et al., 2022).

This review explored all aspects of well-being and included all types of animal contact, including companion, assistance or intervention animals. As a result, broad themes were identified which may have led to some nuances relating to specific types of animal contact or explicit outcomes being overlooked. However, considering the research available at this time, this review was helpful to summarise a broad understanding of the general well-being experiences of autistic people in relation to animal contact, before more targeted reviews can be undertaken.

While the DEP can provide a useful framework to consider social communication differences, currently the framework's theoretical basis appears under-researched and under-specified. Livingston and colleagues (2025) have described the DEP framework as an example of a "weak derivation chain in psychological science" (p. 744). They explain that due to conceptual ambiguity, the DEP framework fails at the first link rising from imprecise definitions and broad descriptions, without clear specification of which social cognitive processes are involved. This has led to possible "jingle-jangle" (p. 747) problems in relation to DEP where the framework is being applied to refer to a variety of constructs, and various concepts are being attributed to the DEP (Livingston et al., 2025). As a result of this conceptual ambiguity, there may also be downstream measurement issues. For example, DEP

research may lack psychometric robustness due to poor validity and lack of replication, resulting in weak methodological grounding (Livingston et al., 2025).

Another critique of DEP is the unclear theoretical boundaries. Currently, important contextual factors have not been well considered, and the framework is largely applied to autism, despite Milton's (2012) paper originally referring to a mismatch in 'disposition' (Livingston et al., 2025). Finally, due to conceptual and measurement issues, studies have employed the concept of double empathy heterogeneously, which has likely contributed to the mixed research results in this area. For example, recent research found that autistic people were able to share information with other autistic people as successfully as non-autistic people to other non-autistic people, whereas information sharing was less successful in mixed-neurotype interactions (Crompton et al., 2020). At first glance, this pattern is consistent with, but does not uniquely support, the DEP framework. When this study was replicated, no difference between single-neurotype and mixed-neurotype groups was identified (Crompton et al., 2025). Livingston et al. (2025) surmise that DEP is unable to generate precise statistical predictions, due to the aforementioned upstream issues.

By comparison, alternative social cognitive theories and processes, such as theory of mind (Baron-Cohen et al., 2000; Happé, 2015) benefit from being more robustly conceptualised, with clearer theoretical underpinnings, definitions and better-established measurement tools (Livingston & Happé, 2021; Livingston et al., 2025). Theory of mind research is an example of how social cognitive constructs can be defined more robustly and consistently and supports the need for more rigorous research into the DEP to strengthen the derivation chain and allow for better translation into clinical and applied settings.

Despite these conceptual uncertainties, the DEP resonates with many autistic people, autistic researchers and PPI contributors (Verrier et al., 2024), including the EBE involved in this study. It offers a helpful alternative perspective to research undertaken from a more deficit-based view of autism. The support for this framework within autistic-led communities suggests that the DEP more meaningfully captures their experiences of empathy and the reciprocal nature of communication difficulties (Verrier et al., 2024) and covers aspects of social interaction that may be overlooked by other accounts. This is supported by Dark (2024), an autistic researcher who presented the "Eight Principles of Neuro-Inclusion" tool to support inclusive research practices. Dark's (2024) first principle, 'respect', highlights the importance of respecting and valuing the lived experiences of autistic people. Dark (2024) specifically cites Milton's (2012) paper to support the importance of understanding autistic perceptual differences. Given this, to truly reflect lived experience and inclusive research, neglecting the DEP entirely may risk marginalisation of autistic perspectives. Instead, translation and application of findings based upon the DEP framework should be interpreted with caution.

Future Research

At present, males receive a diagnosis of autism at higher rates than females (Zeidan et al., 2022). While multiple theories have been proposed to explain this disparity, clearer definitions of existing concepts and robust research exploring gender differences in relation to social cognition may shed further light on the underlying reasons for variations in diagnostic prevalence. Although gender was not specifically explored in this study, it may be worthwhile to explore gender differences in relation to animal contact and wellbeing in autistic populations.

As discussed, to reduce risk of bias and to mitigate the role of masking it would be helpful for future research to focus on first-hand experiences of autistic individuals, including children, through semi-structured interviews to ascertain direct and personal insights (Rogoff et al., 2018). This would give voice to the individuals' own interpretations, without relying on the interpretations of others.

Future research may also wish to further explore this topic area using larger and more diverse samples, with an experimental and/or longitudinal design, preferably with a comparison group to determine possible causality and highlight any sustained effects. With more robust studies, arguments could be put forward in support of animal contact as part of the growing evidence base for holistic, nature-based and inclusive interventions that fall outside of more traditional therapies and interventions for autistic individuals (Fan et al., 2023; Friedman et al., 2025; Salsabila & Muna, 2023).

Conclusion/Summary

The findings of this review suggest that animal interaction may enhance the well-being of autistic individuals in a variety of ways. Unfortunately, as urbanisation continues to expand in the modern world, access to natural environments and animal interactions is increasingly limited. In addition to this, society continues to develop in ways which prioritise non-autistic people (Singh & Bunyak, 2019), resulting in various service (Wallace-Watkin et al., 2023), socioeconomic (Khougar et al., 2023) and educational, social and occupational (Barry et al., 2020; Harmuth et al., 2018; Vasilevska Petrovska et al., 2019) disparities. This review emphasises the significance of creating opportunities for autistic individuals to feel safe, comfortable and make meaningful social connections (Feeney & Collins, 2015) through engaging with animals (Wilson, 1984), should they choose to. By enhancing these

opportunities and incorporating animal contact into everyday life, we may improve intervention accessibility and promote overall well-being for autistic individuals.

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Supplementary Material A

Excerpt from Codebook

This is an excerpt from the codebook that includes all codes used to categorise and analyse the available data, including an illustrative quote.

Code	Illustrative Quote	Study
A need to be patient	I think that when people choose to get an animal, I think they need to be patient with…	22
Ability to access new places and experiences	With the AAD, families were able to explore new experiences and stay in public spaces longer.	3
Ability to generalise new skills or learning	engagement in therapy sessions also led to the generalization of skills to everyday environments…	6
Acquiring new knowledge	provides an opportunity to gain new knowledge not only about the animals, but the knowledge and skills gained can be applied to oneself…	2
Active interest in learning	A major theme was that children were interested in learning more, either from their parents or by practicing or reading about it…	10
Actively seeking out animals for support	animals as a strategy during times of distress, as she actively sought the animals to help her to relax…	8
Adjustment period	In terms of challenges, Sarah reported that her family required time to adjust to assistance…	5
Affirmation	The transcendental relationship provided affirmation for the autistic participants…	13
Animal as a trigger for emotion dysregulation	the only time if there's any problematic things is sometimes she'll get frustrated if Chloe won't come over…	10
Animal contact decreased negative feelings	Kathryn interacts with animals to alleviate negative emotion, suggesting once a positive…	8

Supplementary Material B

Reflexive Journal

This reflexive journal records the primary researchers' thoughts, feelings and reflections throughout the research process.

Reflexive journal:

- Scoping: I am pleased that I have a topic that I feel connected to and excited to think about this more and explore the research in this area. I am in the process of being assessed for ADHD and I wonder how this may influence the way I undertake this research and how I interpret results.
- Searching: 1,039 articles. Feeling overwhelmed with the number of articles I must review. Also concerned as part way through this and have found very few that are related to my topic. This surprises me as I expected there to be more. As a pet owner who finds comfort in their animal I assumed more would have been done.
- Diagnosed with ADHD: I have been diagnosed with ADHD and feel my connection to this study makes even more sense now. I feel so connected to animals and nature, which for me this is partly explained by a lack of social pressure and reciprocal unconditional love.
- Full text screening: Pleased that I have a secondary reviewer who can help me screen results. It seems that all my texts are in Western countries so far, and many only look at parent perceptions. My secondary reviewer is a black young woman who has lived in multiple countries and may bring interesting insights that I would otherwise miss.
- Data extraction: My studies use a variety of animal contact methods, but mostly from parent perspectives. There also exists lots of comorbidities in the research. I wonder

whether this will come up in the data, or whether this would be an interesting future research point.

- Thematic synthesis: Feeling overwhelmed at the thought of this as I have so many studies to review. However, I am also keen to explore the findings as there is so much data and the effects seem far reaching.
- I am noticing that many of the codes are similar, and I will have to amalgamate these once I have finished coding. I am also noticing that many of the codes are completely unique, showing the individual differences of each participant.
- I am mostly through the coding/theming; many interesting themes so far, some that I feel very connected to. I think it is possible that my interest in this topic, being neurodiverse, a pet owner and animal lover may inform the way I conceptualise these results. We discussed this in supervision today and reflected that we are all animal lovers and that it would have been helpful to have a non-animal lover on the supervision team. During our discussions we remain mindful of our positioning.
- Discussion: I am coming to the end of writing up this research and feel animals offer a range of support, which is in line with my own experiences. I wonder whether the participants who participated in research had an infinity for animals, and whether this skewed results.

Supplementary Material C

Thematic Map Displaying Additional Interconnections

Thematic map depicting additional interconnections that were not presented on the included thematic map.

Chapter 3: How do Autistic Adolescent Females Make Sense of their Masking Behaviours? A Thematic Analysis

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Note: This report is written and formatted in line with the Journal of Autism and Developmental Disorders submission guidelines (Appendix C).

Abstract

Purpose

Autism spectrum disorder has historically been understood to be male preponderant. However, the concepts of a female autism phenotype and masking suggest this may be misleading. Previous research has investigated masking and the experiences of autistic individuals; however, few qualitative studies explore masking in autistic adolescent females. This qualitative study aims to explore how autistic middle-late adolescent females make sense of their masking behaviours.

Methods

Through patient and public involvement, this study was co-designed with autistic experts by experience. Ten female autistic adolescent females (aged 13-19) took part in semi-structured interviews exploring how they understand their masking. The interviews were analysed using reflexive thematic analysis (Braun & Clarke, 2006; 2021; 2023) from a relativist-constructionist orientation.

Results

Ten participants aged between 13-19 (average = 16 years) completed the study. Reflexive thematic analysis resulted in four themes; Social Dynamics; Emotional Well-being; Masking is a safety net; The (Un)Masking Journey.

Conclusion

Results suggest that masking in adolescent autistic females is a socially motivated, complex coping strategy driven by a pressure to conform to non-autistic norms. While masking was viewed by some as a "safety-net" to help cope with the challenges of daily life,

it was associated with several difficulties. Many participants expressed a desire to unmask; however, this was challenging due to fear of social judgement and the deeply rooted nature of unmasking. The results emphasise the importance of encouraging autonomy over masking and increasing societal awareness and inclusive practices to reduce the pressure to conform.

Keywords

Autism Spectrum Disorder, Masking, Females, Adolescence, Reflexive Thematic Analysis.

Chapter 3: How do Autistic Adolescent Females Make Sense of their Masking Behaviours? A Thematic Analysis

Autism is a neurodevelopmental condition with a worldwide prevalence of approximately 1% (Zeidan et al., 2022). While the exact aetiology of autism remains unknown, the available evidence suggests that it is a multifactorial disorder, best explained by both genetic and non-genetic factors (Rutter, 2005).

Autism and Gender

While current research estimates suggest a male-to-female global ratio of 4.2:1 (Zeidan et al., 2022), figures vary widely depending on sampling methods, diagnostic criteria and study design. This can make it difficult to determine whether observed differences truly reflect gender prevalence disparities or whether they are the result of detection and diagnostic biases. Several explanations have been proposed to understand and justify this male preponderance including the female protective effect (FPE) and the female autism phenotype (FAP).

The FPE posits that there is something inherent in the female sex that offers a protective effect against autism and reduces the likelihood of its development (Jacquemont et al., 2014). This theory suggests that while it is not impossible for females to develop autism, a greater genetic, environmental and/or biological load is required for them to develop and exhibit the same "level" of autism as males (Robinson et al., 2013). This model builds on the extreme male brain theory, which proposes that males and females typically possess Type S (systemising) and Type E (empathising) brains, respectively, and that autism represents an extreme form of a typical male Type S cognitive profile (Baron-Cohen, 2002). However, this theory remains speculative, as there is no consensus on the mechanism that would explain the lower mutational burden in males (Werling, 2016). Furthermore, some research has

concluded that the male neuroanatomical phenotype does not inherently carry a higher risk for autism compared to females (Ecker et al., 2017).

The FAP theory, another highly debated explanation, suggests that females may exhibit a distinct presentation of autism (Hull et al., 2017; Kirkovski et al., 2013). For example, compared to males, females tend to display lower levels of externalising difficulties (e.g., aggression and hyperactivity) and higher levels of internalising problems (e.g., anxiety and depression) (May et al., 2014; Oswald et al., 2016; Werling & Geschwind, 2013). Likewise, research has found that females display either fewer restricted and/or repetitive patterns of behaviour, interests or activities (Allely, 2019; Mandy et al., 2012), or these behaviours are expressed in non-male typical ways and are therefore not identified by the current diagnostic criteria (Mandy et al., 2012). Furthermore, historically, autism research has focused on male populations. This research has informed subsequent screening measures, assessment tools and diagnostic instruments and criteria, possibly resulting in a male-biased understanding and conceptualisation of autism and leading to a lack of sensitivity to female populations (Lai et al., 2015; D'Mello et al., 2022; Øien & Nordahl-Hansen, 2018; Rujeedawa & Zaman, 2022; Stroth et al., 2022). Despite this and possible gender differences, current diagnostic thresholds are the same for both males and females which may contribute to the underdiagnosis of autistic females (Constantino & Charman, 2012; Lai et al., 2015; Navarro-Pardo et al., 2021).

Despite an increase in research in recent years, the FAP is a relatively new concept and there does not yet exist any uniform or concrete evidence for a consistent female-phenotype with distinct trait patterns. Instead, some studies seem to indicate no or limited gender differences across autism-related domains, and those that differed were not consistent across studies (Lai et al., 2011; Wiggins et al., 2021).

While both the FPE and FAP suggest that the higher number of diagnosed males is in part due to some kind of bias, it is possible that males are just more likely to develop autism due to their biological make up. Considering this, the diagnostic sex disparity may reflect a difference in natural susceptibility, not detection or diagnostic bias. However, evidence for a purely biological explanation remains inconclusive (Ecker et al., 2017; Werling, 2016) suggesting that this alone may not explain diagnostic disparities. Moreover, growing research indicates that many autistic females engage in masking behaviours to a greater extent than males (Hull et al., 2020). This, combined with possible diagnostic bias due to research based on male populations, suggests that autistic females may be chronically underdiagnosed due to systemic under identification (Gould, 2017).

Masking and Gender

Masking refers to the conscious or unconscious practice of reducing, concealing or suppressing autistic traits and behaviours in a social setting, whether explicitly learned or implicitly developed (Hull et al., 2020; Lai et al., 2011). Masking behaviours vary widely from person to person but may include altering facial expressions, maintaining eye contact, suppressing certain behaviours (e.g., stimming), avoiding or limiting discussion related to oneself and scripting conversations (Cook et al., 2022).

Although present across all genders, masking has been found to be more common in autistic females than males (Hull et al., 2020; Lai et al., 2017; McQuaid et al., 2022; Schuck et al., 2019). The ‘camouflage hypothesis’ was coined following research that linked the diagnostic gender gap and the greater social and communication abilities of some autistic females (Wing, 1981). Research began exploring the concept of autistic individuals using

specific strategies to mask social difficulties ('masking'), thus appearing socially neurotypical, despite experiencing chronic underlying difficulties (Kopp & Gillberg, 1992).

Bernardin and colleague's (2021) qualitative research into masking focused on the experiences of male and female adolescents, including non-autistic and autistic participants. The results highlighted that the experiences of masking in terms of motivations and consequences, were different depending on both sex and diagnosis. One possible explanation is rooted in developmental psychology, and rests on the assumption that a child's development is influenced by their social environment, including experiences and interactions with individuals of the same gender, and the associated societal expectations of masculinity or femininity. Each of which encompass their own distinctive norms for certain social characteristics. For example, empathy and reciprocity, are typically greater in social femininity (Krahn & Fenton, 2012). Compared to autistic males, research suggests that autistic females face greater social pressures to conform to social/gender norms from an early age and therefore feel a greater need to mask (Krahn & Fenton, 2012).

This is supported by evidence exploring autistic females' social skills. For example, autistic females tend to display higher reciprocity on diagnostic assessments and make better first impressions, despite demonstrating similar levels of autistic traits when compared to autistic males (Cage & Troxell-Whitman, 2019; Cola et al., 2020 Wood-Downie et al., 2021). Similarly, autistic females are more likely to display greater social interest and motivation, possess more advanced abilities to maintain a reciprocal conversation, and initiate friendships and reportedly have similar quality of friendships to non-autistic females (Head et al., 2014; Hiller et al., 2014; Sedgewick et al., 2016).

However, Pearson and Rose (2021) suggest that while masking may contribute towards diagnostic disparities, masking should not be strictly associated with gender. Instead, they view the development and maintenance of masking through a sociodevelopmental lens. Considering this, it could be argued that the elevated rates of masking in autistic females is due to the pressure to conform to feminine gender norms such as compliance (Rudman & Glick, 2001) and friendliness (Brescoll & Uhlmann, 2008), rather than biological sex.

Current empirical evidence proposes several possible motivations for masking, including increased social access and contentment/comfort with social situations, enhanced social connections and levels of acceptance by others and reduced risk of harm and judgement from others (Bradley et al., 2021; Cage & Troxell-Whitman, 2019; Hull et al., 2017; Sedgewick et al., 2016). However, the pressure to mask is associated with increased mental health challenges and internalising symptoms (Ross et al., 2023; Somerville et al., 2024) as well as poor physical health, loss of identity, delayed diagnosis and social isolation (Bradley et al., 2021). Furthermore, higher levels of masking are linked to self-identity confusion, exhaustion (Bargiela et al., 2016) and elevated psychological distress and functional difficulties (Beck et al., 2020). These consequences can result in feelings of disempowerment, a reduced sense of agency and low self-esteem, as individuals may suppress their authentic self to meet societal norms. This tendency to prioritise conforming above their own needs may hide support needs, leaving them without appropriate or timely care and vulnerable to manipulation and exploitation (Bargiela et al., 2016; Tierney et al., 2016).

The implications of masking extend beyond social navigation and into several other aspects of well-being which underscores the pressing need to better understand masking so we can more effectively support autistic individuals.

Adolescence

Adolescence is a crucial developmental stage where individuals undergo significant cognitive, physical, emotional and social changes (Scott & Saginak, 2016). Puberty often occurs during adolescence, bringing further changes and commencing the transition from childhood to physical and reproductive maturation and adulthood (Breehl & Caban, 2018). During this developmental phase, young people can shift away from prioritising parental and familial attachments, to form new bonds and connections with peers, partners and individuals outside of their family (Ainsworth, 1989; Bowlby, 1969; 1979). It is also a vulnerable time with 50% of psychiatric disorders starting by age 14 (Kessler et al., 2005)

This Study

As masking begins at an early age and in line with development (Petrolini et al., 2023), many autistic people can face significant pressures to live inauthentically during childhood and into adolescence. Therefore, it is crucial to consider the impact of masking during such an important developmental stage and consider whether masking during adolescence has a detrimental impact on a person's life and ongoing development. Furthermore, as autistic females disproportionately present with masking behaviours, which is, in-part, thought to contribute to the under diagnosis of females (Hull et al., 2020), it is important to explore this demographic to better understand masking.

This novel study will specifically focus on how autistic middle-late adolescent females make sense of their masking behaviours, with the aim of contributing to the gap in the literature and improving our understanding of the experiences of autistic adolescent females.

Methods

Design

A qualitative study design was chosen to explore the experiences of middle-late autistic adolescent females to obtain detailed data and personal perspectives that are difficult to capture through quantitative measures (Tenny et al., 2017). Data was collected using semi-structured interviews, which allowed for flexibility for the interviewer to ask questions relating to the research question, while also remaining responsive to the participant by exploring the "who, what and where" of their individual experiences (Sandelowski, 2000).

Participatory Research

This study integrated patient and public involvement (PPI) and autistic experts by experience (EBE) at all stages of the research process to ensure meaningful and accessible findings (den Houting & Pellicano, 2019; Gillespie-Lynch et al., 2017; Grant & Kara, 2021; Hobson et al., 2023).

Materials

A screening questionnaire (Supplementary Information E) was created in relation to the inclusion/exclusion criteria to ensure participant suitability and establish demographic information. To determine eligibility for the study, the Clinical Outcomes in Routine Evaluation-10 (CORE-10) and Young Person-Clinical Outcomes in Routine Evaluation (YP-CORE) were used to record level of psychological distress, and the Camouflaging Autistic Traits Questionnaire (CAT-Q) was used to establish the presence of masking behaviours (as indicated by a score >100 on the CAT-Q; Hull et al., 2019). Participants scoring below 100 on the CAT-Q were assessed on a case-by-case basis by the primary researcher and two supervisors, all of whom had relevant expertise in child and adolescent mental health and

intellectual disabilities, to determine whether they masked based on a qualitative review of CAT-Q responses.

Participants reporting significant suicidal ideation in the week preceding the interview, as assessed by the CORE-10 were excluded for ethical reasons. Participants who were experiencing significant mental distress, as determined by a score of ≥25 on the CORE-10 (Connell & Barkham, 2007) and threshold scores of 14.4 (for females aged 11–13) and 15.9 (females aged 14–16) on the YP-CORE (Twigg et al., 2016) were initially excluded. However, as standard outcome measures may not allow for accurate reporting of distress for autistic individuals (Proctor & Cahill, 2019), clients exceeding these parameters were discussed by the primary researcher and supervisors to assess eligibility (including their parent/carer, where appropriate) based on risk and psychological distress.

A semi-structured interview schedule was co-designed with an EBE and the research team to elicit the individual experiences of masking in autistic adolescent females. This was further refined following a pilot interview with an autistic adolescent (aged 18). The final interview protocol (Supplementary Information F) began with the researcher re-informing the participants about the focus of the study, their rights, confidentiality, the structure of the interview and a pre-determined definition of masking. All questions were asked with the aim of gaining further insight into how autistic people perceive their own masking behaviours.

Sample

Autistic adolescent females were recruited with the aim of recruiting between eight and 20 participants (Turpin et al., 1997). Considering that diagnostic oversight is common for many autistic females (Hull et al., 2020), this study included those awaiting formal assessment. By including this cohort, we gave a voice to an often-overlooked population and

promoted inclusivity by challenging gatekeeping in research that typically focuses on confirmed clinical cases. This also added depth to the sample by capturing pre-diagnostic perspectives, resulting in richer and more nuanced data. However, participants who were suspected of being autistic without being on a waitlist for assessment or formal diagnosis were excluded to maintain clarity and ensure the integrity of the data. This decision was made to prevent potential confounding factors that could arise from including individuals who may not be autistic. The inclusion/exclusion criteria can be found in table 2.1.

Table 2.1

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria:
Female (those assigned female at birth). Aged 13-19 at the time of the interview. Capacity to consent to participation. Confirmed autism diagnosis or awaiting assessment. The presence of masking behaviours (as determined by the CAT-Q).	Male (including those assigned male at birth and those who were assigned female at birth but currently identify as male). Significant levels of distress or risk (as determined by the CORE-10 or YP-CORE) and clinical assessment. Participants who were suspected of being autistic without being on a waitlist for assessment or formal diagnosis.

Table 2.2 shows the demographic information and allocated pseudonym for each participant. Ten participants aged between 13-19 (average = 16 years) completed the study. One participant was excluded due to possible risk and significant psychological distress. Two

Table 2.2

Participant Demographic Information

Participant ID (pseudonym)	Age	ASD status	Service	Ethnicity	Gender identity	Core-10	YP-CORE	CAT-Q
1 (Amy)	17	Diagnosed	NHS	White	Woman/girl	N/A	16	124
2 (Olivia)	18	Diagnosed	NHS	White	Woman/girl	N/A	18	153
3 (Emma)	14	Diagnosed	NHS	White	Woman/girl	N/A	11	140
4 (Erin)	14	Diagnosed	NHS	White	Woman/girl	N/A	12	108
5 (Lilly)	15	Waitlist	NHS	White	Woman/girl	N/A	17	122
6 (Sam)	19	Waitlist	NHS	White	Woman/girl	22	N/A	145
7 (Grace)	15	Waitlist	NHS	White	Non-binary/genderqueer/agender/gender fluid	N/A	13	127
8 (Sophia)	13	Diagnosed	NHS	White	Woman/girl	N/A	10	96
9 (Rachel)	18	Diagnosed	NHS	White	Woman/girl	20	N/A	101
10 (Hannah)	19	Diagnosed	NHS	White	Woman/girl	29	N/A	150

additional participants were recorded as having dropped out after attending the initial conversation and then ceasing contact.

All participants were female by birth and recorded their ethnicity as White. Nine identified as women/girls and one identified as non-binary/genderqueer/agender/gender fluid. Seven participants were diagnosed autistic and three were on the waitlist for an autism assessment. All participants received their diagnosis or were on the waitlist for an assessment through the National Health Service (NHS) in the United Kingdom. Three participants completed the CORE-10, with an average score of 23.7 (ranging between 20-29). Seven participants completed the YP-CORE with an average score of 13.9 (ranging between 10-18). All participants completed the CAT-Q with an average score of 126.6 (ranging between 96-153).

Procedure

Using purposeful sampling, participants were recruited from a non-clinical sample through social media and autism support groups via an advert (Appendix D). Anyone that expressed interest in participating attended an initial conversation with the primary researcher (via phone call or Microsoft Teams) to outline the study aims and assess capacity to consent. If an individual remained interested in taking part, they were emailed the YP-CORE/CORE-10, the CAT-Q and a screening and demographic questionnaire to complete (Supplementary Information A-C). If eligible, they were sent a consent form and, if applicable, a parental consent form (Appendix E-G), and participant information sheet (Appendix H). After consent was obtained, they attended a semi-structured interview conducted by the primary researcher via Microsoft Teams. Participants were given a £15 voucher as a token of thanks for their time.

During recruitment, it was identified that the participant pool consisted entirely of White British individuals. To increase participant diversity, purposeful sampling was used, and the study advertisement was shared on several social media pages aimed at a diverse range of cultural and ethnic backgrounds. However, this did not generate any interest.

Interviews were recorded via Microsoft Teams and transcribed verbatim by a University approved transcription service. All participants were allocated a participant number, potentially identifying data was removed and transcripts were anonymised for analysis. Data was collected and stored in accordance with the University of Southampton's data procedures and General Data Protection Regulation (Data Protection Act, 2018).

Ethics

Ethical approval was gained from the University of Southampton Ethics and Research Governance Online II (ERGO II) system (see Appendix I). All participants, and where relevant parents/carers, provided written consent. To mitigate distress, participants were given a clear and accessible description of the study aims, expectations and their rights via the participant information sheet. The researcher worked flexibly, encouraging the participants to engage in any way that felt most comfortable to them (e.g., inviting parent/carers to join if this was the young person's preference, location of call, breaks in interview). Participants had allocated time to debrief with the interviewer post-interview and were given a debrief sheet containing signposting and other sources of support (Appendix J).

Analysis

Reflexive thematic analysis (RTA; Braun & Clarke, 2006; 2021a; 2021b; 2023) was chosen to enable a comprehensive inductive exploration of how participants interpret their masking behaviours through identifying common themes across individuals, while

considering the subjectivity of the research team. Analysis followed Braun and Clarke's (2006) six phases of RTA: familiarising yourself with the dataset; coding; generating initial themes; developing and reviewing themes; refining, defining and naming themes; and writing up.

Researcher Reflexivity

In research, reflexivity relates to the ongoing evaluation of the self as a researcher and the consideration of how our beliefs and preconceptions may impact the research procedure (Berger, 2015). To remain cognisant of any assumptions regarding the content matter and analytic procedure in this study, the research team in regular reflexive conversations, and the primary researcher kept field notes (Supplementary Information G) and a reflexive journal (Supplementary Information H) during the interview and data analysis stage, respectively.

The primary researcher was diagnosed with Attention-Deficit Hyperactivity Disorder (ADHD) during the data collection stage of research, thus moving from an "outsider" to "insider" researcher, from a neurodiversity perspective (Berger, 2015). Following diagnosis, the primary researcher re-read the interviews completed pre-diagnosis and coming from this new lens noticed alignment to the participants' experiences of masking as a neurodiverse person, identifying nuances that had been overlooked previously. Moving into a neurodiverse position, the primary researched noticed increased awareness and personal connection relating to the stigma and stereotypes of neurodiversity in media (e.g., that neurodiversity is a medical issue that can be cured; Hungerford et al., 2025; Yücel, 2023) and within the research and professional sphere (e.g., gender biases and prejudicial assessment instruments; VanDaalen et al., 2025; Visser et al., 2024).

The primary researcher acknowledges that, as a newly diagnosed neurodivergent researcher, they may have been heightened to certain themes, such as stigma, authenticity and

unmasking. They also recognised the use of language, and that the framing of autism may have been influenced by their neurodiverse positioning, and through their work with autistic people, placing emphasis on affirming and strengths-based languages, over deficit-based language. Additionally, being a female researcher studying autistic adolescent females, the primary research was conscious that this shared gender identity may have influenced data collection and interpretation. Being aware of the societal pressures placed on women, the primary researcher may have been more attuned to how masking is encouraged or rewarded in females, particularly through an emotional lens, over other domains.

Philosophical Positioning

This research comes from a relativist-constructionist orientation. Ontologically, relativism rejects the idea of a singular, independent reality and conceives that reality is subjective and shaped by human action and interaction (Denzin & Lincoln, 2005). Constructionist epistemology views knowledge as a human construct, shaped by context and perspective rather than objective reality. Adopting a relativist-constructionist orientation allowed a rich, nuanced understanding of the masking experiences of autistic adolescent females, acknowledging both the researcher's subjectivity and the diversity of the participants lived experiences.

Results

Information Power

Information power suggests that the more relevant information a sample contains, the fewer participants are needed (Malterud et al., 2016). It is assessed across five items. First, the study aim was relatively narrow, focusing on masking experiences within a defined age, gender sand autistic presentation, though with some breadth, suggesting the need for a moderate sample size. Second, sample specificity was high with participants possessing

characteristics closely aligned to the research question, suggesting the need for fewer participants. Third, while supported by well researched theories, these remain contested and are relatively new in autism research, indicating the need for a larger sample. Fourth, the quality of dialogue was strong with an interview guide co-produced with EBE and clear communication, supporting the need for fewer participants. Lastly, the analysis strategy of this study, exploring the lived experiences of multiple participants to draw themes, suggests a larger sample size. On balance, a sample size of 10 was judged sufficient to meet information power for responsible analysis.

Analysis

Our relativist-constructionist thematic analysis primarily took an inductive and semantic approach to the data set, identifying several hundred codes initially. Many codes were inter-related and so we were able to amalgamate them from a latent orientation, forming a final codebook of 376 codes (Supplementary Information I). Initially, the codes were clustered into three potential broad themes related to social factors, well-being, and masking as a safety mechanism (see initial thematic map; Supplementary Information J).

After re-reading the transcripts and the codes, we identified an overarching theme related to participants' masking journey whereby each participant was undertaking their own journey with both unique and shared insights reflecting this. Hence, a final structure of four themes (social dynamics; emotional well-being; masking is a safety net; and the overarching theme the (un)masking journey) and four associated subthemes were established (Table 2.3 and Figure 2.1).

Table 2.3

Description of Identified Themes and Subthemes

Theme	Subtheme
Social dynamics	• Social motivations for masking • How others perceive masking
Emotional well-being	• Mental health and masking • Identity
Masking is a safety net	
The (un)masking journey	

Fig. 2.1

Final Thematic Map

Theme 1: Social Dynamics

This theme encompasses the social nature of masking, including participants' motivations for masking, other people's perceptions of masking, and the resultant desire for increased societal understanding and acceptance.

Theme 1: Subtheme 1: Social Motivations for Masking. Motivations for masking were primarily social in nature, including to avoid judgement, harm, bullying and unwanted attention or to fit in, be liked, make friends and appear more sociable or approachable. Additionally, some participants reflected on being told off for their behaviours, or that their natural way of being was wrong.

Participants described significant pressures to conform to societal norms. All participants described a desire to "fit in" with those around them, particularly in school settings, or with peers, e.g., "when you're 14 or 15 all you want to do is fit in … no one wants to stand out. That was, I think, a time where I heavily masked all the time" (Hannah).

For some, social stigma of autism was pervasive, resulting in them feeling or perceiving themselves as being seen as "weird" (Lilly), "less able[d]" (Erin) or "different" (Rachel). For these participants, masking helped them appear or feel "normal" (Olivia), and helped them blend in and avoid standing out, like a "black sheep" (Sam). For many it extended beyond this to a defence mechanism meant to protect themselves from harm, threat, judgement or bullying, which some participants had unfortunately experienced in the past: "Because when you meet new people, you don't wanna look like weird because people do talk about you behind your back" (Lilly).

Some participants masked to avoid unwanted attention or communication, something which made them feel anxious or uncomfortable. For others masking helped them avoid

certain social situations, confrontations, conflict or social circumstances they were uninterested in, e.g., “it kind of puts me around the side of situations I don’t want to have to, like, be a part of” (Grace).

In addition to avoiding certain negative circumstances, many participants masked to gain something. For example, several participants masked to help them to build connections and make friends, which they may otherwise have found difficult. Some participants described how they achieved this, including using social scripts, asking questions, limiting the amount they talk about themselves or their interests, social smiling, making eye contact and changing their facial expressions, to appear more “approachable” (Olivia).

Beyond this, some participants masked to make other people feel comfortable. For example, Sam described how she reduces her fidgeting as others find it “annoying” and Hannah reported avoiding joking around with certain people who she feels may find her humour “inappropriate”. Grace and Hannah both explained that they change their facial expressions as they felt people would be upset or offended should they not:

> If it was my way and it was socially acceptable … I think my face would be quite, not rude but quite not nice … And I think I've realised that from quite a young age, so I've always just smiled … because I know that if my actual facial expressions came out, then people would probably get quite upset (Hannah)

Unfortunately, some participants had been penalised or punished for their natural behaviours or told that what they were doing was wrong. For example, Rachel explained, “I’d get told off … you’d get told off for very stupid things. And…I wouldn’t be able to do it [stimming] in the classroom, like, I would get sent out and stuff”. As a result, participants described supressing various behaviours while around others for fear of punishment, or due to believing that it was somehow wrong.

This theme encapsulated the significant social pressure adolescents can face and the consequences of not abiding by these norms, which was worsened by the social stigma associated with being autistic. Participants spoke about feeling afraid of judgement or harm and that masking helped them avoid standing out. In addition, for some, masking was helpful in avoiding unwanted social situations and supported them to build social connections that they may otherwise struggle to do. Finally, it seemed some participants engaged in masking to avoid being disciplined or due to positioning other people's needs above their own, by changing, supressing, or avoiding certain behaviours that they believed others may find uncomfortable or deem 'wrong'.

Theme 1: Subtheme 2: How Others Perceive Masking. Considering these social motivators, an understandable theme that arose was how others perceive masking and the impact of this on participants.

Participants felt that some people in their lives understood, and were able to identify, masking, including friends, boyfriends, parents (particularly mothers) and some family members. Participants reflected that it was mostly those closest to them, who they had known for a long time, that were aware of their masking and understood the reasons for it. These were also often the people they felt most comfortable to unmask and be themselves around, without fear of judgement.

Interestingly, although perhaps unsurprisingly, most participants felt that other autistic and neurodiverse individuals were the people who best understood their masking. This was mostly attributed to other autistic people having an insider awareness of masking, in addition to being less likely to judge or negatively perceive them, e.g., "autistic people like can relate and like possibly do the same thing, so I feel like they would understand more" (Olivia).

Unfortunately, all participants reflected on some people's lack of understanding about autism and masking. They discussed family members and friends who were unable to tell when they were masking, and in some cases family who did not believe that they were autistic at all:

> They'll say, "Oh, she's not autistic," because they can't see it because I've masked sort of thing I guess … They don't know me and they don't understand me. So, like my Nana, she literally, if you ask me, don't think she knows me because if she can look at me and say she's not autistic, it's either one, she doesn't understand autism or really know it, or two, she just doesn't know me. Which I guess is kind of sad to think about. (Hannah)

All participants described most teachers as not understanding or being able to identify masking. Some felt misunderstood, and their masking behaviours were incorrectly labelled as them being "anxious" (Grace) or "shy" (Amy). For example, Lilly explained that she avoided certain situations as a way of hiding that she was struggling in school. However, this was interpreted as misbehaviour which perpetuated her difficulties: "They don't understand why I like, run away from stuff and don't like facing like my problems. They think that I'm really naughty" (Lilly).

Sophia acknowledged that teachers have only ever known her as how she presents when masking, which would make it difficult for them to be able to notice her masking: "I mean, at school, teachers, they've only really known me when I had the masking, so I don't think they realise I'm doing it" (Sophia). However, all participants described a general lack of awareness in society around masking, and a strong desire for increased awareness, understanding and appropriate support. They spoke about wanting people to listen to them, get to know them and understand their experiences, and for people to understand "the

detrimental effects" (Rachel) masking can have on their daily lives. Overall, there was an underlying appeal for people to be more accepting of the differences that make us who we are, "we're all people, we're all humans, so why should it matter if someone's a bit different?" (Lilly).

Kayleigh believed one of her teachers understood masking, and when asked about this, she was able to reflect that he gave her time and really got to know her for herself, not who she was when masking. This meant that he was able to implement appropriate support which contributed to her success in his class:

> Just to listen and like see what you've got to say or what you're struggling with and like then support on what they're saying … Check in with you to see if you understand or explaining stuff a bit slower and not just like getting your lesson done, actually think about the kids are actually understanding and taking information in. (Kayleigh)

Theme 2: Emotional Well-being

This theme explores the intersection of masking and emotional well-being, including the short-term and long-term consequences, and its significant impact on self-identity.

Theme 2: Subtheme 1: Mental Health and Masking. Participants described a bi-directional relationship between mental health and masking. For example, some participants found masking helped them cope with high levels of anxiety ("it's because the situations in which I have to mask are the ones that make me more anxious" (Grace)), or to hide their anger or frustration. Masking seemed to generally help participants navigate everyday life, mitigating some of the otherwise troublesome effects that this may have on their emotional well-being.

However, it seemed that while masking helped them cope in the short-term, they could feel overwhelmed and need to decompress after extended masking. Sometimes, this took the form of physically resting or spending time alone or with their cat, whereas others described episodes of emotional dysregulation, typically when returning home and unmasking.

> I don't know, sometimes it's just really exhausting and it's like really stressful because sometimes I get like really like anxious about things and then I have to pretend I'm not anxious about them at all because it, like, it doesn't look like anybody else is worried about what I'm worried about, so I just…I'm like "Okay, well, I'll just… Pretend I'm not until I get home and then cry about it. (Sam)

All participants spoke about the cognitive, physical and emotional energy associated with masking for long periods of time, resulting in feeling tired, exhausted or burnt out. Masking was described as all-encompassing, requiring them to think about their own and other people's actions, making it hard to focus on anything else. This had knock on effects on their education, physical health, social life and self-identity. As a result, in the long term, participants described feeling a variety of negative emotions (e.g., sad, depressed, stressed, irritable, anxious, angry) which they partially attributed to the impact of masking or the idea of having to mask in the future.

> Sometimes the anxiety is caused purely by having to mask … "Oh no, this person doesn't know how I act normally, so I'm just going to mask and see how it goes," because I never have a plan for anything. I kind of start freaking out about that. So that's how it's not useful because I'm, like, silently freaking out, like, "What am I going to do?". (Grace)

It appeared that many were unable to unpick which originated first, masking or emotional and mental health difficulties. For many, it seemed that they were stuck in a cycle;

masking to help them cope with daily life, resulting in exhaustion and feeling burnt out, which in turns effects their emotional and mental health, e.g., “yeah, it's just like a cycle and they just keep affecting each other” (Olivia).

Theme 2: Subtheme 2: Identity. All participants described masking as having an impact on their identity, which negatively influenced their emotional and mental well-being.

Some participants explained that few people know their authentic self because of masking. Amy shared that her family have only got to know her true self more recently, as prior to learning about masking she was unable to “fully” unmask:

> Before I knew that I was masking, I felt kind of like nobody actually like knew who I was, if that makes sense … because like I could almost drop it like from a change to when I was at school to at home, but I couldn't like fully drop it, if that makes sense. (Amy)

While participants found masking could help them build connections, Amy and Olivia described forming closer and more authentic relationships when unmasking. Other participants wondered whether their friends are truly their friends, or whether they are friends with the persona that they have presented to them whilst masking:

> Sometimes I get worried because I feel like I've made friends but I know I haven't really made friends because I’m only really asking about them and I try to avoid talking about myself … like trying to decipher whether I've made a friend properly through masking or if it's just somebody I know how to talk to. It's quite stressful because I'm like … I don't know if I've actually got any friends based on them liking me or just like liking who I like make myself into when I talk to them. (Sam)

Amy reflected on the emotional impact of this, explaining it was deeply confusing and upsetting for her to realise she had been unconsciously masking for a long time, meaning other people did not know her true self: “And it made me feel quite sad, especially when I didn't realise I was doing it because it was like nobody knew who I actually was” (Amy).

For some participants, this extended to self-identity confusion where they were questioning their likes and interests, and whether their experiences were a true reflection of them or a masking persona. Several participants expressed confusion around which of their personas was the ‘real’ one, or whether it was a combination of personas, or perhaps none of them. This led to deep existential confusion for some of the participants around their own self-identity and a feeling of “I don’t even know who I am” (Sam). Kayleigh explained, “I masked like all the time. Like, I literally didn't know who I was…I felt like I was just…I don't know how to explain it, but just like everything just felt fake”.

This seemed to contribute to participants emotional difficulties (such as isolation and feeling inauthentic), thus contributing to the negative cycle described by some participants.

Theme 3: Masking is a Safety Net. Although participants reflected on the negative impact of masking on their lives, they also positioned masking as helpful. Some participants shared that masking is like a social safety net (Erin) or handrail (Grace) helping them navigate, or sometimes totally avoid, complex social situations. Sam likened her masking experiences to ‘accessorising’, explaining that she was able to wear different ‘accessories’ in different settings:

> I think it's like me, but with a mask and then like different accessories that I put on for like different social situations. Like I'm wearing a mask, right? But then I'm also wearing a hat, or I'm wearing a mask but now I’ve put on a different coat. So like different things that I have with me for different social situations. (Sam)

For some, masking increased comfortability in situations including school, speaking to teachers, participating in hobbies, during job interviews, and other formal situations. Masking allowed them to present as non-autistic and maintain the expectations of others to succeed or get by, where they may otherwise feel awkward, uncomfortable or anxious:

> When I'm in like a serious like situation. Like if I went to a job interview, which I did once, masking when you can act like more serious and like polite, definitely helps you get more out of it. Like people see you as more good. (Lilly)

Half of all participants referenced masking as being better than the alternative, explaining that despite the cost, masking is less harmful than what they would experience should they not mask. It seemed that masking was a conscious and acceptable pay-off for some participants:

> If people like didn't like me or thought I was weird it would make me feel really bad, and I'd rather just feel tired after masking than know that people didn't like me or thought I was weird because I think that would make me quite anxious. (Amy)

This theme encapsulated the idea that masking is a survival mechanism that may be beneficial in certain situations for some participants, helping them to navigate some of the more complex or nuanced social situations of everyday life in a world designed for non-autistic people:

> It takes effort and energy, but like, not the same amount of energy I'd have to use if I wasn't masking, because if I wasn't, it would cause me more anxiety which would take way more effort and energy to, like, avoid having an anxiety attack. So, like, I prefer to mask rather than have anxiety attack at the end of the day. (Grace)

Theme 4: The (Un)Masking Journey

Although masking could be helpful at times, there was an overarching theme related to the journey of masking and the struggle for authenticity. This theme describes masking over time, the internal conflict between the desire to be the authentic self (unmasking) and the need to fit in or protect oneself (masking) and the impact of acceptance.

All participants described masking as starting in childhood/early adolescence. For many, it started when they first attended school. It seemed the social pressures of being in an education setting with other peers around their age triggered an awareness of possible differences between them and their peers, and of being perceived as "different" by others, e.g., "I think I probably started masking like as soon as I started school, in like reception or something, but I wasn't aware of it back then" (Olivia).

All participants reported masking as being somewhat unconscious initially (e.g., "I don't really notice when I mask, it comes really natural to me, so it feels like kind of not masking" [Sophia]) and that for many they did not know the extent of their masking was not typical. They described having a general awareness of being socially different, but that masking was mostly an unconscious process they implicitly developed and automatically and unintentionally engaged in as a way of coping with daily life. For many, it was only when they became informed about autism and the concept of masking, they were able to attribute a name to their experiences. For example, regarding her awareness of masking, Rachel commented "No, not always. Well, a lot of the time, like now, when I'm more aware of it. But when I was in school … I wasn't really aware". However, participants also described times they intentionally developed their masking abilities or consciously opted to mask in certain situations, e.g., "I think most of the time whenever I go out in the mornings, I'm like "Right, okay, so this is what I have to do whenever I get to this place"" (Sam).

Generally speaking, masking changed over time; it began around childhood, peaked in adolescence and (for some) decreased around late adolescence as participants intentionally sought opportunities to unmask. This desire to unmask was felt by most participants, particularly the older adolescents who expressed wanting to be themselves. However, they conveyed challenges with this due to masking being so ingrained e.g., Olivia commented "it's not really a good thing because I want like to be myself, I don't want to be putting on a front like consciously or like automatically … I've been trying to like unmask more, but it's quite difficult".

All participants described times when they felt most able to unmask and be themselves. This was largely related to safety and comfortability, such as familiar surroundings and people whom they knew well and could trust to not judge them. However, unmasking was also associated with an internal conflict between reconciling one's identity with external expectations (e.g., "I feel like I'm being myself a bit more, but then obviously trying to fit in as well" Kayleigh). For many participants acceptance from others, in addition to self-acceptance, led to them being able to mask less.

Masking was discussed in a range of ways depending on the experiences and the lens of the individual. Each participant described a unique (un)masking journey with some depicting masking as a "safety net" (Erin) that could be helpful or a set of "different accessories" (Sam) they felt pressured to wear. Some participants described intentional unmasking and feelings of relief, happiness, self-discovery and freedom, in addition to challenges associated with navigating a new way of being and the potential for social harm should they unmask.

Discussion

To the best of the author's knowledge, this study presents the first qualitative data specifically exploring how autistic adolescent middle-late females make sense of their

masking behaviours. Previous research has examined adults or included males and/or non-autistic people (Bernadin et al., 2021) with the male and non-autistic view as being the baseline from which all is referenced. In this study, adolescent autistic female participants were asked about their experiences of masking, without comparison to males and or non-autistic individuals. This offered a more nuanced perspective and provided individualised insights into their unique experiences of being an autistic adolescent female who masks. RTA resulted in four themes; social dynamics; emotional well-being; masking is a safety net; and the (un)masking journey.

Theme 1 (Social Dynamics) encompassed the social nature of masking, including participants motivations which were largely socially driven. These findings substantiate pre-existing research, highlighting motivations for masking such as enhanced social inclusion, connections and acceptance, increased comfort with social situations, and to reduce harm and judgement (Bradley et al., 2021; Cage & Troxell-Whitman, 2019; Hull et al., 2017; Sedgewick et al., 2016). Participants also described masking as both conscious and unconscious, and reported complex, detailed and well-thought-out systems of masking, meaning that many people in their lives were unaware of the masking, or even that they were autistic. This corroborates evidence reporting some autistic females as possessing strong social skills (such as reciprocity and friendship quality) despite high levels of autistic traits (Sedgewick et al., 2016; Wood-Downie et al., 2021).

Participants provided rich insights regarding perceived social pressures, supporting the idea that some females may feel the weight of gender norms and societal expectations from a young age (Krahn & Fenton, 2012). As such, some females may be more attuned to these social norms and more able to identify when their own behaviours do not align and so may feel pressured to mask and conform to these norms. This can make them appear socially

adept, despite this taking considerable effort, similar to how a swan will glide gracefully across a lake whilst its feet paddle frantically beneath the surface. As a result, some individuals appear 'non-autistic' in many situations. These findings contribute to the evidence that raise concerns that current autism assessment measures and diagnostic criteria lack sensitivity to female populations and may result in a diagnostic gender bias (Lai et al., 2015; D'Mello et al., 2022; Gould, 2017; Øien & Nordahl-Hansen, 2018; Rujeedawa & Zaman, 2022; Stroth et al., 2022).

Theme 2 (Emotional Well-being) summarised the intersection between mental health and masking, finding a bi-directional relationship between the two. It seemed that masking provided participants with a way of coping with the stressors of everyday life and the emotional challenges associated with living in a world designed for non-autistic people. However, masking could also negatively impact a participant's mental health, upholding the evidence linking masking and poor mental health outcomes (Bradley et al., 2021; Ross et al., 2023; Somerville et al., 2024). It also supported the concept of the "compressed spring" and "Jekyll and Hyde" character, whereby after masking and conforming all day, the contained emotional tension must be released (Attwood, 1997, p.39), thus likely resulting in emotional dysregulation, a need for decompression and eventual burn-out.

This theme also substantiated evidence suggesting masking may impact a person's identity (Bradley et al., 2021; Bargiela et al., 2016). Research suggests that self-identity formation begins in early childhood (Guardo & Bohan, 1971; Jackson et al., 2020). As such, masking from a young age may result in identity disconnection, due to moving between the authentic self and the masking self while navigating the social world. Over time, this may lead to self-estrangement where individuals are unable to distinguish between their true self and their masked self (Evans et al., 2024). Additionally, while masking may stem from a

desire for social connection, it seemed to unintentionally result in difficulties forming genuine connections, which may further contribute to a lack of authenticity and isolation, despite increased social involvement.

Theme 3 (Masking is a Safety Net) included reflections on masking as a necessary survival mechanism that helps individuals navigate a world that is not built with their needs in mind. The findings highlighted that masking serves an adaptive purpose and has value in certain contexts, similar to how a non-autistic person may employ a particular persona during specific situations (e.g., during an interview). Although arguably universal, masking behaviours may be employed more frequently and intensely by autistic people, often requiring significant energy and resulting in a substantial emotional cost (Bargiela et al., 2016; Bradley et al., 2021). However, some participants considered masking as preferable to the alternative. These findings suggest that masking is not inherently bad and that the goal should not be to eliminate masking, but to reduce the pressure to mask so that each individual has autonomy over when, where and how they mask.

Each participant described a unique journey of masking and unmasking (Theme 4; The (Un)Masking Journey). Participants reflected on how masking typically began at a young age and often coincided with commencing school, supporting the evidence that masking corresponds with the social development of a child (Petrolini et al., 2023). Masking appeared to start as an unconscious survival mechanism and many participants were initially unaware that their experiences were not typical. However, after learning about autism and becoming self-aware of masking, some participants consciously developed strategies to mask in certain situations to cope with the complexities of everyday life. For some, acceptance may be an important mechanism for unmasking. Participants reported an intentional shift to seek opportunities to unmask in later adolescence when they found accepting friends, entered

more accepting settings (e.g., college) and developed self-acceptance. However, fears of social judgment and unpicking established behaviours meant intentional unmasking was challenging for some individuals.

These findings suggest that reducing masking and "authentic self-disclosure" (Fox-Muraton, 2025, p. 293) can feel liberating with participants experiencing identity clarity, deeper connections, emotional relief, and improved mental well-being. However, as masking is an important safety mechanism for many individuals, eradication of masking should not be the goal, instead we should aim to support masking autonomy and independence for each person.

Clinical Implications

Autistic diagnostic criteria, screening measures and assessment tools and instruments may lack sensitivity to female populations, due to a male-biased understanding of autism (Lai et al., 2015; Constantino & Charman, 2012; D'Mello et al., 2022; Øien & Nordahl-Hansen, 2018; Rujeedawa & Zaman, 2022; Stroth et al., 2022). This research highlights the need for the development of appropriate gender-sensitive screening measures and diagnostic tools that consider the way autism may present differently across and within genders, including the presence of complex and highly refined masking behaviours. Furthermore, masking may emerge differently depending on independent and socialisation differences, upbringing, and environment, rather than being purely sex or gender dependent (Pearson & Rose, 2021). As such, it would be helpful to develop masking-sensitive tools that are effective across genders and autistic presentations.

Many strategies that aim to support autistic people draw on learning and behavioural theory principles, such as operant conditioning and reinforcement (Skinner, 1958). While these skills can be effective in developing skills and promoting change, their focus on

reducing behaviours seen as atypical and increasing behaviours seen as typical may inadvertently perpetuate pressure to mask by teaching autistic people to supress behaviours and conform to current societal norms (Evans et al., 2024). For example, social skills groups (Reichow & Volkmar, 2010) and social stories (Scattone et al., 2006) aim to teach individuals to respond and interact in neurotypical ways with the aim of increasing confidence and enhancing social and educational engagement. However, they may inadvertently promote suppression of authentic self-expression if used without sensitivity to an individual's needs and context. Similarly, applied behavioural analysis (ABA) which relies heavily on reinforcement and extinction, has been associated with increased levels of post-traumatic stress symptoms (Kupferstein, 2018) and social trauma (Evans et al., 2024), particularly when used in a rigid manner in autistic populations.

Considering this and the negative impact of masking for many autistic individuals, practitioners should seek to explore alternative coping strategies that are individualised and do not rely on suppressing the true self. Instead, work should focus on supporting individuals to live authentically (should they choose to), in everyday situations through creating a more inclusive society that accepts neurodivergent behaviours, making it safer to unmask when desired. Increasing the awareness of autism, masking and the female experience through teaching and training (e.g., in education, health, occupation and government settings) may lead to more inclusive practices and supportive environments that embrace autism and makes space for individual differences to help reduce the need for masking as a default mode (Cremin et al., 2021; Tipton & Blacher, 2014).

For individuals who would like to unmask, it may be helpful to develop specific interventions or practices to achieve this. Some resources already exist (e.g., Kemp, 2024;

Penot, 2024; Price, 2022), however it would be beneficial to undertake evidence-based research and subsequent national guidance to further this.

Limitations

This study did not include those without a formal diagnosis or assessment waiting list status. As a result, the study may have missed individuals who are exceptionally skilled at masking and were overlooked in diagnosis. However, focusing on individuals with a confirmed or pending diagnosis ensured that the findings were directly relevant to the experiences of autistic individuals and reduced the risk of inaccurate or inconsistent data that could arise from participants whose neurodevelopmental profile may not align with autism, thus enhancing the reliability of the study's results.

Despite attempts to recruit participants from a range of cultural and ethnic backgrounds, all study participants (and members of the research team) were White British. The conceptualisation and understanding of autism vary widely across cultures (Kim, 2012), and it is possible that many cultural norms and experiences were overlooked due to the lack of diversity in both the participant pool and research team. As such, the relevance of results may not be applicable to other cultures, ethnicities, or locations. This is particularly important when considering there is a lack of culturally sensitive screening and diagnostic tools (de Leeuw et al., 2020). and that autistic individuals from different cultural backgrounds may face additional challenges due to being disproportionately impacted by numerous health inequalities (Ames et al., 2022; Singh, 2023).

This study employed RTA; an interpretive method of analysis that relies on the data being analysed through the researcher’s lens. As a non-autistic researcher who is diagnosed with ADHD, it is inevitable that certain assumptions and biases informed the data analysis and theme development. Further, as RTA encourages depth and flexibility, it is possible for

over-interpretation, misunderstanding, or exaggeration of results, with conclusions that do not align with the participants' intended meaning. However, the study used an autistic EBE and engaged in reflexive activities to mitigate the risk of bias and over-interpretation of results and consider how the researcher's perspective may have influenced the results.

Lastly, this study has not explicitly considered the significant and valid debates around sex, gender and autism, including non-binary and gender-diverse perspectives. These discussions are key in developing a comprehensive and individual-focused understanding of autistic experiences and have significant implications for how concepts such as masking are conceptualised and applied. However, it was felt that this topic could not be sufficiently addressed in a manner that was sensitive, constructive and thoughtful, given time constraints and word count limits. The omission of this important topic should not be interpreted as a lack of recognition or relevance in this area. Instead, it underscores the need for future work to meaningfully integrate gender diverse perspectives and experiences into autism research.

Future Research

Future research could focus on repeating this study with self-identified autistics, including those who did not receive a diagnosis after assessment. This would offer a voice to a cohort that is often ignored and offer an opportunity for individuals who are adept at masking to provide contributions to this topic, thus increasing our awareness of autism in this cohort, and hopefully the development of more rigorous and sensitive diagnostic and assessment tools.

It may be valuable to conduct a longitudinal study following autistic adolescents who mask into adulthood, to explore and understand how masking is understood and experienced over time. It may also be helpful to include quantitative measures exploring associations between level or intensity of masking and ratings of different domains, such as confidence,

self-esteem, mental health and identity. Another interesting future research area would be to retrospectively explore how late-diagnosed adult autistic women made sense of masking in their teenage years. Although still deeply stigmatised, autism awareness and understanding in the public and professional sphere has significantly changed over time (Grinker, 2020) and it would be interesting to explore possible generational difference considering this.

While existing literature has illuminated gender differences in masking and its associations with social functioning and adaptation, literature gaps remain. For example, much of the current literature is cross-sectional and without longitudinal studies, the direction of causation for associations between masking and health outcomes cannot be confirmed (Lei et al., 2024). Furthermore, recent evidence suggests that masking should not solely be positioned as a facet of autism and instead may have a close association with anxiety. Lei et al. (2024) identified that higher levels of masking predicted elevated anxiety, even when controlling for autism characteristics. This suggests that masking may function as a coping response to anticipated social threat or stigma. This raises questions around masking and causality and whether masking may be a coping mechanism observed across neurotypes in response to perceived threat or stigma. Longitudinal and experimental studies are needed to determine the causality and relationship between anxiety, autism and masking. By addressing this gap, masking may be better understood across neurotypes, improving diagnostic accuracy and supporting development of better and more targeted interventions that reduce the needs for masking by creating a safer and more inclusive social environment.

Conclusion

This study highlighted the social nature of masking for adolescent autistic females and supported existing literature denoting masking as socially motivated, complex and nuanced. The findings suggest that females may experience significant social pressure to conform to

non-autistic behaviours and that skilled masking abilities may partially contribute to the female diagnostic delay, highlighting the need for gender- and masking-sensitive measures and instruments. The data also suggests a negative bi-directional relationship between masking and mental health, emphasising a need for alternative coping strategies that do not rely on masking and conforming.

There was a shared sense of masking being a “safety-net” that was helpful in some scenarios and better than the alternatives of possible judgement and harm from other people. Even so, for many participants there was a desire to unmask and be themselves, which was supported through acceptance from self and others. However, participants reported a fear of social judgement and masking as deeply ingrained, meaning intentional unmasking could be challenging. The findings suggest that rather than seeking to eliminate masking, the focus should be to empower individuals with the autonomy to choose when, where, and how they mask. Overall, participants felt society lacked awareness and understanding of masking. By increasing awareness and creating more inclusive and accepting environments (e.g., in education, healthcare, and wider society), the need for constant masking may reduce.

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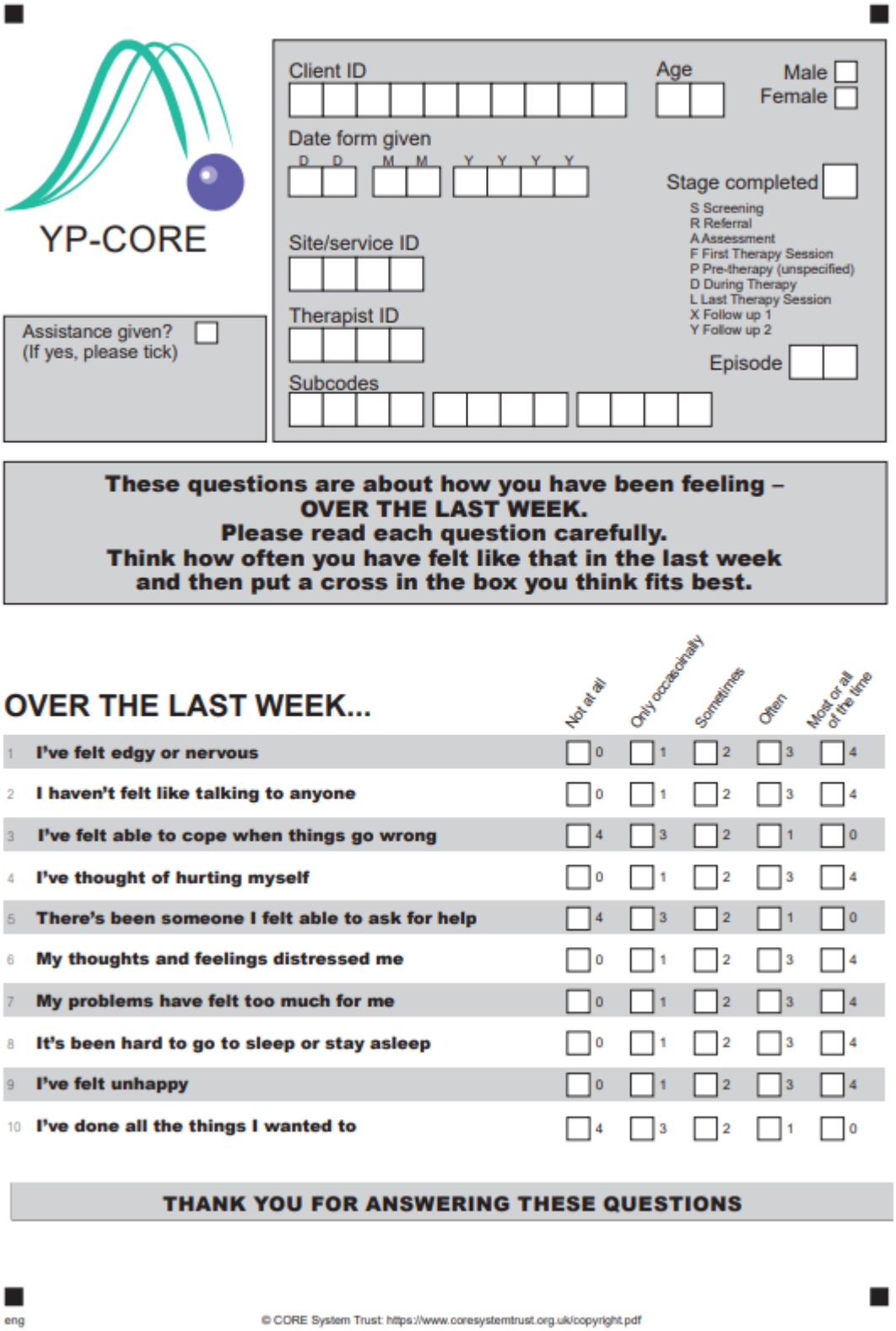
Supplementary Information A

YP-CORE



YP-CORE

Client ID

Age

Male ☐
Female ☐

Date form given
D D M M Y Y Y Y

Stage completed

S Screening
R Referral
A Assessment
F First Therapy Session
P Pre-therapy (unspecified)
D During Therapy
L Last Therapy Session
X Follow up 1
Y Follow up 2

Site/service ID

Therapist ID

Episode

Subcodes

Assistance given? ☐
(If yes, please tick)

These questions are about how you have been feeling – OVER THE LAST WEEK.
Please read each question carefully.
Think how often you have felt like that in the last week and then put a cross in the box you think fits best.

OVER THE LAST WEEK...	Not at all	Only occasionally	Sometimes	Often	Most or all of the time
1 I've felt edgy or nervous	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2 I haven't felt like talking to anyone	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3 I've felt able to cope when things go wrong	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
4 I've thought of hurting myself	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5 There's been someone I felt able to ask for help	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
6 My thoughts and feelings distressed me	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7 My problems have felt too much for me	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8 It's been hard to go to sleep or stay asleep	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9 I've felt unhappy	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10 I've done all the things I wanted to	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

THANK YOU FOR ANSWERING THESE QUESTIONS

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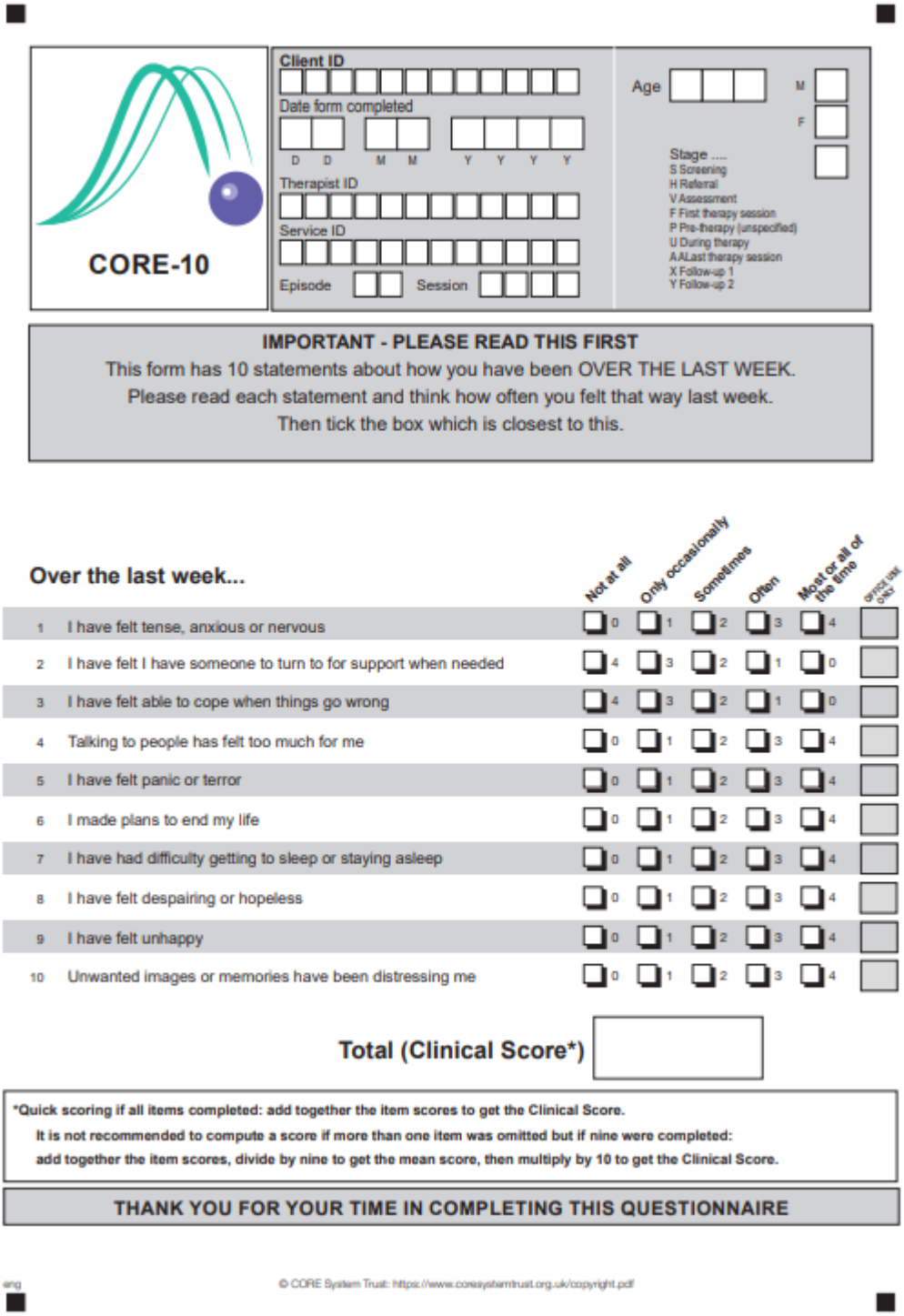
Supplementary Information B

CORE -10



CORE-10

Client ID

Date form completed

D D M M Y Y Y Y

Therapist ID

Service ID

Episode Session

Age M F

Stage ....
S Screening
H Referral
V Assessment
F First therapy session
P Pre-therapy (unspecified)
U During therapy
A ALast therapy session
X Follow-up 1
Y Follow-up 2

IMPORTANT - PLEASE READ THIS FIRST

This form has 10 statements about how you have been OVER THE LAST WEEK.
Please read each statement and think how often you felt that way last week.
Then tick the box which is closest to this.

Over the last week...	Not at all	Only occasionally	Sometimes	Often	Most or all of the time	OFFICE USE ONLY
1 I have felt tense, anxious or nervous	0	1	2	3	4	
2 I have felt I have someone to turn to for support when needed	4	3	2	1	0	
3 I have felt able to cope when things go wrong	4	3	2	1	0	
4 Talking to people has felt too much for me	0	1	2	3	4	
5 I have felt panic or terror	0	1	2	3	4	
6 I made plans to end my life	0	1	2	3	4	
7 I have had difficulty getting to sleep or staying asleep	0	1	2	3	4	
8 I have felt despairing or hopeless	0	1	2	3	4	
9 I have felt unhappy	0	1	2	3	4	
10 Unwanted images or memories have been distressing me	0	1	2	3	4	

Total (Clinical Score*)

*Quick scoring if all items completed: add together the item scores to get the Clinical Score.
It is not recommended to compute a score if more than one item was omitted but if nine were completed:
add together the item scores, divide by nine to get the mean score, then multiply by 10 to get the Clinical Score.

THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE

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Supplementary Information C

CAT-Q

Self-Report Camouflaging Autistic Traits Questionnaire

Please read each statement below and choose the answer that best fits your experiences during social interactions.

Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Neither Agree nor Disagree (4)	Somewhat Agree (5)	Agree (6)	Strongly Agree (7)

1. When I am interacting with someone, I deliberately copy their body language or facial expressions
2. I monitor my body language or facial expressions so that I appear relaxed
3. I rarely feel the need to put on an act in order to get through a social situation*
4. I have developed a script to follow in social situations (for example, a list of questions or topics of conversation)
5. I will repeat phrases that I have heard others say in the exact same way that I first heard them
6. I adjust my body language or facial expressions so that I appear interested by the person I am interacting with
7. In social situations, I feel like I'm 'performing' rather than being myself
8. In my own social interactions, I use behaviours that I have learned from watching other people interacting
9. I always think about the impression I make on other people
10. I need the support of other people in order to socialise
11. I practice my facial expressions and body language to make sure they look natural
12. I don't feel the need to make eye contact with other people if I don't want to*
13. I have to force myself to interact with people when I am in social situations
14. I have tried to improve my understanding of social skills by watching other people
15. I monitor my body language or facial expressions so that I appear interested by the person I am interacting with
16. When in social situations, I try to find ways to avoid interacting with others

Hull, L., Mandy, M., Lai, M-C., Baron-Cohen, S., Allison, C., Smith, P. & Petrides, KV. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q) (2018). *Journal of Autism & Developmental Disorders, 49*(3), 819-833.

17. I have researched the rules of social interactions (for example, by studying psychology or reading books on human behaviour) to improve my own social skills
18. I am always aware of the impression I make on other people
19. I feel free to be myself when I am with other people*
20. I learn how people use their bodies and faces to interact by watching television or films, or by reading fiction
21. I adjust my body language or facial expressions so that I appear relaxed
22. When talking to other people, I feel like the conversation flows naturally*
23. I have spent time learning social skills from television shows and films, and try to use these in my interactions
24. In social interactions, I do not pay attention to what my face or body are doing*
25. In social situations, I feel like I am pretending to be 'normal'

Scoring:

All items are scored 1-7, with higher scores reflecting greater camouflaging. Items with an asterisk (*) should be reverse scored.

Factors:

Compensation (behaviours used to compensate for autism-related difficulties in social situations) = 1, 4, 5, 8, 11, 14, 17, 20, 23

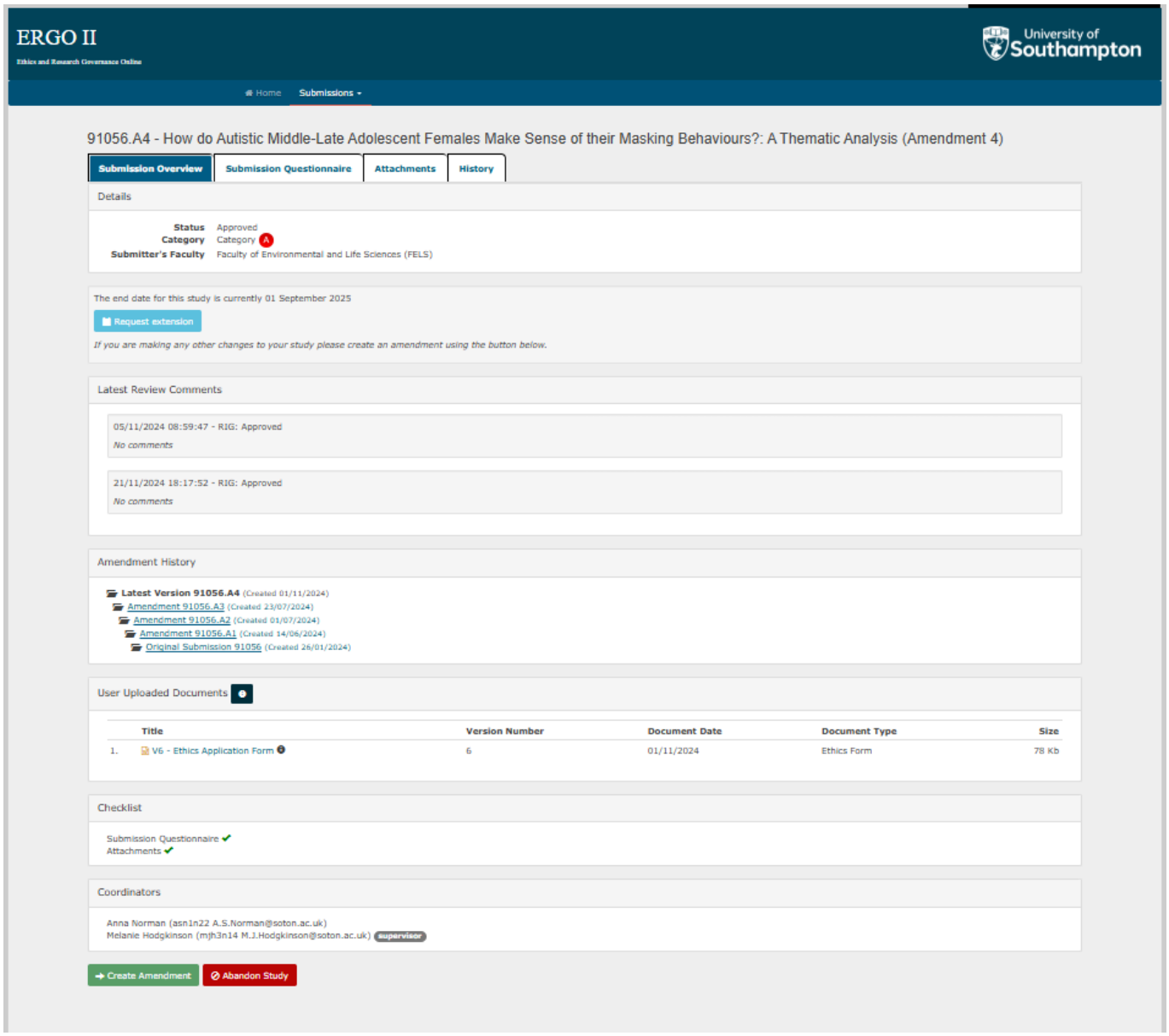
Masking (behaviours used to hide autistic characteristics or present a non-autistic personality) = 2, 6, 9, 12, 15, 18, 21, 24

Assimilation (behaviours used to fit in with others/not stand out from the crowd) = 3, 7, 10, 13, 16, 19, 22, 25

Hull, L., Mandy, M., Lai, M-C., Baron-Cohen, S., Allison, C., Smith, P. & Petrides, KV. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q) (2018). *Journal of Autism & Developmental Disorders, 49*(3), 819-833.

Supplementary Information D

University Ethics Application Approval



ERGO II
Ethics and Research Governance Online

University of Southampton

Home | Submissions

91056.A4 - How do Autistic Middle-Late Adolescent Females Make Sense of their Masking Behaviours?: A Thematic Analysis (Amendment 4)

Submission Overview | Submission Questionnaire | Attachments | History

Details

Status Approved
Category Category A
Submitter's Faculty Faculty of Environmental and Life Sciences (FELS)

The end date for this study is currently 01 September 2025

Request extension

If you are making any other changes to your study please create an amendment using the button below.

Latest Review Comments

05/11/2024 08:59:47 - RIG: Approved
No comments

21/11/2024 18:17:52 - RIG: Approved
No comments

Amendment History

Latest Version 91056.A4 (Created 01/11/2024)
Amendment 91056.A3 (Created 23/07/2024)
Amendment 91056.A2 (Created 01/07/2024)
Amendment 91056.A1 (Created 14/06/2024)
Original Submission 91056 (Created 26/01/2024)

User Uploaded Documents

	Title	Version Number	Document Date	Document Type	Size
1.	V6 - Ethics Application Form	6	01/11/2024	Ethics Form	78 Kb

Checklist

Submission Questionnaire ✔
Attachments ✔

Coordinators

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Melanie Hodgkinson (mjh3n14 M.J.Hodgkinson@soton.ac.uk) supervisor

Create Amendment | Abandon Study

Supplementary Information E

Screening and Demographic Questionnaire

Screening and Demographic Questionnaire

To check whether you meet the criteria for this study, please complete all of the questions below:

Name	
Age	
Ethnicity	What best describes you (please tick): o Asian or Asian British o Black, Black British, Caribbean or African o Mixed or multiple ethnic groups o White o Other ethnic group
Gender	What do you identify as: o Woman/girl o Man/boy o Transwoman/transgirl o Transman/transboy o Non-binary/genderqueer/agender/gender fluid o I don't know o Prefer not to say o Other
Autism Status	What best describes you (please tick): o I have a confirmed diagnosis of autism. o I am on the waitlist for an autism assessment. o I do not have autism, and I am not on a waitlist for an autism assessment.
Service Type	Which type of service are you/were you under for your autism assessment (please tick the most accurate option): o NHS o Private o Both (e.g., you were under the NHS, and they passed your details to a private provider to carry out your assessment)
Please tell me how you came to get a referral for an autism assessment (e.g., did you complete any screening questionnaires in advance, did you meet with a clinician before referral, or something else?)	

Supplementary Information F

Interview Protocol

Introduction	• Aims • Reminder of rights, e.g., can pause/stop/withdraw, do not have to answer anything you do not want to • Confidentiality • Structure of interview
Definition	Masking refers to ways a person can blend into their social surroundings, or present themselves as different from who they are, or to hide behaviours that they think might make them stand out in some way. Masking can be used by both neurodiverse and non-autistic people. For example, I tend to behave differently at work, then when I am at home. But for some people masking is more than this, and many autistic people will mask in lots of different situations. This might mean acting, talking, and/or dressing a certain way in order to fit in with a social group. It may also go deeper than this and autistic people may feel they have to mask certain behaviours to try and hide their autism in social situations. So, in summary masking is a way of changing ourselves to be deemed appropriate, or to fit in, with the groups we want to be included in.
Opening question	• Can you tell me about your experiences of masking?
Presentation	• Can we think together about what masking looks like for you? - What might you do when masking? - What might you not do when masking? - Are there any times or places when you might mask more or less? - If I could see you when you mask, what might I notice? - Are you always aware that you are masking?
Motivations	• Can you tell me a little bit about why you think you might mask? - What do you "get" out of masking? - What do you avoid by masking?
Impact	• Is there anything that you find helpful about masking? • Is there anything that you find unhelpful about masking? • Can you tell me about the impact of masking on your life on: - social life - mental health - education - physical health - any other consequences or areas of your life that is impacted by masking?
Others' perceptions	• Can you tell me how other people might make sense of your masking behaviours? E.g., mum, teachers, your friends… - Do you think they understand why you mask? - Do you think they notice when you are masking? • Is there anything you would like other people to know about your experiences of masking? - Any advice? - Any information?

Supplementary Information G

Excerpt from Field Notes

Date: 28.10.2024 Time: 10.30
Location: Microsoft Teams
Participant: P1

First impressions: P1 appeared nervous and may have masked initially. With some rapport building and reassurance she seemed to settle and appeared to mask less (e.g., less eye contact and more looking around the room). P1 was very insightful and thoughtful in her responses. It felt like P1 was well read on both autism and masking. The interview felt fairly conversational. Her mum was present, who remained quiet throughout, although did share afterwards that this was difficult and that she experienced/understood/remembered P1's masking differently in some ways.

Reflections: I felt that my topic guide covered most of the main areas that P1 raised, although I added two additional points from this interview to ask in future interviews (age they first started/noticed masking and how masking has changed over time). The topic of feeling tired came up several times and I wonder if this may be a reoccurring theme throughout. After interviewing P1, I realised that my own experience of feeling tired after socialising and may be influencing how I interpreted this discussion. Having struggled with feeling exhausted after being at school/college/work myself, I feel very connected to P1's experience. I need to remain aware of this and consider how this may influence my responses to conversations, follow-up questions and my analysis.

Date: 28.10.2024 Time: 14.00
Location: Microsoft Teams
Participant: P4

First impressions: P4 seemed happy to engage and was very articulate and reflective in her responses. Her mum was present and often spoke for her during the introduction. After explaining that this was a session for P4 specifically, the mum agreed to give her daughter the opportunity to share without her, although acknowledged this would be difficult as she had to do this for the autism assessment and struggled. P4 was very open with me, which allowed for a conversation style throughout, and we sometimes deviated from the topic guide. On a couple of occasions her mum tried to answer for her, but this was managed well, and P4 was able to provide her own thoughts and experiences. It seemed that having her mum there was comforting to P4 and they seemed to have a close relationship.

Reflections: The topic of exhaustion came up again, as did the desire to fit in and feeling inauthentic. It was also interesting to hear about how P4 saw masking as uncomfortable but that it was worth it to reduce the uncomfortableness of possibly not fitting in/being judged. She likened it to a safety net that she would not give up as it allows her to fit in. I became aware that I need to remain open to different perspectives. Although I have my own understanding of masking, some participants may have found positive aspects that I may miss

Supplementary Information H

Reflexive Journal

Empirical Research Reflexive Journal (Data Analysis stage):

Reflection

I observed that several participants shared similar experiences, resulting in overlapping of many codes that I will have to amalgamate. While there are themes emerging, all participants journeys are completely unique to them.

Reflexivity

As a researcher who has ADHD, I wonder whether my interpretation of the data is influenced by my own experiences of being neurodiverse. I notice that I feel connected to many of the participants experiences, particularly those who discussed their identity and are learning to unmask in different situations.

I noticed a real connection and felt particularly moved by one participant (6) and her reflections on identity. I noticed that I spent more time coding her transcript and understanding her narrative – was I just engaging deeply, or perhaps over-identifying and over-interpreting?

Reflection

I have observed that masking seems socially driven for all participants but their behaviours and the way they mask and the social reason that they mask is unique and individual to them, possibly due to their past experiences but also where they are in life now.

Reflexivity

I wonder whether I noticed this pattern as I am interested, I have worked with many patients in the past who have wanted to understand their masking motivations and this particular thread has really caught my eye as it is helping me to retrospectively understand some of my patients in a deeper way. Working with patients who masked and have explored this in sessions also helped me recognise certain patterns, language and connections, which helped me draw out particular nuances. However, I had to check myself several times to make sure I was not over interpreting the participants experiences.

Reflection

I have also observed the beginnings of an association between masking and mental health and emotional well-being.

Reflexivity

This is not surprising as I have read so much research highlighting this association. I wonder whether my prior knowledge in this area guided my analysis in any way, almost as if I was expecting it to come from the data. As someone who struggled with mental health during adolescence, I do wonder whether I may be particularly attuned to narratives around this, and the emotional struggles related to masking and mental health. These stories resonate with my own journey and may make me quicker to connect to points that reflect this pattern.

Reflection

I have noticed that my understanding of masking is changing.

Reflexivity

Initially, my understanding of masking was that it was both good and bad. I know see it as neither. I see it as something that is infinitely complex and completely unique to each person. It can be protective, damaging, strategic, supportive, a lifeline, exhausting, and so much more. The term “safety net” has really resonated with me and I wonder whether this is because I can “feel” this concept myself. Initially, my understanding of masking was simple and rigid. It is now messier but more complex.

Reflection

I have started clustering codes into themes and am aware that this is not just down to frequency.

Reflexivity

I have asked myself HOW I made these decisions. As I go through this process, I am noticing that a multitude of things influence my decision. While the frequency of codes/themes has been key, I have identified the themes partly due to the participants emotional response or connection. I again wonder if my own personal resonance with them may have influenced these decisions and have had to check in with myself several times.

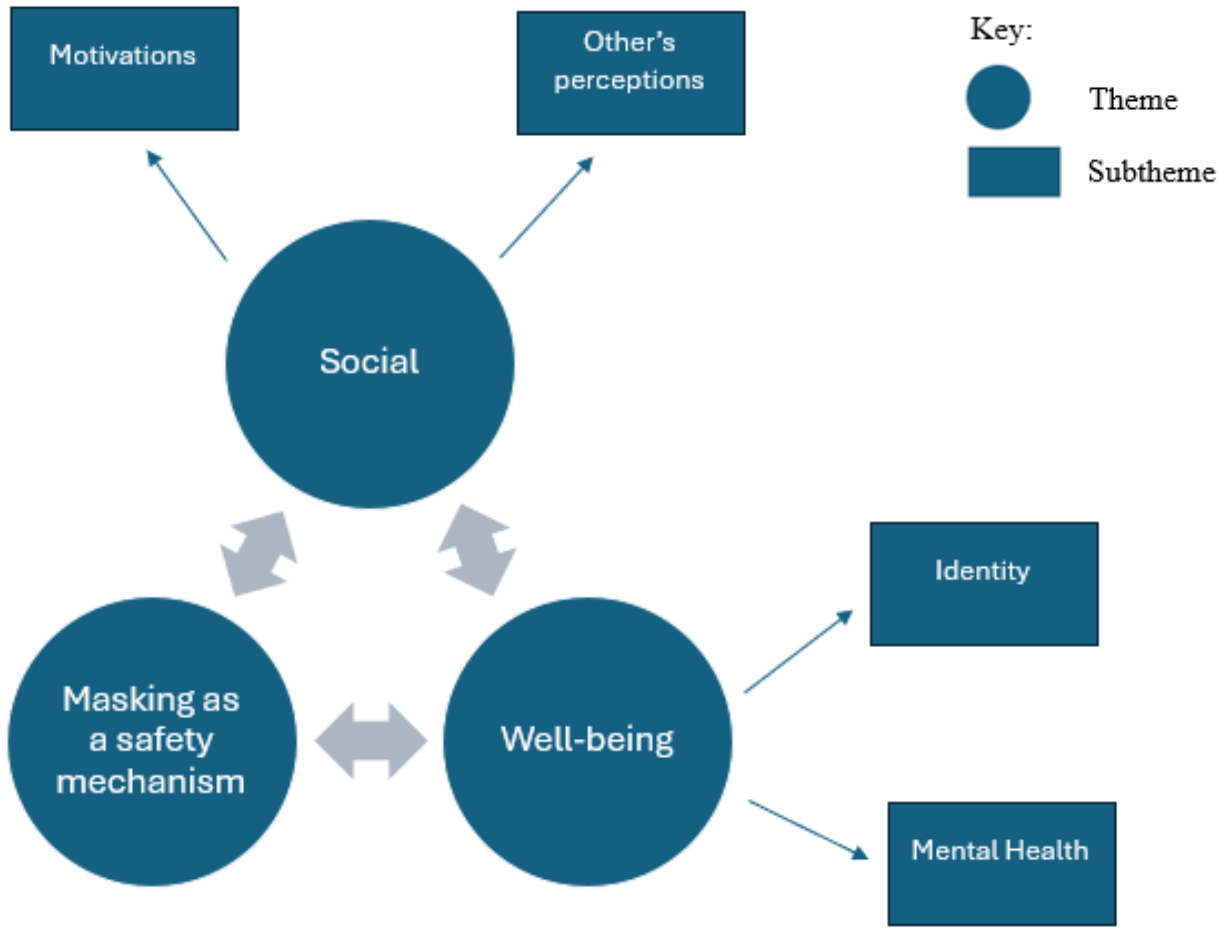
Supplementary Information I

Excerpt from Codebook

Code	Illustrative Quote	Participant
A professional first raised the possibility of masking	like, I think in like a CAMHS session or something she mentioned that it might be masking without realising it. It was just…	1
A system for masking	for different situations. So like just trying to like figure out like an actual system for it, so it's been a long time before I was able…	6
Able to form closer relationships when unmasked	be closer to my friends because I'm like actually like acting more like who I actually am so I feel like I can form closer relationships with people…	1
Able to unmask when they feel understood	the people since I was very young and like they, kind of, understood me more and seemed to like just let me be myself. And…	4
Able to unmask with mum	will probably get quite upset. It's like my mum, I think, I don't really do that with her and so my facial expressions come out with my mum.	10
Acceptance of being autistic	And so, I think that I would rather be emotionally intelligent and have autism than not have autism and be like other people.	10
Acting different at school and home	I feel like I do have different personalities at home and at school, because like, I feel like I need to be more like other people at school…	8
Actively learnt and practiced social norms	remember when I was younger I had an iPad and I videoed myself making different facial expressions in the iPad so I could watch…	2

Supplementary Information J

Initial Thematic Map



Appendix A

Research in Autism's Guide for Authors

After discussion with the supervisory team, it was agreed to include a URL link to Research in Autism's guide for authors, in replacement of the full guide due to the substantial length of the guidance:

https://www.sciencedirect.com/journal/research-in-autism/publish/guide-for-authors

Following discussion with the supervisory team, there are some minor exceptions to ensure the thesis report is also in accordance with the Universities thesis recommendations:

1. Labelling of tables to differentiate between Chapter Two and Three
2. Word count requirements: it has been agreed that for the purpose of thesis submission, this chapter may exceed the journal's word limit as the content is relevant to the thesis requirements. At point of submission, the manuscript will be edited to meet word count criteria.

Appendix B

CASP Quality Assessment Tool

CASP Checklist:

For Qualitative Research

Reviewer Name:	
Paper Title:	
Author:	
Web Link:	
Appraisal Date:	

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐ Yes ☐ No ☐ Can't Tell

CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	
5. Was the data collected in a way that addressed the research issue?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	☐ Yes ☐ No ☐ Can't Tell

CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	
8. Was the data analysis sufficiently rigorous?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	
Section C: Will the results help locally?	
10. How valuable is the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature* • *If they identify new areas where research is necessary*	

- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*		
Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**

Referencing recommendation:

CASP recommends using the Harvard style referencing, which is an author/date method. Sources are cited within the body of your assignment by giving the name of the author(s) followed by the date of publication. All other details about the publication are given in the list of references or bibliography at the end.

Example:

Critical Appraisal Skills Programme (2024). CASP (insert name of checklist i.e. systematic reviews with meta-analysis of randomised controlled trials (RCTs) Checklist.) [online] Available at: insert URL. Accessed: insert date accessed.

Creative Commons

Appendix C

Journal of Autism and Developmental Disorders Submission Guidelines

After discussion with the supervisory team, it was agreed to include a URL link to Journal of Autism and Developmental Disorders submission guidelines, in replacement of the full guide due to the substantial length of the guidance:

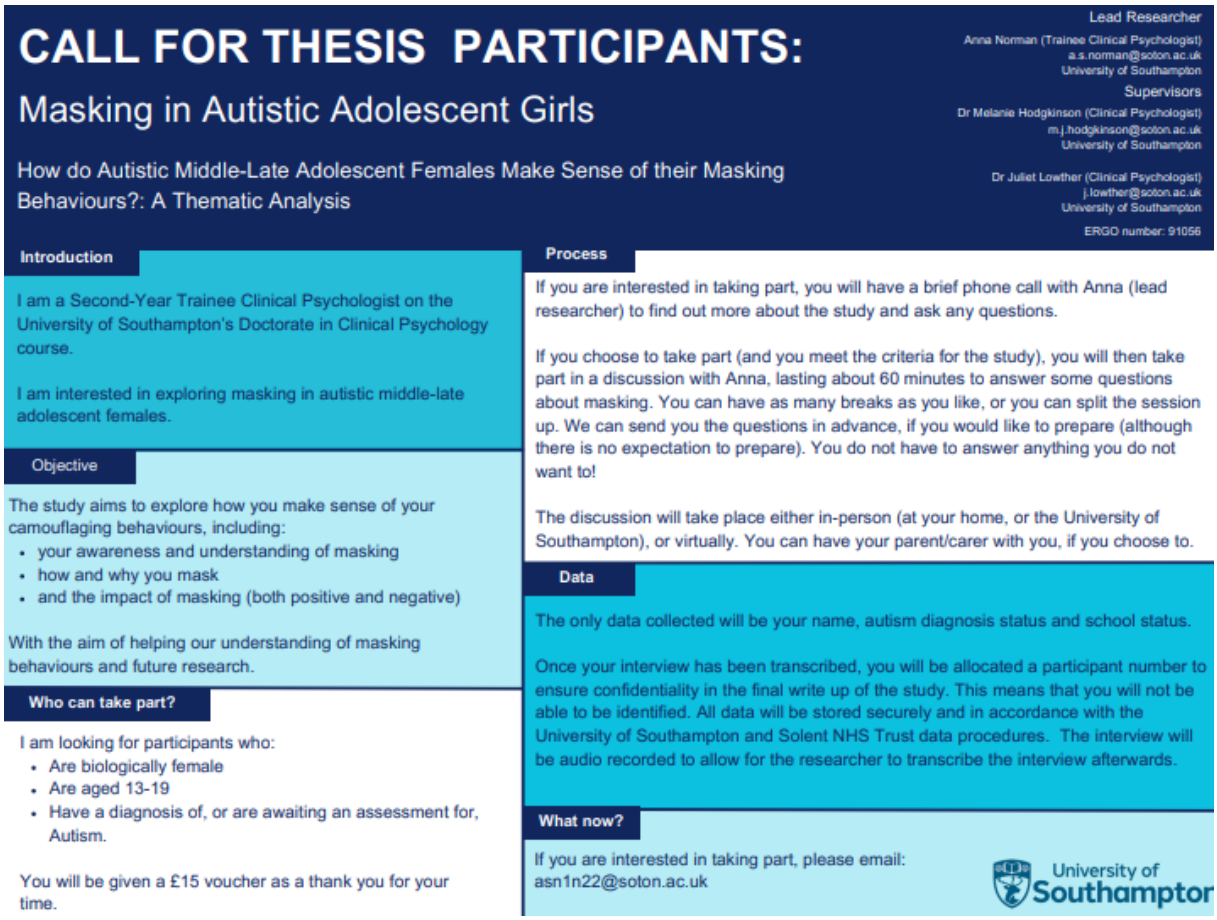
https://link.springer.com/journal/10803/submission-guidelines

Following discussion with the supervisory team, there are some minor exceptions to ensure the thesis report is also in accordance with the Universities thesis recommendations and/or to improve readability:

1. Labelling of tables to differentiate between Chapter Two and Three.
2. Inclusion of tables and figures embedded in text.
3. Five levels of displayed headings used.
4. Word count requirements: it has been agreed that for the purpose of thesis submission, this chapter may exceed the journal's word limit as the content is relevant to the thesis requirements. At point of submission, the manuscript will be edited to meet word count criteria.

Appendix D

Study Advert



Appendix E

Consent Form (Age 13-15)

CONSENT FORM (age 13-15)

Study Title: How do Autistic Middle-Late Adolescent Females Make Sense of their Camouflaging Behaviours?: A Thematic Analysis
Researcher: Anna Norman (Trainee Clinical Psychologist); Dr Melanie Hodgkinson (Clinical Psychologist); Dr Juliet Lowther (Clinical Psychologist).
ERGO number: 91056

Please initial the box(es) if you agree with the statement(s):

I have read and understood the participant information sheet [08.04.2024/Version 2] and have had the opportunity to ask questions about the study.	
I agree to take part in this study and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw from the study within 2 weeks following interview, for any reason and without my participation rights being affected.	
I understand that if I withdraw from the study that it may not be possible to remove the data once my personal information is no longer linked to the data.	
I understand that any personal information collected about me such as my name will not be shared beyond the study team.	
I understand that I will not be directly identified in any reports of the study.	
I understand that I may be quoted directly in reports of the study but that I will not be directly identified (e.g., that my name will not be used).	
I understand that I will be quoted directly in reports of the study and that age, autism diagnosis status and school status/year group may be included.	
I understand that taking part in the study involves audio recording (via a Dictaphone, or Microsoft Teams) which will be transcribed by a transcription service (PageSix) and then destroyed for the purposes set out in the participation information sheet.	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that these will be recorded using audio.	

Name of participant (print name):	
Date:	

Signature:	
Name of parent/carer (print name):	
Date:	
Signature:	
Name of researcher:	
Date:	
Signature:	

Appendix F

Consent Form (Age 16-19)

CONSENT FORM (age 16-19)

Study Title: How do Autistic Middle-Late Adolescent Females Make Sense of their Masking Behaviours?: A Thematic Analysis

Researcher: Anna Norman (Trainee Clinical Psychologist); Dr Melanie Hodgkinson (Clinical Psychologist); Dr Juliet Lowther (Clinical Psychologist).

ERGO number: 91056

Please initial the box(es) if you agree with the statement(s):

I have read and understood the participant information sheet [08.04.2024/Version 2] and have had the opportunity to ask questions about the study.	
I agree to take part in this study and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw from the study within 2 weeks following interview, for any reason and without my participation rights being affected.	
I understand that if I withdraw from the study that it may not be possible to remove the data once my personal information is no longer linked to the data.	
I understand that my personal information collected about me such as my name will not be shared beyond the study team.	
I understand that I will not be directly identified in any reports of the study.	
I understand that I may be quoted directly in reports of the study but that I will not be directly identified (e.g., that my name will not be used).	
I understand that I will be quoted directly in reports of the study and that age, autism diagnosis status and school status/year group may be included.	
I understand that taking part in the study involves audio recording (via a Dictaphone, or Microsoft Teams) which will be transcribed by a transcription service (PageSix) and then destroyed for the purposes set out in the participation information sheet.	

I agree to take part in the interview for the purposes set out in the participation information sheet and understand that these will be recorded using audio.	

Name of participant (print name):	
Date:	
Signature:	
Name of researcher:	
Date:	
Signature:	

Appendix G

Consent Form (Parent/Carer)

CONSENT FORM (parent/carer's)

Study Title: How do Autistic Middle-Late Adolescent Females Make Sense of their Masking Behaviours?: A Thematic Analysis

Researcher: Anna Norman (Trainee Clinical Psychologist); Dr Melanie Hodgkinson (Clinical Psychologist); Dr Juliet Lowther (Clinical Psychologist).

ERGO number: 91056

Please initial the box(es) if you agree with the statement(s):

I have read and understood the participant information sheet [08.04.2024/Version 2] and have had the opportunity to ask questions about the study.	
I agree for my child to take part in this study and agree for my child's data to be used for the purpose of this study.	
I understand my child's participation is voluntary and that my child may withdraw from the study within 2 weeks following interview, for any reason and without my child's participation rights being affected.	
I understand that if my child withdraws from the study that it may not be possible to remove the data once my child's personal information is no longer linked to the data.	
I understand that any personal information collected about my child such as my child's name will not be shared beyond the study team.	
I understand that my child will not be directly identified in any reports of the study.	
I understand that my child may be quoted directly in reports of the study but that my child will not be directly identified (e.g., that my child's name will not be used).	
I understand that my child will be quoted directly in reports of the study and that age, autism diagnosis status and school status/year group may be included.	

I understand that taking part in the study involves audio recording (via a Dictaphone, or Microsoft Teams) which will be transcribed by a transcription service (PageSix) and then destroyed for the purposes set out in the participation information sheet.	
I agree for my child to take part in the interview for the purposes set out in the participation information sheet and understand that these will be recorded using audio.	

Name of participant (print name):	
Name of parent/carer (print name):	
Date:	
Signature:	
Name of researcher:	
Date:	
Signature:	

Appendix H

Participant Information Sheet

Participant Information Sheet

Study Title: How do Autistic Middle-Late Adolescent Females Make Sense of their Masking Behaviours?: A Thematic Analysis

Researcher: Anna Norman (Trainee Clinical Psychologist); Dr Melanie Hodgkinson (Clinical Psychologist); Dr Juliet Lowther (Clinical Psychologist).

ERGO number: 91056

You are being invited to take part in the above study. To help you decide whether you would like to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this study. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?
I am a Second-Year Trainee Clinical Psychologist on the University of Southampton's Doctorate in Clinical Psychology course.

I am interested in exploring masking behaviours in autistic middle-late adolescent females.

The study aims to explore how you make sense of your masking behaviours, including your awareness and understanding of masking, how and why you mask and the impact of masking (both negative and positive), to help inform our understanding of masking behaviours and future research.

What is masking?

- Video: Autism and Masking, Purple Ella: https://www.youtube.com/watch?v=2gOZFK9H5dQ&t=43s
- Video: The Problem with Masking ADHD and Autism (burnout, etc.): https://www.youtube.com/watch?v=Jk-FtgGV8I8

- Graphic Novel: Camouflage: The Hidden Lives of Autistic Women by Dr Sarah Bargiela (2019)
- Guide for Parents: Taking Off the Mask: Practical Exercises to Help Understand and Minimise the Effects of Autistic Camouflaging by Dr Hannah Louise Belcher

Why have I been asked to participate?
You have been asked to participate as you are a biological female, aged 13-19 and have, or are awaiting an assessment for, Autism.

What will happen to me if I take part?
Should you choose to take part, you will be invited to have a discussion with the lead researcher, with questions that aim to explore how you make sense of your masking behaviours.

Should you choose to take part, questions will be sent to you in advance to give you time to review and prepare (if you would like to, although there is no expectation for you to prepare if you do not want to).

The discussion will last no longer than 60 minutes, although you can have as many breaks as you like, or the discussion can be split into multiple sessions.

You do not have to answer anything that you do not want to.

The discussion will take place either in-person at the University of Southampton, your home, or virtually (via Microsoft Teams).

The discussion will be audio recorded (via Dictaphone, or Microsoft Teams) to allow for the discussion to be transcribed afterwards.

Recorded discussions will be transcribed verbatim by a transcription service (PageSix) and anonymised for analysis. The transcription service will maintain confidentiality and is approved by the University.

Are there any benefits in my taking part?

If you choose to participate, you will be given a £15 voucher as a thank you for your time.

Additionally, this study does aim to better our understanding of masking behaviours, inform future research and possibly improve support for people with Autism who mask.

Are there any risks involved?
There are no significant risks involved in taking part in this study. However, some questions asked are related to sensitive issues and personal experiences, which can result in psychological discomfort or distress for some people. You are entitled to pause or stop the discussion at any point, should this occur, and you will be provided with the details of support services you can contact (including Mind). You will also be given a debrief form following taking part which will include support services, should you require them.

Sources of Support:
https://www.mind.org.uk/
https://www.autism.org.uk/

What data will be collected?

The only data collected will be your name, autism diagnosis status (whether you are diagnosed, or awaiting an assessment) and whether you are in school/education (including your year group).

Will my participation be confidential?
Your participation and the information we collect about you during the course of the study will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the study is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a study participant, strictly confidential.

The only data collected will be your name, autism diagnosis status (whether you are diagnosed, or awaiting an assessment) and whether you are in school/education (including your year group). Once your discussion has been transcribed by a transcription service (PageSix), you will be allocated a participant number and any potentially identifying data will be removed from transcripts, to eradicate the risk of identification and ensure confidentiality in the final write up of the study. No other identifiable data will be collected. The transcription service will maintain confidentiality and is approved by the University.

Personal data (e.g., consent forms) will be handled securely and stored in accordance with the University of Southampton and Solent NHS Trust data

procedures. Any hard data will be stored in a lockable cabinet on the University of Southampton campus.

Audio recordings will be password-protected and stored securely on a University of Southampton device whilst the data is transcribed. The audio recordings will then be stored/destroyed in accordance with the University of Southampton and Solent NHS Trust data procedures. Transcriptions will be password-protected and stored securely on a University of Southampton device.

Do I have to take part?
No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

If you would like to take part, please contact Anna Norman (Trainee Clinical Psychologist) via email: a.s.norman@soton.ac.uk.

What happens if I change my mind?
You have the right to change your mind and withdraw from the study within 2 weeks following interview, for any reason/without giving a reason and without your participant rights being affected.

If you would like to withdraw, please contact Anna Norman (Trainee Clinical Psychologist) via email: a.s.norman@soton.ac.uk.

What will happen to the results of the research?
Your personal details will remain strictly confidential. Study findings will be presented in a report and submitted to the University of Southampton as part of a research module. Findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Where can I get more information?
If you would like any further information, please contact Anna Norman (Trainee Clinical Psychologist) via email: a.s.norman@soton.ac.uk.

What happens if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

Researcher: Anna Norman (Trainee Clinical Psychologist) via email: a.s.norman@soton.ac.uk.
Supervisor: Dr Melanie Hodgkinson (Clinical Psychologist), via email: m.j.hodgkinson@soton.ac.uk

Secondary supervisor: Dr Juliet Lowther (Clinical Psychologist), via email: j.lowther@soton.ac.uk
If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice
The University of Southampton conducts research to the highest standards of research integrity. As a publicly funded organisation, the University has to ensure that it is in the public interest when we use personally identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking time to read this and considering taking part in this study.

Appendix I

University of Southampton Ethics and Research Governance Online II (ERGO II) ethical approval

Appendix J

Debriefing Sheet

Debriefing Form

Study Title: How do Autistic Middle-Late Adolescent Females Make Sense of their Masking Behaviours?: A Thematic Analysis

Researcher: Anna Norman (Trainee Clinical Psychologist); Dr Melanie Hodgkinson (Clinical Psychologist); Dr Juliet Lowther (Clinical Psychologist).

ERGO number: 91056

University email(s): a.s.norman@soton.ac.uk

Version and date: 08.04.2024/Version 2

Thank you for taking part in our study. Your contribution is very valuable and greatly appreciated.

Purpose of the study
The aim of this study is to explore how autistic middle-late adolescent females make sense of their masking behaviours, including their understanding of masking, how and why they mask and the impact of masking (both negative and positive). Your data will help us to understand masking behaviours and inform future research.

Confidentiality
Results of this study will not include your name. The study will include some quotes from your interview and your age.

Study results
If you would like to receive a copy of the dissertation when it is completed, please let us know by using the contact details provided on this form.

Further support
If taking part in this study has caused you discomfort or distress, you can contact the following organisations for support:

https://www.mind.org.uk/
https://www.autism.org.uk/

Further reading

If you would like to learn more about masking, you can refer to the following resources:

What is masking?

- Video: Autism and Masking, Purple Ella: https://www.youtube.com/watch?v=2gOZFK9H5dQ&t=43s
- Video: The Problem with Masking ADHD and Autism (burnout, etc.): https://www.youtube.com/watch?v=Jk-FtgGV8I8
- Graphic Novel: Camouflage: The Hidden Lives of Autistic Women by Dr Sarah Bargiela (2019)
- Guide for Parents: Taking Off the Mask: Practical Exercises to Help Understand and Minimise the Effects of Autistic Camouflaging by Dr Hannah Louise Belcher

https://21andsensory.wordpress.com/2019/09/29/what-is-masking-%F0%9F%8E%AD/
https://21andsensory.wordpress.com/2019/09/29/what-is-masking-%F0%9F%8E%AD/

If you would like to learn more about this area of research, you can refer to the following research studies:

- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. Journal of autism and developmental disorders, 47, 2519-2534.
  - https://link.springer.com/article/10.1007/s10803-017-3166-5
- Chapman, L., Rose, K., Hull, L., & Mandy, W. (2022). "I want to fit in … but I don't want to change myself fundamentally": A qualitative exploration of the relationship between masking and mental health for autistic teenagers. Research in Autism Spectrum Disorders, 99, 102069.
  - https://www.sciencedirect.com/science/article/pii/S1750946722001568

Further information

If you have any concerns or questions about this study, please contact Anna Norman (Trainee Clinical Psychologist) on a.s.norman@soton.ac.uk, who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this study.