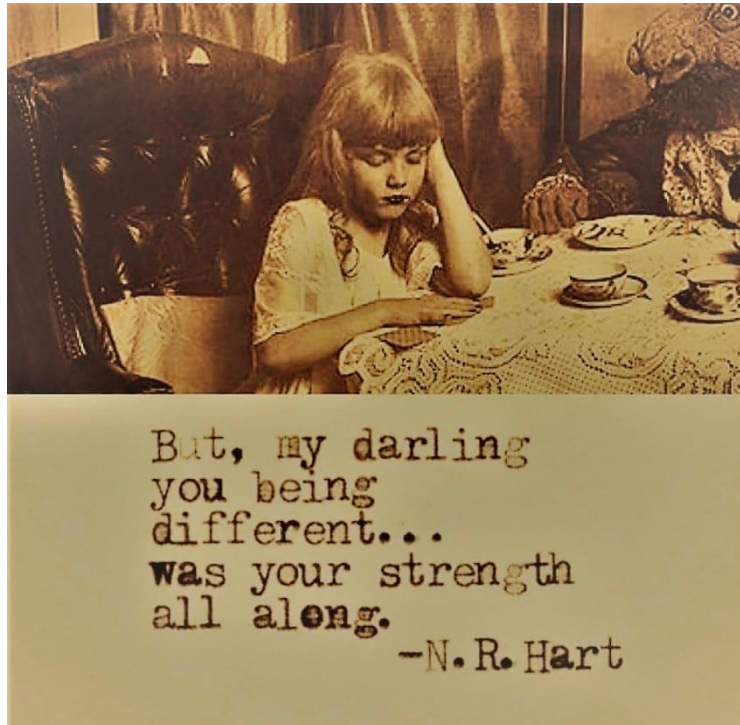


The impact of a late autism diagnosis on the experience of motherhood among women and gender-diverse individuals



by
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TABLE OF CONTENTS

TABLE OF CONTENTS	2
ACKNOWLEDGEMENTS.....	5
ABSTRACT	6
TERMINOLOGY	8
CHAPTER 1 INTRODUCTION	10
CHAPTER 2 SOCIAL AND HISTORICAL CONTEXT	12
Autism as a social construct.....	12
Autism as a neurodevelopmental difference	20
Social communication and interaction differences	21
Sensory sensitivities and restricted, repetitive behaviour	23
Co-occurring mental health conditions	25
Masking, camouflaging, or passing	26
Gender bias in the diagnostic process	28
Value of an adult autism diagnosis	35
CHAPTER 3 THEMATIC SYNTHESIS OF STUDIES ON THE EXPERIENCES OF MOTHERHOOD AMONG AUTISTIC WOMEN AND GENDER-DIVERSE INDIVIDUALS ...	39
Introduction	39
Methods	40
Search strategy	40
Study selection	42
Quality appraisal	44
Data extraction	45
Findings	45
Studies identified	45
Thematic synthesis	49
Discussion.....	54
Conclusions	57
CHAPTER 4 METHODOLOGY	60
Research questions	60
Ontology and epistemology.....	60
Interpretative phenomenological analysis (IPA)	62
Positionality	64
Reflexivity.....	68

Theoretical framework.....	70
The medical, social, and social-relational models.....	70
Neurodiversity.....	72
Intersectionality.....	73
Methods	76
Recruitment of participants	76
Interviews	78
Transcription.....	81
Data analysis	82
Ethics committee approval	83
Autistic community involvement	83
CHAPTER 5 PARTICIPANT DEMOGRAPHICS AND OVERVIEW OF THEMES.....	89
Participants demographics.....	89
An overview of the superordinate themes and subthemes.....	91
CHAPTER 6 THEME ONE – TRANSITION TO NEW MOTHERHOOD	92
Findings of Theme One - Transition to new motherhood	92
Challenges.....	92
Responsibilities.....	95
Pressure to be a ‘good mother’.....	98
Discussion of Theme One - Transition to new motherhood	102
Challenges.....	102
Responsibilities.....	106
Pressure to be a ‘good mother’.....	112
CHAPTER 7 THEME TWO – AUTISTIC IDENTITY DEVELOPMENT	119
Findings from Theme Two - Autistic identity development.....	119
Receiving an autism diagnosis	119
Identifying as autistic	122
Impact on the mothers’ maternal self-efficacy	125
Discussion of Theme Two – Autistic identity development.....	128
Receiving an autism diagnosis	128
Identifying as autistic	136
Impact of the mothers’ maternal self-efficacy	142
CHAPTER 8 THEME THREE – Diagnostic disclosure	148
Findings from Theme Three – Diagnostic disclosure	148
Family	148

Friends, work, and education.....	151
Health and social care professionals	155
Discussion of Theme Three – Diagnostic disclosure.....	158
Family	158
Friends, work, and education.....	164
Health and social care professionals	170
CHAPTER 9 THEME FOUR – An ‘authentically autistic’ family	177
Findings from Theme Four – An ‘authentically autistic’ family.....	177
Undiagnosed lived experiences	177
Shielding the children	181
Perceived benefits of an ‘authentically autistic’ family	186
Discussion of Theme Four – An ‘authentically autistic’ family	189
Undiagnosed lived experiences	189
Shielding the children	195
Perceived benefits of an ‘authentically autistic’ family	201
CHAPTER 10 CONCLUSIONS	207
Research Question 1: What challenges do undiagnosed autistic mothers experience when transitioning to new motherhood?.....	207
Research Question 2: How does receiving a late diagnosis of autism impact a mother’s maternal self-efficacy?	208
Research Question 3: How do family members respond to an autistic mother’s disclosure of their diagnosis?	210
Research Question 4: What are the perceived benefits of living in an ‘authentically autistic’ family home?.....	212
CHAPTER 11 LIMITATIONS	214
CHAPTER 12 RECOMMENDATIONS	216
APPENDICES	218
Appendix A Published article	218
Appendix B CASP Qualitative Checklist.....	251
Appendix C Study invitation poster	257
Appendix D Participant Information Sheet	258
Appendix E Consent form	261
Appendix G Short biographies of each of the ten participants	265
REFERENCES	273

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ABSTRACT

The majority of autistic women and gender-diverse individuals are undiagnosed and under-represented in research. This has contributed to a male-biased understanding of autism, which has consequences for access to timely diagnosis and support for other genders. Studies have shown that females, when compared to males, are more likely to receive an autism diagnosis in adulthood rather than in childhood. Furthermore, for many mothers, diagnosis occurs after they recognise their condition whilst researching their children's autistic behaviours. In the past few decades, there has been growing recognition that individuals of all ages and genders may be autistic and that research should better serve diverse needs. However, a literature search of qualitative research articles describing the experiences of motherhood among autistic women and gender-diverse individuals found only five studies published relatively recently. Autistic motherhood remains poorly understood despite the critical significance of this life period.

In this research, I aimed to explore, through a qualitative study, the impact of a late autism diagnosis on women's and gender-diverse individuals' experiences of motherhood and the impact that their new identity may have on their maternal self-efficacy. I drew upon both intersectionality and neurodiversity theory for my theoretical framework to support my interpretations. As a mother of an autistic child who received a late diagnosis of autism when I was 50 years old, I believe that my 'insider knowledge' was beneficial in understanding and interpreting my participants' lived experience.

I advertised in two private Facebook groups for people who identified as autistic, and ten participants were selected who had met the inclusion criteria. These mothers were all verbal, well-educated, and in contact with other autistic people through social media. Seven of the mothers identified as women and three as gender-diverse. Eight mothers were White British, one was Asian Indian, and one was White Roma. All the mothers had received their diagnosis after they gave birth to their first autistic child. Only two participants had a child whom they categorised as neurotypical. Semi-structured interviews were carried out on MS Teams in a relaxed conversational style. Data analysis was carried out using Interpretative Phenomenological Analysis supported by NVivo software.

From my data analysis, four superordinate themes emerged. The first, **“Transition to new motherhood”**, described the participants’ experiences of becoming new mothers without knowing they were autistic, including the challenges they faced, how they coped with their new child-rearing responsibilities, and the pressure they felt to be ‘good mothers’. Most of the participants had compared themselves to neurotypical mothers they had met, whom they believed were coping far better than they were. The second superordinate theme, **“Autistic identity development”**, explored the mothers’ lived experiences of seeking out, or being sent for, an autism diagnosis, the development of their new autistic identity, and its impact on their experience of motherhood. They had embraced their autistic strengths and had contacted the autistic community, from whom they learnt strategies that worked for their whole family. The third superordinate theme was called **“Diagnostic disclosure”** and described the mothers’ experiences of disclosing their autism diagnosis to their close and extended families, friends, workplaces, and educational establishments, the various reactions received, and the impact it had on their relationships. Many of the mothers feared the potential consequences of disclosing their diagnosis to health and social care professionals. They described the accusations and discrimination they had encountered from these professionals after sharing that they were autistic. The fourth and final superordinate theme, **“An ‘authentically autistic’ family”**, described the mothers’ lived experiences from their childhood, adolescence, and undiagnosed adulthood, and how they had reframed them following their diagnoses, their wish to shield their children from similar negative experiences, their battle to get their children diagnosed and supported, and their determination to provide an ‘authentically autistic’ and neurodiversity-affirming home for their family. Receiving their diagnoses proved to be a positive ‘turning point’ for the autistic mothers, improving their mental health and well-being as well as their maternal self-efficacy.

Counselling or psychotherapy should be offered to those receiving a late diagnosis of autism, especially when mental health conditions, childhood trauma, neglect or abuse are indicated. There is an urgent need for more up-to-date, co-produced training for health and social care staff to accommodate the needs of autistic individuals, whether diagnosed or undiagnosed, particularly for women, gender-diverse individuals, and those from ethnic minority groups. Due to the heritable nature of autism, professionals should be aware that, if a person has a close relative who is autistic, the likelihood of that person also being autistic is high, even though they may not realise this.

TERMINOLOGY

The terminology a person chooses to use may work as an instrument to affect other people's views and opinions, and may be used to shape the way people discuss topics such as neurodiversity and disability (Hartman et al., 2023). It may also perpetuate dehumanising narratives and stigma (Botha et al., 2021). In the past couple of decades, the autistic community have reclaimed identity-first language that was once thought to suggest 'pathology', for example, they may use the phrase 'I am autistic' rather than using person-first language such as 'I have autism' (Bottema-Beutel et al., 2021). In the Minority World, which represents regions where a smaller proportion of the population inhabits and was historically termed as 'developed' nations, autistic people generally prefer 'identity-first' rather than 'person-first' language (Kenny et al., 2016). This is because they do not wish to be set apart from their neurotype, as if it is somehow shameful (Sinclair, 2013). A person cannot be 'cured' of their autistic behaviour; there is no non-autistic person hidden inside them waiting to be revealed (Hartman et al., 2023). Many autistic individuals perceive their autism as a fundamental aspect of their identity (Sedgewick et al., 2022).

I believed it was important to ask my participants how they usually described themselves, and nine of the ten mothers in this study stated "as an autistic person", and one mother did not have a preference (Zajic & Gudknecht, 2024). Therefore, I chose to use identity-first language (Kelly et al., 2024). The American Psychological Association (APA) states that using the language preference of any disability group is a sign of professional awareness and respect, as well as a way of offering solidarity with that group (APA, 2022). I also asked what pronouns they preferred to be used in the dissertation, and the three gender-diverse mothers were happy to be referred to as 'they/them/their'. I used the term 'autism' as a shorter and less ableist adaptation of the diagnostic term 'autism spectrum disorder' and did not assume the addition of a learning disability (LD) or language delay (APA, 2013; WHO, 2018). The term 'disorder' is often associated with stigma and emphasises a person's difficulties while ignoring their strengths (Kenny et al., 2016). The profile of the participants in this study was similar to that of Asperger syndrome (AS), which is no longer a diagnostic category and has been encompassed within the autism spectrum disorder category in the diagnostic manuals (APA, 2013; WHO, 2018). Individuals with an AS profile have average to above-average intelligence and no significant delays in language development, but have difficulties with communication

and social interaction, sensory sensitivities, and restricted and repetitive behaviours (ibid.). I also used the term 'mother' to include individuals that society would generally perceive as fulfilling that social role, and all the participants were happy to be identified as 'a mother' (Natri et al., 2023). I tried to be mindful of how I described other aspects of the autistic experience, for example, using the term 'passions' or 'intense interests', instead of 'special interests' (Bottini et al., 2024).

Throughout this dissertation, I represented autism as a value-neutral difference seen throughout the human population (Bottini et al., 2024). It manifests in a variety of ways of processing sensory, social information, and behaviour that differ from the societal majority (Yixin Chen et al., 2024). Being autistic is a lifelong identity, as a person's neurotype does not change; however, sensory and emotional sensitivity may often vary between and within individuals over time, as can their impact on their life (Beardon, 2017). Autistic individuals have an alternative type of cognition, which may generate what some refer to as a 'spiky profile' (Doyle, 2020). This profile represents a more evident pattern of strengths and challenges in comparison to non-autistic people (Maw et al., 2024). However, autistic people are not homogeneous and, like all humans, they display individual differences across multiple domains, such as in their behaviour and abilities (Pender et al., 2020). An autistic person's happiness, quality of life, and success depend on the compatibility between their physical and social environment and their needs, requirements, skills and talents (Beardon, 2017).

CHAPTER 1 INTRODUCTION

Although autism is now considered to be a complex, lifelong, neurodevelopmental difference with a similar prevalence rate of one per cent across all ages and genders, it was historically regarded as a very rare childhood disorder that mainly occurred in boys with learning disability (LD) and/or language delay (O'Reilly et al., 2020). It was only in 1992 that Asperger syndrome (AS), or autism without any additional LD or language delay, was included in the diagnostic manuals used by clinicians (APA, 1994; WHO, 1992). Consequently, autistic people without additional LD, who were at school before the new category was introduced in 1992, would have been extremely unlikely to be diagnosed during their school years (Kelly et al., 2024). Many lived their lives without an understanding of their differences and without receiving any appropriate support (Paricos et al., 2024).

Following the inclusion of AS in the diagnostic manuals in 1992, the number of diagnoses in boys and men increased substantially (Russell, 2021). However, autistic girls, women and gender-diverse individuals remained undiagnosed and under-represented in research, contributing to a male-biased understanding of autism (Rippon, 2024). In the past decade or so, there has been a growing recognition that individuals of all genders may be autistic (Greene et al., 2024). The importance of women's voices has been highlighted in feminist disability studies, particularly among groups whose lived experiences have been overlooked in research (Garland-Thomson, 2005; Wilde & Fish, 2025).

Studies have shown that females, when compared to males, are still more likely to receive an autism diagnosis in adulthood rather than in childhood, and often only after they have had children (Garcia-Molina & Cortes-Calvo, 2025). In fact, many mothers begin to recognise their condition whilst researching their children's autistic behaviours (Garcia-Molina & Cortes-Calvo, 2025). Autistic mothers' experience of parenthood has received very little attention in research, despite autism being a lifelong and highly heritable condition (Adams et al., 2021). Many autistic children will have at least one parent or close relative who is autistic, although they are likely to be undiagnosed (Bai et al., 2020). The impact of an autism diagnosis on a mother needs to be explored, as only a few qualitative studies have been conducted in this group in the last few years (Hernández González et al., 2024).

My aim for this qualitative study was to explore the impact of a late autism diagnosis on women's and gender-diverse individuals' experiences of motherhood and their maternal self-efficacy. I drew upon both intersectionality and neurodiversity theories for my theoretical framework to support my interpretation of the experiences of the participating autistic mothers (Kelly et al., 2024). The methodology that I used was Interpretative Phenomenological Analysis (IPA), as it is an ideal methodology for exploring phenomena that have not been well understood, because it provides in-depth views of complex processes and illuminates the multifaceted nature of human experience (Nizza et al., 2021).

By employing curiosity and open-mindedness, I listened closely to the mothers' narratives and created a detailed interpretation of how they made sense of their lives. I explored the challenges that the participants had experienced after transitioning to new motherhood while undiagnosed, as well as their journey to receiving an autism diagnosis and the impact their new autistic identity had on their maternal self-efficacy. I was also interested in examining the various responses they received from friends, family, colleagues, schools, and health and social care professionals after they disclosed their diagnoses. Finally, I described some of their memories from their undiagnosed lives that they had reframed in light of their new self-understanding, their determination to shield their autistic children from similar negative experiences, and their conviction to provide a neurodiversity-affirming family home where their autistic children would feel safe and secure. I used an exploratory approach for my study, with four quite broad research questions, to secure enough material to provide an insightful interpretation of my participants' lived experiences (Braun & Clarke, 2024). The four questions were:

What challenges do undiagnosed autistic mothers experience when transitioning to new motherhood?

How does receiving a late diagnosis of autism impact a mother's maternal self-efficacy?

How do family members respond to an autistic mother's disclosure of their diagnosis?

What are the perceived benefits of living in an 'authentically autistic' family home?

CHAPTER 2 SOCIAL AND HISTORICAL CONTEXT

A person's understanding of a phenomenon is often influenced by its historical context and the evolution of knowledge related to it over time (Waltz, 2023). Understanding the historical development of the concept of autism in the Minority World as a distinct diagnostic category is needed to comprehend the social context experienced by autistic individuals (Pearson & Rose, 2023). In this chapter, I describe the history of autism as a social construct by identifying various discourses and institutional practices that have contributed to the naming and interpretation of autistic behaviours (Botha, 2025). I then discuss autism as a neurodevelopmental difference, as I believe both of these perspectives are valuable and offer distinct lenses through which to appreciate the complexity of autism (Morris-Rosendahl & Crocq, 2020). Within this second section, I introduce the diagnostic criteria for autism, the mental health conditions that often co-occur in autistic women and gender-diverse individuals, masking, and how the diagnostic process may frequently be biased towards a white, cisgender, male, 'stereotypical' presentation of autism (Cruz et al., 2025). I complete this chapter by discussing the value of an adult autism diagnosis to those who have been undiagnosed for many decades.

Autism as a social construct

The social construct of autism developed in the Minority World in response to shifting social, economic, and gender norms, as well as new scientific and medical knowledge (Chapman, 2021). It is important to appreciate that determining that autism is socially constructed does not imply that it is not real, since constructs can incorporate naturally occurring features (Chapman, 2020). Autism can be considered a product of interconnected social and biological processes (Hunt & Procyshyn, 2024).

The social construction of autism should be contextualised within the broader social and political circumstances of its emergence in the Minority World (I. Moore et al., 2024). It has been a fluid and dynamic concept whose meaning has been constantly in flux because of changing norms of social interaction, as well as updates to the diagnostic classification (Dyck & Russell, 2020). The types of behaviours deemed unacceptable in 'polite' society, and in need of correction or support, have varied over time and by location (Wright et al., 2020). The

concept of autism has been used to make sense of those behaviours and a label with which to characterise those who present with them (Fennell & Johnson, 2022).

Throughout history, there have been individuals who have had behaviours that would now be grouped and categorised as autistic (Waltz, 2023). At the beginning of the 19th century, standards of 'normality' were much more lenient and social surveillance methods, so much a part of our lives today, had not yet been developed (Zaks, 2023). An autistic child with LD would probably have been abandoned, neglected or institutionalised, but those without LD may have just been regarded as 'eccentric', if regarded at all (Morris-Rosendahl & Crocq, 2020). However, the following decades began to see rapid urbanisation and industrialisation, lower infant mortality, and the emergence of new strategies for monitoring and dividing populations to ensure social stability. There became a need to distinguish 'social deviance' in order to respond to the assumed social threat that any variation from the mythical 'norm' may carry with it (Waltz, 2023). Surveillance extended over wider areas of social life, and institutions and workhouses were created that aimed to segregate society according to those who were 'healthy' and 'unhealthy', 'sane' and 'insane', 'mentally retarded' and 'not mentally retarded' (Foucault, 1991). Asylums were developed as spaces where those with cognitive differences were kept apart from the rest of society (Foucault, 1965). They were also convenient places for medical professionals to study inmates, as confinement allowed for detailed examination (Ash et al., 2020).

The terminology and criteria that made autism visible emerged in the 20th century (Wilson, 2025). Between the Great War (1914 to 1919) and the Second World War (1939 to 1945), eugenics attracted a wide following in many countries, including the UK, the US, and, most notoriously, Nazi Germany (Standley & Kaufman, 2024). Eugenics is a social movement dedicated to improving the quality of the human race through the science of heredity (Redvaldsen, 2024). The movement proposed that societal ills could be attributed to those who displayed undesirable qualities, such as low intelligence, a criminal background, and living in poverty (Wilson, 2025). The eugenicist perspective theorised that there was a genetic predisposition to many childhood diagnoses (Pearson & Rose, 2023). Cognitively impaired children were institutionalised with only minimal formal evaluation, and it is highly plausible that many would have been diagnosed today as being autistic (Standley & Kaufman, 2024). The economic and social burden associated with the rise of institutionalisation led to cries for

more definitive solutions in the form of sterilisation, and ultimately, the systematic elimination of disabled people in wartime Nazi Germany through forcible euthanasia (Czech, 2018; Tarasenko-Struc, 2024). The idea of 'normal' and 'abnormal' children became more prevalent as eugenicist ideals proliferated within academic thought, and the requirement grew for workers and military personnel to meet industrial and wartime needs (Jason, 2025).

The term 'autism' was first published in 1911 by Bleuler (1911/1950), a Swiss psychiatrist who characterised it as a symptom of childhood schizophrenia. He defined it as a reduction of social engagement by children with schizophrenia and their withdrawal into an internal world (Pearson & Rose, 2023). In 1943, Kanner, a child psychiatrist in Baltimore, used 'autism' to characterise a condition he observed in 11 non-verbal children, comprising eight boys and three girls (Kanner, 1943, 1944). Subsequently, 'classic autism' or 'Kanner's autism' came to be referred to as a 'disorder marked by severe cognitive and communication problems' (Lotter, 1966).

In 1944, around the same time, Asperger, working at the University of Vienna after Austria's annexation by Nazi Germany, observed a similar set of behaviours in four boys without LD and with good language development (Asperger, 1944/1991; Wing, 1981). He highlighted the presence of intellectual gifts in many of these children, alongside social 'deficits', and characteristic behaviours (Asperger, 1944/1991). Asperger followed the progress of several of these gifted children who went on to achieve outstanding success (ibid.). Austrian historian Czech (2018) located paperwork indicating that, in common with many of his peers under the Nazi regime, Asperger may have referred children under his care with 'severe mental retardation' to hospitals that were known euthanasia centres (Czech, 2018). The Nazis had established the 'Aktion T4' programme, under which disabled children were removed from homes, institutionalised, and euthanised without parental consent (Dwyer, 2020). Many physicians cooperated with the Nazi regime for personal gain or professional survival (Kaplan, 2024).

The capacity of an autistic person to hyperfocus on a topic and study it continuously was highlighted as beneficial by Asperger, who used 'little professors' as a term to describe the autistic children he studied (Asperger, 1944/1991). Autistic individuals tend towards a monotropic cognitive approach, characterised by highly focused interests, rather than having

a polytropic or broad attentional style (Brosnan & Camilleri, 2025). This explains why autistic people often become hyper-focused on their passionate interests but frequently get distressed by interruptions to their attention (P. Dwyer et al., 2024). Kanner, however, dismissed these behaviours as meaningless (Kanner, 1943). Monotropic behaviour, such as rumination, may be counterproductive in one context (Lee et al., 2024). In another context, such as research, this behaviour may be considered a strength (Chow & Cooper, 2024).

Nearly fifty years after it had been published in German, Frith (1991) translated Asperger's paper on his syndrome into English (Asperger, 1944/1991). Asperger's descriptions of the presentation of autism as seen in these boys influenced the creation of AS in 1992 in the two diagnostic manuals used by clinicians: the International Classification of Diseases, 10th Revision (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) in 1994 (APA, 1994; Asperger, 1944/1991; WHO, 1992). The 'stereotypical' autism presentation of young, white males from middle-class families became associated with autism; the characteristics of those described in his early case studies (Tien, Pearson, et al., 2025).

In the 1950s and 1960s, psychoanalysis attained substantial recognition and prominence (Kadiri, 2022). Even though previous medical thinking had suggested that autism was organic, the lack of a confirmed biological marker for diagnosis led to speculation that it may result from a crisis of the 'self' (Morsa, 2023). In his seminal study, Kanner (1943) considered autism to be a mental health condition brought on by the lack of a warm and loving family environment. He described autistic children as having been subjected to "... parental coldness, obsessiveness, and a mechanical type of attention to material needs only ... left neatly in refrigerators which did not defrost (ibid.). Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude" (Kanner, 1943, p. 425). Psychoanalytical theory referred to autism as a unique psychological 'disorder' caused by the actions of 'refrigerator mothers' (Bettleheim, 1967). Perhaps the appeal of psychoanalytical theory lay in the idea that 'treatment' was possible (Waltz, 2023). If the mother had regular sessions with a psychoanalyst, she should be able to 'bring back' the child whom she had 'lost' (Morsa, 2023). The blame and hopes for recovery were solely on the mother (Kapp, 2022).

Bettleheim (1967), a psychologist who had referred to his earlier work with Freud and Jung, although they had never actually met, also suggested that autistic children 'withdraw' from the

world because of the 'abnormal' behaviour of their mothers (Pearson & Rose, 2023). His theory of the 'refrigerator mother' was based on his claim that "the precipitating factor in infantile autism is the parents' wish that the child should not exist" (Bettelheim, 1967, p. 125). Bettelheim stated that this parental attitude was understandable, considering the 'burden' associated with parenting an autistic child with their behavioural demands (ibid.). He adopted Kanner's beliefs, claiming that parents of autistic children often seemed cold, obsessive, and 'mechanical' in their interactions with each other, despite Kanner having subsequently retracted his comments (Kanner, 1949).

Although some may maintain that Bettelheim's work contributed to the understanding of the environmental impact on child development, it was also fundamental in shaping 'treatment' and intervention strategies for autistic children for decades to come (Pearson & Rose, 2023). His work has now been almost universally dismissed; however, the consequences of his claims have been considerable (Douglas & Klar, 2019). The parent shaming initiated by Bettelheim is still widespread, with parents being blamed for the 'atypical' behaviour of their children (Pearson & Rose, 2023).

Bettelheim's theory remained popular throughout the 1970s and formed the basis for the behaviourist research used in the 'treatment' of autistic children (Pearson & Rose, 2023). Lovaas developed a form of Applied Behaviour Analysis (ABA) referred to as the Lovaas Method as an intervention for autistic children (Lovaas et al., 1974). He held the belief that they were not fully human: "You start pretty much from scratch when you work with an autistic child. You have a person in the physical sense – they have hair, a nose, and a mouth – but they are not people in the psychological sense" (Chance, 1974, p. 76). He administered 'aversives', including electrical shocks and physical violence as negative reinforcement, when they exhibited autistic traits, and claimed that they needed this training to communicate (Lovaas et al., 1966; Pearson & Rose, 2023). ABA is still a widely recommended therapeutic approach for autistic children, particularly in the US, despite concerns regarding the validity of its evidence base and long-term effects (Anderson, 2023).

During the 1970s and 1980s, there was a growing feeling of disillusionment with psychoanalysis (Vivanti & Messinger, 2021). There were also significant developments in neuropharmacology, which advanced psychiatry as a highly respected discipline (Pearson &

Rose, 2023). Psychiatry established new boundaries for behaviour, including what was considered 'normal' and 'abnormal,' and, consequently, who was and was not eligible for support (Pearson & Rose, 2023). Scales of functioning and intelligence were used as measures of a child's capabilities (Ash et al., 2020). A child who failed to meet their developmental milestones was considered 'abnormally developing' and 'outside the normal range' (Kniola et al., 2024). Any deviation from the assumed norm was viewed as requiring remediation and intervention (Benevides et al., 2020).

With the help of child guidance literature, parents became more attuned to their children's development and were more likely to seek expert advice if they were financially able (Glasby et al., 2021). A combination of medical, social, and educational concerns about the prevention of 'social maladjustment' produced a new focus on disabled children (Clements & Aiello, 2021). The medicalisation of societal difference and the intervention industry that sprang up around it sought to pathologise anyone who did not fit within a narrow societal ideal (Zaks, 2023). It also terrified caregivers into ever more unachievable standards of parenting (Hollingworth et al., 2023).

Autism research has developed significantly since the 1980s, with most studies focusing on biological and genetic aspects, disproving previous psychogenesis claims (Manoli & State, 2021). The diagnosis then reemerged as a 'neurodevelopmental disorder', a classification that dominates today (Thapar & Rutter, 2021). However, healthcare professionals were not aware of autism without LD or language delay until after Asperger's paper was translated into English and AS was subsequently included in the two diagnostic manuals: the ICD-10 in 1992, and the DSM-IV in 1994 (APA, 1994; Asperger, 1944/1991; Frith, 1991; WHO, 1992). Unfortunately, any child who was at school before the mid-1990s who presented with autistic behaviours, but without additional LD or language delay, would have missed the opportunity to be identified with AS and would not have been given any autism-specific educational support (Nyrenius et al., 2023).

Due to the addition of the new diagnostic category, the prevalence of autism in the United Kingdom (UK) and the United States (US) increased, and then in other regions in the Minority World, such as Europe and Australia (WHO, 1992). At the same time, the prevalence of other developmental and psychiatric conditions fell due to diagnostic switching or substitution

(Russell, 2021). Assessment centres were established, and society became more aware of autism due to an increase in media interest in the subject (S. C. Jones et al., 2023). Several autobiographies have been written by autistic individuals (Lilley et al., 2022). It became more likely that a person might consider autism as an explanation for their differences, or those of a family member (Eaton, 2024). All these factors further increased the prevalence, creating what Hacking (1995) termed a 'looping effect'.

In the most recent diagnostic manuals, the International Classification of Diseases, 11th Revision Version (ICD-11) and the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), all the autisms, including AS, have been merged into one overarching term: autism spectrum disorder (ASD) (APA, 2013; WHO, 2018). The term 'autism spectrum' was coined by Wing, who intended to capture the multidimensionality of individuals who had socio-communicative differences (Wing, 1996). Grinker (2010) praised the concept of envisioning autism as a spectrum for helping people grasp its many strengths, flaws, tendencies, and sensitivities. However, Hacking (2009) argued that the spectrum metaphor presents one major drawback: "Spectra are linear and autism is not. Autism is a many-dimensional manifold of abilities and limitations." (p. 503). Indeed, the autistic spectrum did become widely perceived as a linear concept with 'high-functioning' autistic people, classified as having normal or higher intelligence, at one end and 'low-functioning' autistic people, classified as having intellectual disability, at the other (Pearson & Rose, 2023). This division of autistic individuals sometimes resulted in 'high functioning' people having their support reduced and in 'low functioning' people being denied autonomy and agency, particularly if they were non-verbal (Chapple & Worsley, 2021). Ultimately, 'functioning' is transient and contingent upon social expectations, the quality of support provided, and the degree to which the environment is 'autism-friendly', as portrayed in Luke Beardon's equation (autistic person + environment = outcome) (Beardon, 2017).

A prevalent conventional image of autistic boys as technically competent but socially inept led to the label of 'nerd' or 'computer geek' and the 'Geek Syndrome' on social media (Alper, 2023). This stereotype gained prominence during the period of shifting economic production between 1992 and 2002, driven by the rise of the internet, known as the 'dot-com bubble', and may have reflected people's fears about technology and the cognitive skills it privileged (Brick, 2024). Unfortunately, this stereotypical male 'computer geek' character may have misled

diagnosticians and researchers into taking the presentation seen in boys and men as representative of autism in general (Tien, Pearson, et al., 2025)

In the last three decades, many countries in the Minority World have seen a steep rise in the number of people being diagnosed as autistic (Zeidan et al., 2022). The reason for this may be the inclusion of AS in the diagnostic manuals and professionals getting better at recognising and diagnosing the condition (Russell, 2021). Currently, the estimated population prevalence of autism in all ages is one per cent; half of whom have no additional LD (Russell et al., 2022). Unfortunately, this rise in autism prevalence led to false claims regarding its causation, including a link to the measles, mumps and rubella (MMR) vaccine (Miller et al., 1999; Wakefield et al., 1998).

The twin study by Folstein and Rutter (1977) is cited as being the first clear evidence of a substantial genetic influence on autism (Volkmar, 2021). Their work focused on monozygotic (identical) and dizygotic (non-identical) twins (Thapar & Rutter, 2021). Where the twins were identical, meaning both formed from one egg that split, the instance of both being autistic was statistically significant, suggesting there are clear genetic factors that lead to a person being autistic (Folstein & Rutter, 1977). Only a handful of rare conditions associated with autism are caused by mutations of a single gene, such as Fragile X and Rett syndrome (White et al., 2021). However, for the vast majority of autistic individuals, there is not one definitive autism gene (Thapar & Rutter, 2021). More than 100 genes are involved in autism, and rather than being 'faulty,' these genes are a standard part of our genetic makeup as a population (Oswald, 2025). A recent large-scale study found autism to have a very high heritability rate of approximately 80% without any contribution from maternal effects, indicating that its occurrence is mainly due to inherited genetic factors (Bai et al., 2019). Maternal effects are defined as influences of the environment provided by mothers on offspring that act in addition to or in interaction with an offspring's genotype and other environmental influences (Sandin et al., 2024).

In England, rates of autism show little significant evidence of decline with increasing age, although the vast majority of autistic adults are undiagnosed (Samuel J Tromans et al., 2024). The assessment process for autistic children has improved over the past twenty years with the production and validation of new diagnostic instruments (Frazier et al., 2024). However,

this has not occurred for adults as adult specialist services are almost entirely limited to those who have LD or are mentally or physically ill (NICE, 2012). Much less research has been undertaken evaluating the diagnosis of adult autism in comparison to the vast amount conducted on childhood autism (Mason et al., 2022).

The first national, disability-specific parliamentary act, the Autism Act 2009, was passed with all-party support in response to the growing realisation that many autistic adults are undiagnosed and have been excluded both socially and economically (Autism Act, 2009). Statutory guidance was published in 2014 to ensure that the Autism Act and its subsequent strategy were implemented and actioned appropriately for autistic people living in each NHS trust and local authority area of England (DoH, 2014). This statutory guidance was recently refreshed by the Department of Health and Social Care and the Department of Education, and includes themes: “improving understanding and acceptance of autism within society; improving autistic children and young people’s access to education, and supporting positive transitions into adulthood; supporting more autistic people into employment; tackling health and care inequalities for autistic people; building the proper support in the community and supporting people in inpatient care; and improving support within the criminal and youth justice systems” (DoH & DoE, 2021).

In recent years, many autistic individuals have shared their first-person accounts of what it feels like to be autistic and their perceptions of the predominantly neurotypical world (Benedetto, 2024). More focus has been given to the co-production of studies that involve autistic people in the entire research process, rather than merely providing conclusions drawn from them as subjects (Fletcher-Watson, 2024a). The autistic community has begun to contribute to the shaping of autism research through meaningful participation and to advocate for policy and services that genuinely meet their needs (Pellicano et al., 2021).

Autism as a neurodevelopmental difference

At present, there is no reliable biological marker for autism (Loth, 2023). Consequently, a diagnosis is subjectively determined by a clinician’s evaluation of a person’s behaviour (Pearson & Rose, 2023). *(Please be aware that some of the language surrounding autism, particularly within the diagnostic manuals, is perceived by many as stigmatising)* The ICD-11 specifies that these behaviours must include “persistent deficits in initiating and sustaining

social communication and reciprocal social interactions” as well as “persistent restricted, repetitive, and inflexible patterns of behaviour” (WHO, 2018). The diagnostic criteria also require that “the symptoms result in significant impairment in personal, family, social, educational, occupational or other important areas of functioning” (ibid). Similarly, the DSM-5 specifies that “symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning” (APA, 2013). There are likely many autistic people within the population who go unidentified due to either intersecting issues that contribute to diagnostic disparities by gender, ethnic group, socio-economic status and access to healthcare, or not meeting the criteria for ‘significant impairment’ (Jellett & Muggleton, 2022).

Social communication and interaction differences

Defining features of autism include a lack of social understanding of the non-autistic majority, finding their social signals confusing, and the need to specifically learn social skills that non-autistic people would acquire intuitively (Gould & Ashton-Smith, 2011). Using these skills adds a significant cognitive load to social interaction, making autistic individuals vulnerable to high levels of stress and subsequent mental health problems (Belcher, Morein-Zamir, Stagg, et al., 2022). Even highly verbal autistic individuals find some aspects of social communication challenging, for example, pragmatic language skills, such as turn-taking, and non-verbal communication, such as neurotypical gestures and facial expressions (Sturrock et al., 2021).

Mandy et al. (2018) found that autistic characteristics become more evident during adolescence, as the neurotypical social world becomes more demanding and subject to different social rules than previously encountered. This is particularly apparent for autistic girls, who face specific cultural expectations around social relationships and gender roles (Hutson & Hutson, 2023). A study by Cook et al. (2017) highlighted how gender stereotypes may impact autistic girls in social settings, with the heightened expectation of closeness within friendship groups harder to navigate due to communication differences with neurotypical peers (S. Mo et al., 2021).

Problems with social interaction have been well documented in autistic individuals across the lifespan and relate to difficulties in identifying, interpreting, and responding to various non-autistic social cues (Forbes & Hamilton, 2020). Adults on the autism spectrum often struggle

to comprehend social inferences and implied meanings in a conversation (Wilson & Bishop, 2021). During social interaction, an autistic person may repeat themselves or continue to discuss their hobbies or passions without being aware that others are not interested or that the subject matter is socially inappropriate (Black et al., 2023). Autistic individuals exhibit different patterns of eye contact, facial expressiveness, tone of voice, and body movements compared to most non-autistic individuals (Zampella et al., 2025). Not having a neurotypical communication style may result in difficulties forming and maintaining friendships and romantic relationships with non-autistic individuals, as well as challenges with job retention and career progression (Geelhand et al., 2025).

Because of their social cognition differences, autistic adults tend to find less pleasure in polite conversation, or 'small talk', compared to non-autistic people (Morrison et al., 2020). Autistic adults may experience high levels of social anxiety as they become aware of their social interaction differences, leading to the development of excessive apprehension about events and fear of rejection by others (Spain et al., 2020). However, by avoiding social situations, autistic adults can feel alienated and become excluded from their friends and family (Gurbuz et al., 2024). Some autistic people spend much of their time alone, as they may find socialising difficult and draining (Neville et al., 2024).

Baron-Cohen et al. (1985) introduced the concept of theory of mind, where the researchers linked their observations of autistic 'deficits' in false belief and mind-reading tasks to the notion that autistic people lack empathy. More recently, the academic literature drew attention to the mutual misunderstanding and miscomprehension between autistic and non-autistic individuals, termed the 'double empathy problem' (Milton, 2012). Milton et al. (2018) challenged the idea that autistic people lack empathy or a theory of mind, highlighting that individuals with dissimilar life experiences have trouble empathising with each other during social interaction (Milton, 2017). The more dissimilar these experiences and ways of thinking are, the more difficult it might be for one person to make inferences about another person's mental state (Cheang et al., 2024).

The double empathy problem proposes that non-autistic people often have trouble in recognising the feelings and experiences of autistic people, and vice versa (Milton, 2017). Indeed, some suggest that autistic individuals might be better than non-autistic people at

crossing the communication divide, simply because, throughout their lives, there would have been an expectation that they should conform to a normative communication style to function in life; therefore, they get more practice in acquiring this skill (Geelhand et al., 2025). Non-autistic individuals are rarely under the same pressure to cross the divide (D. R. Jones et al., 2023). Furthermore, studies have demonstrated that non-autistic people often misconstrue autistic people or judge them harshly on first impression (Granieri et al., 2020).

The double empathy theory suggests that individuals with comparable dispositions tend to establish connections and rapport more easily (Foster et al., 2024). Studies have shown that autistic people convey information more effectively with each other than with non-autistic people, as well as experience greater rapport and comfort around other autistic individuals, rather than with non-autistic people (Crompton, Ropar, et al., 2020; D. R. Jones et al., 2023).

Sensory sensitivities and restricted, repetitive behaviour

For the first time, the diagnostic criteria for ASD include sensory processing differences within the “persistent restricted repetitive patterns of behaviour” sections of the most recent ICD-11 and DSM-5 criteria (APA, 2013; WHO, 2018). Autistic individuals experience multiple differences in sensory processing compared to the non-autistic population, across various senses, including touch, taste, sound, smell, vision, proprioception, and balance/vestibular function (Kiep et al., 2025). They can be hypersensitive, for example, being more sensitive to specific frequencies of sound, and hyposensitive, being less sensitive to temperature changes (MacLennan et al., 2022). The environment and context of a situation also affect their sensitivities; for example, they may be very sensitive to sound when in a busy environment, but enjoy listening to loud music as a form of sensory seeking behaviour when alone (Neufeld et al., 2021).

Sensitivity can be heightened in specific stressful environments that are not conducive to a calm, serene atmosphere (Harrold et al., 2024). Unexpected, ambiguous or unfamiliar stimuli, such as loud noises, can be stressful and upsetting (Poulsen et al., 2025). Non-autistic brains exhibit sensory adaptation and habituation; prolonged exposure to a sound, smell, texture, or visual cue results in the brain learning to disregard it, allowing it to recede into the background (Schulz et al., 2023). Whereas, for autistic individuals, prolonged exposure to stimuli results in increased neuronal stimulation (Jamal et al., 2021). Furthermore, autistic people exhibit

enhanced abilities in detecting minor details and alterations in their surroundings, which may contribute to their hypervigilance (Soden et al., 2025). However, they often struggle to distinguish between sensory input that should be ignored and input that should be considered (Sibeoni et al., 2022). Each piece of sensory information vies for attention (Green & Wood, 2019). Emotional and behavioural responses associated with autism, such as meltdowns and shutdowns, may be understood as survival mechanisms designed to help individuals cope with potential threats or danger (Phung et al., 2021).

A meltdown occurs when an autistic person feels completely overwhelmed, and emotions such as anxiety, frustration, or anger build up inside them until suddenly they get released in an uncontrolled and explosive way (Montaque et al., 2018; Soden et al., 2025). A shutdown is a less visible response to feeling overwhelmed or reaching a breaking point, where an autistic person internally ‘switches off’ as a protective mechanism (Phung et al., 2021). They may withdraw, become unable to communicate, and temporarily lose skills (Paris et al., 2025). A shutdown may easily be mistaken for disinterest or rudeness when people are not accustomed to this type of response (Clarke, 2025). In the case of those experiencing chronic or acute anxiety, known to be prevalent in the autistic population, these responses may be triggered more often and by a broader range of precipitating factors, such as social difficulties, trauma, or intolerance of uncertainty (Lewis & Stevens, 2023). Meltdowns and shutdowns may be further triggered by other difficulties widespread in the autistic community, such as problems with eating, digestion, stress, and sleep (Belek, 2019; Soden et al., 2025).

Autistic individuals may manage their sensory experiences by reducing or blocking out overwhelming sensory stimuli through self-stimulatory behaviours (Charlton et al., 2021). Restricted, repetitive, self-stimulatory behaviours are generally known as ‘stims’ (Morris et al., 2025). A stim is a repetitive movement or vocalisation that provides sensory input and may comprise behaviours such as hand flapping or complex whole-body movements, for example, pacing, spinning, or jumping (Charlton et al., 2021). Stims have a regulatory function; stimulating or calming specific senses, as required (McCarty & Brumback, 2021). Stimming helps autistic individuals manage anxiety, cope with challenging environments, and control sensory overload; it relaxes, calms, and brings pleasure, and is necessary as it provides a way to process daily events and experiences (Morris et al., 2025). Although stimulating helps autistic people to self-soothe, many ‘treatments’ for autism focus on reducing or eliminating

stimming behaviours (Charlton et al., 2021). Although stims can be suppressed voluntarily, for example, when trying to fit in with non-autistic peers, autistic people find this problematic, especially for long periods, such as a complete work or school day (Sagar et al., 2023).

Autistic individuals often have a specific and personalised sensory profile and perceive sensory stimulation differently from others, thus responding unusually to the world around them (Kirby et al., 2015). Sensory differences account for a large proportion of the non-conforming behaviours seen in autistic individuals (H. K. Schiltz et al., 2023). The inability to share the same 'sensory world' as non-autistic people may be one reason for social interaction, communication, and developmental differences (Beck et al., 2024).

Co-occurring mental health conditions

Autistic people often have one or more co-occurring conditions; in particular, they have an increased likelihood of having a mental health diagnosis compared to the general population (Khasakhala et al., 2023). Research suggests that anxiety is present in up to 84% of the autistic population (McGonigle et al., 2014). Other mental health conditions also appear more likely to coexist, such as depression or obsessive-compulsive disorder (OCD), as well as neurodevelopmental disorders such as dyspraxia, and developmental coordination disorder (DCD) (Lieneman et al., 2024; Mannion & Leader, 2013). Research suggests sleep and eating disorders may also be more prevalent, which may impact mental, physical, and emotional well-being (Brede et al., 2024; Devnani & Hegde, 2015).

Autism and attention deficit hyperactivity disorder (ADHD) often coincide, and there is much overlap in symptoms between the two conditions, especially around attention, executive function, social challenges, sensory processing, and repetitive behaviour. While distinct, the overlap is substantial enough that individuals may be diagnosed with both (AuDHD) or have traits of one while meeting criteria for the other (Waldren et al., 2024). ADHD medications such as methylphenidate may help manage some symptoms like hyperactivity and impulsivity, but they are not as effective for core autistic traits. A review of 35 autism and ADHD co-occurrence studies yielded estimates ranging widely from 37% to 85% (Leitner, 2014).

Autism is not a mental health disorder, yet 70% of autistic people have co-occurring mental health issues (Simonoff et al., 2008). Social anxiety and depression often emerge in autistic

adolescents, so many have received these diagnoses by the time they become adults (Jadav & Bal, 2022). Autistic people's experiences of being misunderstood and not receiving appropriate support tend to increase the risk of mental ill health (Belcher, Morein-Zamir, Stagg, et al., 2022). Unfortunately, autistic people are likely to have more negative life experiences than non-autistic individuals (Douglas & Sedgewick, 2023).

Autistic individuals who have been diagnosed late in life have a higher probability of acquiring mental health diagnoses compared to the general population (Rim et al., 2023). By the time autistic adults reach middle age, they are more likely to have both mental and physical conditions (Bishop-Fitzpatrick & Rubenstein, 2019; Stewart et al., 2021). Unfortunately, research has indicated that autistic females face a heightened risk of suicide in comparison to non-autistic females and autistic males (Pelton et al., 2020; South et al., 2020). They are over nine times more likely to die from suicide than the general population and have a two- to three-decade decreased life expectancy (Hirvikoski et al., 2016). The principal cause of premature death for autistic adults is suicide (ibid.).

Because coexisting conditions are so common, it is important to understand how they can complicate autistic life, from making diagnosis more difficult to intensifying characteristics and difficulties already experienced by autistic people (Lei et al., 2024). Having coexisting ADHD, for example, may intensify difficulties with time management, executive functioning, impulse control, and emotional regulation, and having dyspraxia may increase motor and emotional difficulties (Vaidya & Klein, 2022).

Masking, camouflaging, or passing

Autistic masking (also known as camouflaging or passing) refers to a combination of mirroring the behaviours of non-autistic individuals, fawning, and the conscious or unconscious suppression of one's natural responses and behaviours to compensate for difficulties in social interaction, thereby concealing their traits to be perceived as non-autistic (Brown, 2023; Gonçalves Garcia et al., 2025). The act of suppressing one's emotional responses may include not crying when upset or not showing joy (Dell'Osso et al., 2023). Suppressing sensory responses may involve trying to hide sensory overwhelm or dysregulation due to a fear of being mocked or invalidated (Cai et al., 2019; Y. Chen et al., 2024). Suppression may also comprise the prevention or redirection of physical responses, such as suppressing stims

entirely, or stimming in a more subtle manner that may be less conspicuous to others (Miller et al., 2021). Suppression may also directly relate to the expression of personal identity and values, such as hiding one's passions and avoiding sharing personal information with others (Huang et al., 2022).

Autism research has recently started to explore the suggestion that autistic masking may be driven by stigma (Fulton et al., 2020; Pearson & Rose, 2021). Goffman (1963) suggested that the ability of a person to manage the impression they give is fundamental for others to consider them 'normal'. Hence, those that reveal social interaction differences are likely to be considered 'abnormal' by others and subsequently stigmatised (Gurba et al., 2024). Stigma is defined as the presence of a characteristic or attribute that renders a person 'discreditable' or 'disgraced' through the perceived negativity of its presence (Goffman, 1963). Goffman posited that a negative response to a stigmatised attribute arose by associating it with a negative stereotype, leading those marked by stigma to have a 'spoiled' identity (Pearson & Rose, 2023). This lowered status can also be enforced by 'self-stigma', whereby the person internalises negative perceptions into their self-concept, leading to acceptance of a lower status and a belief that it is deserved (Bachmann et al., 2019; Dubreucq et al., 2020).

Goffman (1963) proposed that some stigmatised attributes are visible (rendering the person discredited), and others invisible (rendering the person discreditable), and that, as a result, people might engage in particular strategies to either camouflage their attributes or adopt a 'normal' persona through impression management (Cook et al., 2023). Whilst some scholars argue that autism is an 'invisible disability', the pathologisation of autistic people's unusual communication style and body movements, such as stimming, renders them 'visible' in a society where non-autistic people can blend in with others due to their majority status (Pearson & Rose, 2023). So, even though autistic people are often considered to have an invisible disability, Radulski (2022) argues that their differences make them stand out, whether they are recognised as autistic or not.

The experience of being stigmatised can lead to the internalisation of shame and self-criticism, and the initiation of autistic masking as a search for acceptance from others and a protective mechanism to avoid bullying, rejection, and ostracisation (Moore et al., 2022). Prolonged masking is exhausting and contributes to autistic meltdowns and shutdowns, low self-esteem,

depression, anxiety, and even suicide ideation (Cassidy et al., 2020; Livingston et al., 2019). Furthermore, the risk of being misinterpreted and the consequences that follow may be high, particularly for individuals with multiple intersecting identities, such as those related to gender, sexuality, ethnic group, and cultural background (Gratton et al., 2023). Thus, the risk of ‘getting it wrong’ may be higher for marginalised people, which may lead to heightened anxiety (Spaeth & Pearson, 2023).

Gender bias in the diagnostic process

‘Sex’ refers to a person’s physical and biological characteristics assigned at birth and recorded on their birth certificate (ONS, 2019). There are other indicators, such as a person’s sex chromosomes, hormones, and anatomy (Bölte et al., 2023). The concept of ‘gender’, however, refers to an identity that is shaped by an individual’s psychological and behavioural mindset, as well as their culture and society, with their accepted gender norms, such as women, men, or non-binary individuals (Sedgewick et al., 2022).

During our lives, our biology, cognition, and behaviour interact with our culture and upbringing to shape our sense of self and how others perceive us (Butler, 1988). Individuals who are brought up as, or are viewed as belonging to, one gender may recognise themselves as another (Bonazzi et al., 2025). Nevertheless, they may continue to encounter societal expectations regarding gendered behaviour (Sedgewick et al., 2022). Butler (2006) drew upon the theory of symbolic interactionism to describe how gender expression is constructed using gesture, movement, and other forms of stylisation. Butler proposed that the outward portrayal of gender is a performance rather than an innate identity (ibid.).

In the Minority World, it is generally presumed that women, or those who society would generally perceive as fulfilling that social role, will be hospitable and act appropriately at social events. Subtleties such as dress codes, etiquette, reading social cues, and being affable are expected of females, so those ‘performing’ inappropriately are considered to be ‘deviant’ (Piening et al., 2023). Gendered expectations of sociability make it more challenging for women and gender-diverse individuals to avoid demanding social interactions than for men (Tien, Pearson, et al., 2025). Having an understanding of gender as a constructed identity, rather than a concrete one, helps one to appreciate how autistic females might appear to fit

normative expectations of what neurotypical 'looks like', by masking their autistic behaviours (Seers & Hogg, 2021).

From 1944 onwards, the stereotypical clinical presentation of white, young males became associated with autism due to the limited sample characteristics of those described in early case studies (Asperger, 1944/1991). There were only three girls among Kanner's original case study samples, but none in Asperger's samples. All were white, with the majority coming from middle-class families (Kanner, 1943). Since then, the majority of autism research has been conducted in the Majority World, with young autistic boys from white middle- or upper-class families most often recruited into studies (Maye et al., 2022). Until recently, there was a significant overrepresentation of men and boys in autism research (Belcher et al., 2023). Some studies included a limited number of females; however, the researchers often did not conduct gender-based analyses of differences, as the sample sizes were too small to explore gender disparities with the necessary statistical power (Sedgewick & Douglas, 2023). Since research and academic literature have primarily focused on boys, diagnosticians' understanding of autism has been based on the stereotypical male profile of abilities and development (Hull et al., 2020). Females face a more challenging road to getting a diagnosis than young males, who are more likely to have the stereotypical profile described in academic publications (Belcher et al., 2023).

As autism does not have an unequivocal biological marker, a clinician's diagnosis is based on their subjective opinion, understanding of a person's differences, previous experience, and the diagnostic criteria, tools, and assessment questions they use (Chahboun et al., 2022). The majority of diagnostic tools, such as the Autism Diagnostic Observation Schedule (ADOS), recognised as the 'gold standard' for autism diagnosis, were created using a sample comprised of 87% boys (Sedgewick & Douglas, 2023). As a consequence, it excels at recognising stereotypical behaviours, such as visibly noticeable stimming and repetitive actions (Rea et al., 2022). What it is not so good at is recognising those with a more nuanced behaviour profile, such as women and gender-diverse people (Sedgewick et al., 2022). To effectively assess autistic people of all ages and genders, diagnostic tools must take into account both young and mature women and gender-diverse individuals (Greene et al., 2024).

A theory that was instrumental in strengthening the association between autism and maleness was the extreme male brain (EMB) theory, which relied upon presumed 'inherent' neuroanatomical differences between males and females (Baron-Cohen, 2010). Interestingly, Asperger had also pronounced in his 1944 research paper that "the autistic personality is an extreme variant of male intelligence ... in the autistic individual, the male pattern is exaggerated to the extreme." (Frith, 1991, p. 84). According to Baron-Cohen, females tend to be more empathetic and focused on other people's feelings, whereas males are more systemising and focused on mechanical and technical procedures (Baron-Cohen, 2010). The EMB theory proposes that autistic people have an extreme form of a more 'typically male' behaviour profile, resulting in 'symptoms' such as a preference for sameness, social difficulties, and childhood atypical behaviours like lining up toys (Baron-Cohen, 2002).

Baron-Cohen (2010) speculated that, if autism was a form of an 'extreme male brain', there ought to be an increase in the hormones associated with the development of sexual dimorphism in males. Currently, there has been no consistent relationship between foetal androgens and the increased likelihood of being autistic (Coscini et al., 2021). Researchers who conducted magnetic resonance imaging (MRI) studies suggested that autistic brains may be perceived as exhibiting even greater 'masculine' traits than those of non-autistic males regarding their structure and neural function. (van Eijk & Zietsch, 2021). However, a systematic review of neuroimaging research conducted over the past 20 years has not yielded conclusive findings indicating that a person's sex affects their brain (K. Mo et al., 2021). The cognitive phenotype associated with autism, such as being detail-focused and systematic, is not indicative of a particular sex or gender, but may reflect a specific cognitive processing style (Megari et al., 2024). Clinicians' beliefs about 'male' and 'female' brains and behaviours often result in autism not even being considered when they assess a person who is not stereotypically autistic (Tien, Wolpe, et al., 2025).

Another theory to explain the significant gender disparity seen in autism diagnoses is the suggestion that females may have a 'protective effect' (Robinson et al., 2013). The female protective effect (FPE) theory states that a larger number of autistic family members is required for the hereditary condition of autism to be expressed in girls, compared to boys (Wigdor et al., 2022). However, this statement relies on an assumption that autistic behaviour in girls is identical to that observed in boys and that the standard diagnostic instrument used

is equally effective for all genders (Hull et al., 2020). Although females may well have a protective effect, more research is needed (Bai et al., 2020).

Studies suggest that autistic females are more likely to mask their autistic behaviours than males, perhaps due to societal gendered expectations that females should behave 'appropriately' (Hull et al., 2020). Researchers propose that autistic females learn correct behaviour from their peers (Bargiela et al., 2016; Cook et al., 2022). Consequently, their more subtle presentation, when compared to that of autistic males, does not get captured by clinicians or by diagnostic tools (Cook et al., 2024). Milner et al. (2022) examined accounts of masking among autistic adults and those with high autistic traits but no diagnosis. They found that autistic masking may be a barrier to diagnosis for both males and females, supporting the notion that it is the lack of a stereotypical profile, rather than a gendered phenotype, that drives under-diagnosis (ibid.). Autistic masking was used across participants of all genders in a study by Hull et al. (2017) as both a defence mechanism and a way to foster social acceptance. The relationship between gender and autistic masking is likely to be driven by the intersection of autistic and gender identities, as well as upbringing, culture, and other factors that impact individual presentations (McQuaid, Lee, et al., 2022). Using an intersectional approach highlights the need to consider the diverse ways autism may present due to other aspects of a person's identity (Benedetto, 2024). Moving away from a narrative which considers masking a feature of the 'female autism phenotype' and moving towards an intersectional perspective allows for a more finely-tuned consideration of the link between gender and masking (Doyle et al., 2022). Sadly, studies on masking behaviours in gender-diverse individuals are lacking (White et al., 2024).

Until recently, the male-to-female ratio of adult autism diagnoses was quoted as 4:1, falling to 2:1 in those with LD, and rising substantially to 10:1 in those without LD (Milner et al., 2019). This suggested that only the 'most visible' autistic females with LD were being diagnosed (ibid.). In 2017, a meta-analysis conducted by Loomes et al. (2017) used epidemiological data from children who would have met the autism diagnostic criteria, rather than those who were currently diagnosed. It concluded that the male-to-female ratio was more likely to be 3:1 across the whole spectrum and that females who meet the criteria for autism were at a higher risk of not receiving a clinical diagnosis due to diagnostic gender bias (ibid.).

Whilst researchers are becoming more aware of the diagnostic barriers and impact that these have on autistic people of all genders, including some men who do not 'fit' the stereotypical profile, this knowledge has not yet fully proliferated across services (Bhargava & Ashwin, 2025). It still has a tangible impact on those seeking recognition (Cage et al., 2022). Studies have shown that adult females are often unable to obtain a referral for an assessment, as their GPs are unaware of the more subtle clinical presentation in this group (S. J. Tromans et al., 2024). GPs may believe that the undiagnosed autistic females' problems should be easily managed with antidepressant medication or cognitive behavioural therapy (Eaton, 2024). Unfortunately, health professionals are inevitably biased in their diagnoses if only one gender's behavioural characteristics are perceived as stereotypical of a condition and regularly get described in scientific and medical journals (Kelly et al., 2024). The Autism Act's statutory guidance emphasises that gatekeepers to diagnostic services, such as GPs and psychiatrists, should have specialised autism training on the presentations seen in all age groups and genders, to refer undiagnosed or misdiagnosed individuals for assessment (DoH, 2014).

Those autistic individuals who do not have a stereotypical male profile may present in such wide-ranging and subtle ways that they may realise that their assessment should be carried out by experienced clinicians (Hayes et al., 2022). A specialist may see beyond a simplistic list of behaviours with strict thresholds and apply a more dimensional approach (Rosen et al., 2021). Gould and Ashton-Smith (2011) suggest that diagnostic assessments should be adapted to identify females who might otherwise be missed. Diagnosticians should conduct a face-to-face interview to understand an individual's full developmental history, which should reveal how they have utilised their intelligence, rather than intuition, to navigate social situations during their lives (Bastan et al., 2025).

Less experienced clinicians may view a socially confident individual, who uses appropriate gestures and engages in reciprocal conversation, as failing to meet the diagnostic criteria (Mansour et al., 2025). This is especially true for mature autistic individuals who often possess valuable insight into their circumstances and have achieved accomplishments that are often deemed too impressive (Castañeda, 2023). They would have had more years' practice in the art of masking than autistic children or adolescents (Belcher, Morein-Zamir, Mandy, et al., 2022). Unfortunately, the vast amount of effort spent over the years to blend in, despite their

differences, may significantly reduce the likelihood of obtaining an accurate diagnosis (Milner et al., 2023).

Research has shown that 'less visible' autistic girls, those without LD, are less likely to be correctly diagnosed, and, if they do manage to get a diagnosis, it is usually given later than boys (Hamdani et al., 2023). Girls are less likely to receive a diagnosis in childhood than boys, even when their levels of support needs are similar (Duvekot et al., 2017). A late diagnosis, misdiagnosis, or no diagnosis at all may impact an autistic person's well-being and their ability to achieve their full potential professionally and personally (Frizell, 2024). Significant mental strain is frequently experienced by women and gender-diverse individuals who have lived with undiagnosed autism for decades, as they have spent years attempting to suppress their autistic behaviour to present themselves as 'socially acceptable' (Rodríguez-Zafra & Garcia-Molina, 2025).

Undiagnosed autistic adults with mental health difficulties may have, at some point in their life, been sectioned under the Mental Health Act 1983, where their autism may have continued to be unrecognised and incorrectly supported (Parry & Mee, 2022). Perhaps if they had received their diagnoses earlier in their lives, they would have been less prone to developing their mental health issues (Belcher, Morein-Zamir, Stagg, et al., 2022). Many late-identified autistic females experience misidentification before receiving a formal diagnosis of autism, usually a personality disorder, bipolar disorder, or social anxiety (McQuaid, Strang, et al., 2022).

Unfortunately, secondary mental health conditions can conceal the presence of autism and make diagnostic assessment more complex (Hosozawa et al., 2021). This can lead to diagnostic overshadowing; for example, a person's difficulty in forming relationships may be attributed to social anxiety as opposed to recognising that they could be autistic (Cook et al., 2024). Ideally, clinicians should be able to recognise that, although autism might not be the presenting difficulty, mental health conditions may be secondary to autism (Rodgaard et al., 2021). However, few health professionals have the level of expertise and training required to diagnose mature autistic people with mental health issues (Curnow et al., 2023). The standard diagnostic criteria and instruments were not developed for adults with these types of multifaceted presentations (Cook et al., 2024). The experience of misdiagnosis can be traumatising and lead to inappropriate forms of medication and therapy (McQuaid et al., 2021).

An autistic person who is not a young, white, cis male should not be seen as a variation of the default; instead, they should be recognised within the diversity of autistic people and humanity (Murray et al., 2023). Dichotomous classification of gender, being divided into two distinct categories of 'male' and 'female', could lead to autistic men who do not fit the traditional stereotype of autism being labelled as expressing 'female autism' (Fennell & Johnson, 2022). Furthermore, undiagnosed autistic people who do not see similar autistic individuals represented in fiction, the media, or even in general information about autism are unlikely to consider seeking a diagnosis (S. C. Jones et al., 2023).

The binary classification of gender completely ignores the experiences of autistic gender-diverse people (Kourti, 2021b). Autistic people often do not identify strongly with gender norms (Grove et al., 2023). Research suggests that they are more likely to be gender-diverse than the general population (Strang et al., 2023). Like many autistic females and males who do not fit the 'expected profile', autistic gender-diverse people often face barriers in the diagnostic process due to not presenting the stereotypical image of what autistic people 'look like' (Greene et al., 2024). Timely identification of autistic gender-diverse people may have a positive impact on their mental health and sense of identity (Genovese et al., 2023). Unfortunately, many have experienced negative social judgments and harassment from others and struggle to access gender-affirming healthcare (Huisman et al., 2024).

Likewise, one should not ignore other intersecting identities, which are likely to shape the experiences of autistic people, such as class, ethnic group, and culture (Cascio et al., 2021). The majority of research on the female autism phenotype has been based on the experiences of white autistic females (Diemer et al., 2022). Although there is currently limited information on autism among ethnic minority individuals, empirical evidence shows that children and young people within this group are less likely to be given an autism diagnosis compared to their white peers, despite having similar levels of autistic behaviours (Fombonne & Zuckerman, 2021). Multiple studies have shown that autism diagnostic services display racialised bias during assessments of children and young people (Jones et al., 2020).

In summary, misdiagnoses and missed diagnoses in adulthood are more common in autistic women and gender-diverse people than in men, because their autistic behaviour does not necessarily conform to the standard diagnostic criteria and instruments, which are biased

towards a stereotypical 'male' profile (Tien, Pearson, et al., 2025). As the criteria are more aligned to behaviour in autistic boys, whether a diagnosis is received for those of other genders and ages depends on the knowledge and experience of gatekeepers, such as GPs, as well as clinical psychologists and psychiatrists, and their ability to recognise more complex and nuanced presentations (Suckle, 2021). As with any clinical assessment process, where one gender seems to be more prevalent, biases occurring in referral, assessment, and within the diagnostic classification system should be investigated (Hartung & Widiger, 1998).

Value of an adult autism diagnosis

There is considerable disagreement over the significance of an autism diagnosis amongst researchers and professionals, parents and carers, and the autistic community (Fletcher-Watson, 2024b). Timimi (2011) and Runswick-Cole (2014) believe that, as an autism diagnosis is linked to a stigmatised identity, laden with negative beliefs about restricted abilities and limited potential, it may lead to the use of interventions to 'correct' autism, low expectations, and social exclusion. Although the principle of inclusion for autistic people in society is rarely disputed, the way that the concept is interpreted, discussed, and written about in the literature varies widely (Bernat et al., 2025).

As an autism diagnosis is ultimately based on a clinician's subjective opinion, some academics question its scientific validity and argue that special autism educational provision should not be provided (Runswick-Cole et al., 2016; Timimi, 2011). They consider medical labelling and specialist provision for autistic children as discriminatory and exclusionist, as they believe that all people, whether autistic or non-autistic, have a right to full participation in all aspects of culture and society in the same way as their peers (Mallett & Runswick-Cole, 2014). They maintain that services should not be 'specific', 'special', 'different to', or 'additional to', but 'common to all' (Runswick-Cole, 2014). Therefore, they feel institutional structures and processes should accommodate full inclusion, not just be for those with a label of autism (Timimi et al., 2011).

In contrast, others fiercely defend the value of an autism diagnosis and believe that the needs of individuals should be identified and met in a fully accessible and, where necessary, specialised way (Cumin et al., 2021). Receiving an autism diagnosis may serve not only as a starting point for support but also as a plausible and acceptable explanation for the behavioural

differences experienced by autistic individuals (Kelly et al., 2024) (see Appendix A, Published article, pages 218-250). When undiagnosed, autistic people often feel alienated, misunderstood, unsupported, and excluded from society, and only have a partial developmental history (Secchi et al., 2023). Describing how they had been misdiagnosed in the past, autistic females have expressed how their feelings of alienation and disconnection from others remained unexplained (Craddock, 2024).

When undiagnosed autistic people continuously question their behaviour to explain their difference, it can lead to the development of secondary mental health issues, such as anxiety and depression (Belcher, Morein-Zamir, Stagg, et al., 2022). Undiagnosed autistic adults often experience high levels of anxiety during their lifetime, resulting from living in a world that does not readily understand or accommodate their needs (Nayyar et al., 2025). Without understanding that a person is autistic, professionals, family, work colleagues, and friends may misinterpret their behaviour, which may have occurred due to naivety or confusion, as deliberate non-compliance, rudeness, poor character, or a flawed upbringing (Rhodes & Seeley-Wait, 2025). Therefore, having and disclosing an autism diagnosis may prevent others from making incorrect, and often damaging, assumptions about a person's 'unusual' behaviour (Camus et al., 2022). In a study on interpersonal violence, many autistic people reported being singled out and pressured by their own families for their differences, which led to a sense of otherness and identity shame (Pearson et al., 2023). Often, an autistic woman will have been called a 'weirdo', a 'freak', or a 'snob' by others during their life (Kelly et al., 2024).

Following a late autism diagnosis, many females reassess their lives and retrospectively try to make sense of their lived experience since childhood (Garcia-Simon et al., 2025). A 'sense-making narrative' is created when a person, who previously had an inadequate understanding of themselves, gains new insight into their past experiences, leading to a deeper self-understanding (Kelly et al., 2024). Late-diagnosed autistic females will have usually felt 'different' but without knowing why (Castañeda, 2023). Autistic females have described feeling a great sense of relief when they finally understood their individuality (Seers & Hogg, 2022). Many females thoroughly research the subject of autism, which appears to help them make sense of their differences (Kelly et al., 2024). Initially, many reflect on the years of feeling misunderstood, on the missed opportunities, and on how different their lives could have been if they had been diagnosed when they were younger. Being able to acquire an informed

explanation for their difference is usually a positive development (Russell et al., 2025). A diagnosis can play a constructive role by drawing attention to an autistic individual's strengths and talents, enabling them to develop and benefit from these areas (Huang et al., 2023). Autistic people may have abilities that lead to success in academic study and the workplace, particularly if nurtured and supported by those with an understanding of autism (Gemma, 2021). However, there is limited guidance available on how to develop an autistic person's strengths (Rosqvist et al., 2020).

For some autistic people, a professional diagnosis may help redefine their sense of self and provide access to an autistic identity and culture (Harmens et al., 2022). It may simply formalise a self-diagnosis and identity that they had already assumed, though not necessarily disclosed (Corden et al., 2021). Newly diagnosed individuals may contact other autistic people, for example, through social media or social groups (Skafle et al., 2024). This connection with the autistic community may help late-diagnosed autistic people to forge a new self-concept and a feeling of belonging (Cooper et al., 2023). Many people find joy in being able to relate to others who understand their experiences. The community may provide them with material and emotional resources that they may have found challenging to acquire due to their stigmatised identity (Botha et al., 2022). When neurological differences are recognised, rather than being adapted and hidden, they may lead to legal and financial assistance, reasonable adjustments in the workplace, benefits, and educational support.

A study by Powell and Acker (2015) reported that adults felt that their autism diagnosis had a positive effect on their lives. By connecting with other autistic people online and feeling proud of their new 'autistic identity', newly diagnosed people may find it beneficial to adopt the 'label' of autism (Gilmore et al., 2023). As Singer (1999) suggests, "Whereas the traditional image of 'diagnosis' is of something reluctantly sought, dreaded, resisted, and imposed from outside, people with 'marginal' neurological differences clamour at the gates, self-diagnosed, and demanding to be let in." (p. 65)

The research presented in this chapter provided the historical and social context that shaped the construction of autism as a distinct diagnostic category in the Minority World. It identified various discourses and institutional practices that contributed to the naming and interpretation of autistic behaviours. Autism as a neurodevelopmental difference was also introduced,

including a description of its defining features, including social communication and interaction difficulties, sensory sensitivities, and restricted, repetitive behaviours. This was followed by an explanation of masking and some of the mental health conditions that may co-occur in autistic women and gender-diverse individuals. The reasons behind the bias in the diagnostic process towards a white, cisgender, male, 'stereotypical' presentation of autism were discussed, followed by a description of the perceived benefits of an adult autism diagnosis to those who have been undiagnosed for many decades. Although there may be varied perspectives on the value of a late autism diagnosis, it may serve as a starting point for accessing support that is badly needed, and to explain the challenges and differences experienced by autistic people throughout their lives.

In the next chapter, I present a literature review and thematic synthesis of the peer-reviewed qualitative articles on the experiences of motherhood among autistic women and gender-diverse individuals that have been reported in academic journals before February 7, 2025.

CHAPTER 3 THEMATIC SYNTHESIS OF STUDIES ON THE EXPERIENCES OF MOTHERHOOD AMONG AUTISTIC WOMEN AND GENDER-DIVERSE INDIVIDUALS

Introduction

Although there has been a steady increase in the number of autistic people being diagnosed in recent decades, many autistic women and gender-diverse individuals continue to be unidentified and poorly represented in research (Putnam et al., 2025). This has contributed to a ‘male-biased’ understanding of autism (Tsirgiotis et al., 2021). Studies have shown that females are more likely than males to receive an autism diagnosis in adulthood rather than in childhood (Harrop et al., 2024). Many do not receive their diagnosis and subsequent support until they have had children themselves (Garcia-Molina & Cortes-Calvo, 2025). They often become aware of their autistic traits while researching their children’s autistic behaviours (Adams et al., 2021) (see Chapter 1, Introduction, page 10).

When I started my doctoral studies in 2017, I was astonished by the absence of qualitative research on autistic motherhood in the academic literature, as autistic mothers are likely to have different mothering experiences than those who are non-autistic (Dugdale et al., 2021). I imagined that motherhood might present particular challenges for autistic women and gender-diverse individuals, due to their sensory sensitivities, the need to adjust to their changing roles and responsibilities, and the lack of support available from adult autistic services. Due to the high heritability rate of autism, autistic mothers tend to produce autistic children (Bai et al., 2020). Studies have shown an association between parenting autistic children and increased levels of stress compared to children who are non-autistic or have other disabilities (Gentles et al., 2024; Thapar & Rutter, 2021).

In 2021, I conducted a preliminary search of the academic literature and identified only two qualitative studies on autistic motherhood that had been published earlier that year. A few quantitative articles had also been published, although these were mainly focused on pregnancy, childbirth, breastfeeding or chestfeeding, and the postnatal period. However, the vast majority of articles identified from my search concentrated on the experiences of non-autistic mothers who were raising autistic children (S. Hampton et al., 2022).

I conducted this thematic analysis to explore the experiences of motherhood for autistic women and gender-diverse individuals. This exploration aimed not only to shed light on their challenges but also to reveal their unique strengths that may have distinguished their parenting journey. My review question was:

What do findings from primary qualitative studies reveal about the experience of motherhood for autistic women and gender-diverse individuals?

I registered this thematic synthesis with the PROSPERO International Prospective Register of Systematic Reviews on 8th April 2025 (Registration Number: 1028827).

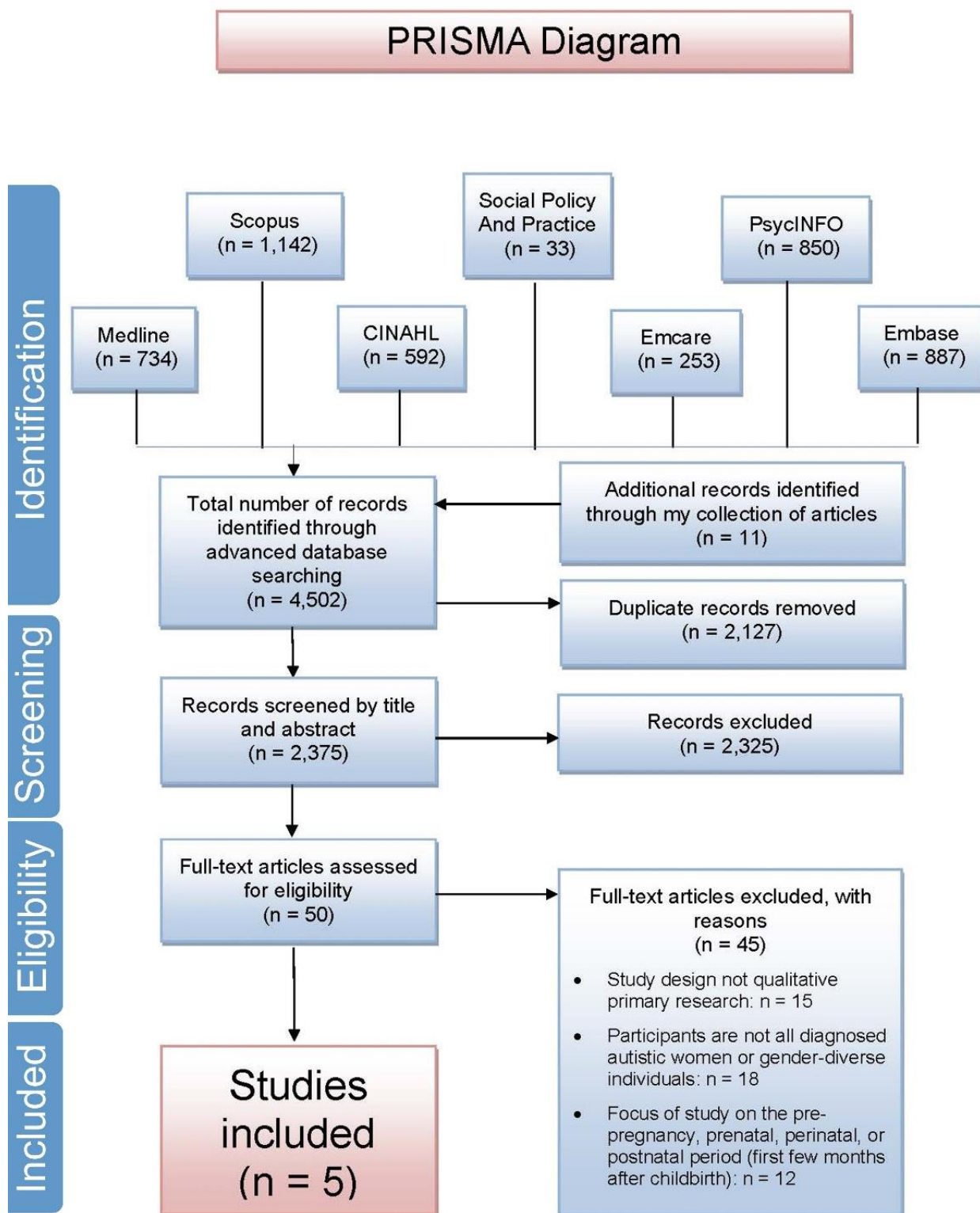
Methods

Search strategy

I conducted a comprehensive and exhaustive literature search to identify all the relevant qualitative evidence for this review. I chose to focus on qualitative research because this approach is particularly well-suited to the exploration of the nuanced and subjective experiences of autistic mothers (Braun & Clarke, 2024). Qualitative enquiry offers a deeper understanding of the lived experiences and personal insights that quantitative approaches may overlook (Bazen et al., 2021). As I was aware of the paucity of qualitative research on this subject, I chose a broad approach to identify papers I might not have otherwise found (Amir-Behghadami, 2024). On 7th February 2025, I systematically searched the literature using the following seven electronic databases for peer-reviewed primary research: Scopus, Embase, Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Policy and Practice, and Emcare (Figure 1).

The search term I used, adapted for each database as necessary, was: ***((autis* OR asperg* OR ASD) AND (wom?n OR mother*))***

Figure 1 PRISMA diagram for the thematic synthesis on autistic motherhood



I limited the articles from my search to studies published in English between 1st January 1940 and 7th February 2025. I identified 4,491 publications as a result of my searches and uploaded the list of publications into the reference management software EndNote version 21. Throughout my doctoral studies, I kept up to date with all the newly published articles on autism and neurodiversity, creating a personal library using EndNote to stay informed about the latest research. From this library, I was able to provide an additional 11 articles that the database searches had missed, which increased my list of publications to 4,502 before deduplication. I found EndNote helpful, as it was relatively straightforward to remove 2,127 duplicate articles, leaving me 2,375 articles to screen (Figure 1).

Study selection

I screened the titles and abstracts of the 2,375 articles by consulting my inclusion and exclusion criteria, and each article was either retained or excluded from my list (Table 1). Articles were only included if they reported data on the experiences provided by formally diagnosed mothers. I was specifically interested in their experiences of mothering their children during their development from infancy through to adulthood, as well as the mothers' descriptions of the strengths and challenges they faced.

The exclusion criteria included literature reporting on studies of non-human subjects, non-autistic parents of autistic children, or parents who had not been diagnosed as autistic (Table 1). Studies that solely reported data from medical records or perspectives of other people, such as health or social care professionals, on the experiences of autistic parents were also excluded (Sandra Thom-Jones et al., 2024). For this thematic synthesis, mothering was defined as the act of caring for and raising a child as a mother. This included biological mothers, stepmothers, and adoptive and foster mothers. The review was not limited to a specific geographical location or setting. The publication types included peer-reviewed journal articles that described qualitative studies on autistic motherhood, using primary data (Table 1). Those that were not peer-reviewed, did not present original data, did not use semi-structured interviews or focus groups for data collection, or were not journal articles were excluded.

Table 1 Inclusion and exclusion criteria of thematic synthesis of autistic motherhood

	INCLUSION	EXCLUSION
<i>Period of publication</i>	Between 1st January 1940 and 7 th February 2025	
<i>Study design/type</i>	Peer-reviewed, primary, qualitative and mixed research studies, using semi-structured interviews or focus groups for data collection	Quantitative research studies and publication types that are not peer-reviewed or are without primary data, e.g., expert opinions, clinical reports, letters, editorials, comments, reviews, books, book chapters, book reviews, blogs and social media posts, conference abstracts, dissertations, news items, or articles not describing studies on the lived experience of motherhood for autistic women
<i>Study population</i>	Mothers with a diagnosis of autism	Mothers who have not received a diagnosis of autism or who self-identify as being autistic
<i>Gender</i>	Women or people who identify as gender-diverse, for example, non-binary or trans women	Men
<i>Subject matter/focus</i>	The lived experience of motherhood in autistic women and gender-diverse individuals	Focus of study on the pre-pregnancy, prenatal, perinatal, or postnatal period (first few months after childbirth) The subject matter concentrates on proposed causes, medications, interventions, therapies or 'cures' Evaluation of methods or diagnostic/screening tools Lab-based, animal, genetic, biochemical, neurological, or molecular studies

The accepted publications had to report on studies about the parenting experiences of diagnosed autistic mothers (Table 1). Therefore, I excluded some studies that focused on the pre-pregnancy, prepartum, intrapartum or early postpartum periods. I also excluded accounts given by non-autistic parents, as well as those concerned with medications, interventions,

'cures', evaluation of methods, diagnostic/screening tools, and animal, genetic, biochemical, neurological, or molecular studies (Sandra Thom-Jones et al., 2024).

During the screening process, I realised that some of the article titles were quite conceptual and abstract, making it challenging to identify potentially relevant publications solely from the title. I realised that it was essential to pay close attention to both the abstracts and titles of the publications. When I was unsure whether to include or reject an article, I opted for inclusivity rather than exclusivity, as I did not want to discount any relevant literature. The number of records excluded during the title and abstract screening process was 2,325, leaving 50 articles to be assessed for eligibility by reviewing the full text of each publication.

I obtained the electronic PDF files of all articles that had passed the screening procedure by downloading them from the databases or the internet. Then I imported these references into the EndNote library. I assessed these articles by reading the full text and determining whether they should be included or excluded based on the criteria outlined in Table 1. I documented the reasons for any full-text exclusions and recorded them on the PRISMA diagram (Figure 1). At the end of my full-text review, I was left with five qualitative publications that met my inclusion criteria.

Quality appraisal

I assessed the methodological quality of the five included studies using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (see Appendix B), which provided a systematic tool for assessing the reliability and validity of the studies (Gore et al., 2024; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Talcer et al., 2021; Winnard et al., 2021). This tool is a tried and tested approach for appraising qualitative research, and many reviews employ this checklist or a variant of it (CASP, 2018; de la Cuesta Benjumea, 2024). The CASP checklist structured my thinking about several key aspects of quality in the publications (de la Cuesta Benjumea, 2024). It contained ten questions addressing the possibility of bias in research design, conduct, and analysis, and was divided into these three sections: "Are the results of the study valid?", "What are the results?" and "Will the results help locally?". Each question needed to be rated "Yes", "No", or "Can't tell". Several prompts below each question drew attention to some critical issues that needed to be considered. A "comments" space allowed me to record my reasoning to support my answers. Currently, there is no consensus on

applying cut-off points or determining whether a study meets a standard, so the judgment of quality was based on my subjective opinion (de la Cuesta Benjumea, 2024).

Data extraction

I extracted study characteristics from the five articles using a data extraction template I created in Microsoft Excel that included fields for the first author, year of publication, country of authors, name of journal, study focus, sample size, analysis method, and key findings or themes (Table 2). I also used a template to record the participants' characteristics, which included fields for the number of autistic mothers participating, their gender, age, age at autism diagnosis, country of residence, ethnic group, number of children, number of autistic children, and the ages of the children (Table 3). Additionally, in Table 4, I recorded data on the researchers' positionality, autistic community involvement, and the type of terminology used in the articles, i.e., person-first or identity-first language (see Terminology section at the beginning of this dissertation). I categorised text from the results section of the five articles into themes and analysed those themes following the thematic synthesis procedure by Thomas and Harden (2008).

Findings

Studies identified

After following the full-text eligibility-checking process previously mentioned, I classified five articles as 'accepted' (Gore et al., 2024; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Talcer et al., 2021; Winnard et al., 2021). The key findings and original themes of the five qualitative studies are provided in Table 2. I assessed the five articles as high quality, scoring seven out of ten or above, including three that I evaluated at the maximum score of ten (Table 5). The measure I assessed that was not evident in two articles was "Has the relationship between researcher and participant been adequately considered?".

Table 2 Key findings of the studies in the five articles included in the review

First author	Year of article	Country of authors	Journal	Study focus	Sample size	Analysis method	Interview procedure	Key findings/themes
Gore et al.	2024	Australia	Autism in Adulthood	Experiences of autistic working mothers	10	Thematic analysis	Video interviews	Three themes: (1) "Wellbeing: work gives me purpose" discussed how work supported mental health and the importance of financial independence; (2) "Challenges: it's hard being an autistic working mother" included the need to constantly juggle the needs of work and children, how guilt was a constant companion, and the challenges of finding suitable part-time work; and (3) "The invisible disability: everyone thinks I look okay" discussed others lack of understanding, the struggle to get support at work, how trying to do it all leads to burnout, and how a lack of support had led to self-sufficiency out of necessity.
Radev et al.	2024	UK	Autism	Experiences interacting with statutory services regarding their autistic child	10	IPA	Telephone and video interviews	Two superordinate themes: (1) "The wider system is the problem" revealed that autistic mothers felt dismissed and unsupported by services, felt that the system was unjust, and they needed to fight for the right support; and (2) "Feeling judged and stigmatised" discussed the use of negative language by services was offensive and misleading, that the training of professionals was not good enough, and usefulness of disclosing their own diagnosis.
Sutcliffe-Khan et al.	2024	UK	Current Psychology	Parents' views on autistic motherhood (Study 1 of 2 only - mixed method)	9	Thematic analysis	Email, face-to-face, and video interviews	Two themes: (1) "Strengths in parenting" which identified various strengths including their focused interest in their children, their reflection on their mental states, their connection with their children, their good coping strategies, how they identified with their children's autism, and not caring what others thought; and (2) "Challenges in parenting" identified difficulties including sensory challenges, having to cope with constant changes, having to socialise, managing mental and physical exhaustion, and not being taken seriously by professionals involved with their children.
Talcer et al.	2021	UK	Journal of Autism and Developmental Disorders	Sensory experiences of autistic mothers	7	Thematic analysis	Face-to-face interviews	Five themes: (1) "Antenatal experiences" described the women's experiences of pregnancy, severe sickness, labour and birth; (2) "Sensory experiences in motherhood" described the women's experiences of auditory and tactile stimuli, smell, vision and changes in body awareness; (3) "The impact of sensory processing difficulties" described how their experiences impacted their social life, work, mental health and anxiety and how they became overwhelmed and fatigued; (4) "Strategies and needs" which included strategies such as downtime, asking for help, sensory strategies, their quest for knowledge and research, finding their tribe, and planning and maintaining a routine as well as needs such as an autistic mother's group and more training for professionals; and (5) "Diagnosis" described the impact of their diagnoses, particularly late diagnoses, and the benefits it brought them.
Winnard et al.	2021	UK	Journal of Autism and Developmental Disorders	Female perspective and experiences of being an autistic parent	8 (4 parents)	IPA	Face-to-face and telephone interviews	Six superordinate themes: (1) "Parenthood: fun and games" described how participants reported that a positive parent-child relationship was important for providing, sharing and receiving 'love'; (2) "Support: giving and receiving" described supporting a child to learn and develop was essential but mothers had difficulties accessing specialist support; (3) "Routine and structure" expressed the participants' remarkable skills in ensuring routine, which they described as a benefit; (4) "Sensory sensitivities" were perceived as causing difficulties in being a parent; (5) "Interaction" discussed the challenges of the increased social interaction as a consequence of having to communicate with teachers, other parents, etc.; and (6) "Unique insight" described how having a shared diagnosis was advantageous and gave the mothers insight to support their children.

Table 3 Participant demographic information from the five included articles

First author	Year of publication	Number of autistic mothers	Gender	Age range	Age at or time since autism diagnosis	Country of residence	Ethnic group	Number of children	Number of autistic or neurodivergent children	Children's ages
Gore et al.	2024	10	All women	34-50 years (mean: 43 years)	Mean: 38 years	Australia	1 white British and 9 white other	All had at least 2 children under 18 years old	9 participants had at least 1 neurodivergent child	All under 18 years
Radev et al.	2024	10	All women	35-55 years (mean: 47 years)	Mean number of years since diagnosis: 3 years	UK	8 White British and 2 mixed race	Unspecified	All participants had at least 1 autistic child, total: 15	3 were 5-10 years and 12 were 11-17 years
Sutcliffe-Khan et al.	2024	9	All women	Unspecified	Unspecified, although 7 had been diagnosed after having children and 2 before	UK	Unspecified	19 children	Unspecified, although 5 participants had at least 1 autistic child, 3 possibly had an autistic child and 1 did not	Age range: 18 months-24 years
Talcer et al.	2021	7	All women	30-55 years	Unspecified	UK	Unspecified	14 children	6 autistic children	Age range: 2-22 years
Winnard et al.	2021	4	All women	Mean age: 51 years	Unspecified	UK	Unspecified	Unspecified	Unspecified, although 3 participants had at least 1 autistic child and 1 did not	Age range: 8-40 years (mean: 23 years)

Table 4 Researcher positionality and community involvement in the five included articles

First author	Year of publication	Researcher positionality	Community involvement	Terminology
Gore et al.	2024	First author autistic mother	Advisory group of five autistic mothers reviewed the interview guide and recruitment materials	Identity-first
Radev et al.	2024	First author autistic mother	Two autistic mothers looked at interview questions and recommended some changes	Identity-first
Sutcliffe-Khan et al.	2024	Researcher	Members of an autistic mothers' project advisory panel provided input on the research topic, design, and interpretation. Participatory research methodology.	Identity-first
Talcer et al.	2021	First author autistic mother	Interview questions were informed following online consultation within closed online groups with autistic mothers.	Identity-first
Winnard et al.	2021	Unspecified	Unspecified	Person-first

I did not consider any of the five studies to have significant problems that would have affected my interpretation of their findings. Based on my ratings, I did not exclude any of the articles from the thematic synthesis.

Two of the five articles were published in 2021, and the remaining three were published recently in 2024 (Table 2). Four of the articles focused solely on the experiences of mothers, but one article included both mothers and autistic females who were not parents. The number of mothers

Table 5 Critical Appraisal Skills Programme (CASP) Qualitative Checklist scores of the five included articles

	Gore et al., 2024	Radev et al., 2024	Sutcliffe-Khan et al., 2024	Talcer et al., 2021	Winnard et al., 2021
Section A Are the results valid?					
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Can't tell
6. Has the relationship between researcher and participant been adequately considered?	Yes	Yes	Can't tell	Yes	Can't tell
Section B What are the results?					
7. Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Can't tell
8. Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes
9. Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes
Section C Will the results help locally?					
10. How valuable is the research?	Yes	Yes	Yes	Yes	Yes
TOTAL	10/10	10/10	9/10	10/10	7/10

who were autistic ranged from four to 10 (mean: eight). Of the 40 autistic mothers who participated in these studies, most were residents of the UK (30), while the rest were residents of Australia (10) (Table 3). The method of data collection used in all these studies was semi-structured interviews, which were conducted in various ways, including face-to-face, telephone, email, and online interviews, with three studies using a combination of modalities (Table 2). Three studies employed thematic analysis to analyse their data, while the remaining two used Interpretative Phenomenological Analysis (IPA).

I determined the disciplinary background of the research teams based on the location of the lead researchers, which revealed that four of the qualitative studies stemmed from psychology and one from occupational therapy. Three of the five articles reported that the research team included one or more autistic mothers (Table 4). One of the two remaining articles indicated that members of an advisory panel, which included autistic mothers, contributed their insights regarding the research topic, design, and interpretation. One study did not report whether any of the research team were autistic mothers, and there was no reference to the involvement of autistic people other than as study participants. Disclosure still carries risks of discrimination for autistic academics, so it may be that the author(s) deliberately chose not to disclose their neurotype

(Jones, 2022). However, this particular article was the only one of the five publications that used person-first language rather than identity-first language (Taboas et al., 2023).

In the five articles, all the mothers identified as women, so none of the 40 autistic mothers were gender-diverse individuals (Table 3). The age ranges, mean ages, and times since diagnosis of participants from each study differed; however, not all articles presented this information, which made it hard to compare their demographic profiles. The ethnic groups of the participants were only reported in two of the articles, indicating that there were at least nine white British, nine white Australian (non-Indigenous), and two mixed-race participants. Due to the varying presentations of data in the five articles, it was also not possible to calculate the total number of children the participants had and which were autistic and which were neurodivergent children. The participants' children ranged in age from 18 months to 40 years.

Thematic synthesis

Strengths

Several participants in the studies by Radev et al. (2024b), Sutcliffe-Khan et al. (2024) and Winnard et al. (2021) believed that they had specific autistic strengths, such as being focused, resilient, determined, and willing to research child-rearing. Having an intense interest in parenting enabled the mothers to make informed, evidence-based decisions that were right for their children. The participants in Talcer et al. (2021) were determined to avoid the struggles they had experienced during their own upbringing from occurring in their children's lives. They had read many books on parenting before becoming new mothers.

In Sutcliffe-Khan et al. (2024), seven of the nine autistic mothers were diagnosed after becoming parents; in most cases, when their child was assessed. The mothers shared how receiving an autism diagnosis had enhanced their confidence, self-acceptance, and overall well-being, allowing them to parent with a deeper understanding of their strengths, challenges, and coping strategies (Sutcliffe-Khan et al., 2024). The participants in the article by Talcer et al. (2021) felt that a period of adjustment was necessary following their diagnosis, which allowed them to accept their differences and be more open about their difficulties. They found that contacting other

autistic mothers on social media had been beneficial, as they seemed to understand their issues better than non-autistic mothers and were not so judgmental.

The advantages of having a shared neurotype with their autistic children were discussed in Sutcliffe-Khan et al. (2024) and Winnard et al. (2021). The mothers' strong connection with their autistic children gave them insight into their own experiences and the ability to relate to their children in a way that non-autistic mothers may not easily achieve. The autistic mothers considered themselves "experts-by-experience" and used practical strategies to manage their children's needs based on their experiential knowledge (Winnard et al., 2021, p. 6). In Talcer et al. (2021), the ability of the autistic mothers to pass on their coping strategies to their children made parenting easier to manage. The four autistic mothers in Winnard et al. (2021) felt that an empathetic "positive parent-child relationship" had proven to be essential for providing and receiving love (p. 4). They explained that supporting a child in their development and enabling them to gain an understanding of life gave them great satisfaction. However, one participant in Sutcliffe-Khan et al. (2024) had a neurotypical daughter whom she found challenging to understand and relate to.

Difficulties

The transition to new motherhood is associated with new roles and responsibilities. Similar to non-autistic working mothers, participants in Gore et al. (2024) found balancing work, caring for their children, household tasks, and self-care to be challenging. However, the stress associated with this juggling was more extreme for the autistic mothers who were raising autistic children, especially as they had to manage their time and energy to go to their autistic children's health and therapy appointments and to apply for educational support. The constant changes in their lives during this period presented difficulties for participants in Sutcliffe-Khan et al. (2024) and Winnard et al. (2021). The mothers were intolerant of uncertainty and had trouble shifting their attention or being interrupted, which made them feel anxious and that they had lost control of their daily routine. To guide their parenting decisions and mitigate stress, they attempted to initiate new systems and schedules, although they constantly needed to adapt them as their children grew and developed.

Motherhood presented many extra-sensory demands that were challenging for the autistic mothers in Talcer et al. (2021) and Sutcliffe-Khan et al. (2024). Almost all participants in Talcer et al. (2021) reported heightened sensitivity to auditory stimuli, which caused increased stress, overwhelm, and mental health issues. The majority also reported increased tactile sensitivity associated with their physical closeness to their children, as well as breastfeeding which they described as extremely painful. In Winnard et al. (2021), the autistic mothers recalled the additional tactile and olfactory stimuli they experienced when preparing food for their children.

Impact

The working autistic mothers in Gore et al. (2024) felt guilty about the necessity of managing their financial need to work and their caregiving responsibilities. This guilt was attributed to societal judgment of mothers who are not “stay-at-home mums” (p. 52). They reported feeling overwhelmed and “burnt out” due to their constant need to juggle work and parenting (p.53). Managing these responsibilities was made more challenging by the additional complexity of having to advocate for their autistic children to access the support they needed. The mothers in Radev et al. (2024b) described the need to endlessly fight for support for their neurodivergent children as a major contributor to their exhaustion. Unfortunately, their exhaustion would subsequently reduce their ability to advocate effectively, so they had to pick “certain battles over others” (p. 1399). Due to the lack of support they received, autistic mothers in the studies by Gore et al. (2024) and Radev et al. (2024b) felt that they needed to rely on themselves rather than consult professionals.

Participants in the study by Gore et al. (2024) described how their sensory preferences and needs, and those of their children, sometimes clashed. However, in Gore et al. (2024), Sutcliffe-Khan et al. (2024), and Talcer et al. (2021), participants prioritised their children’s needs over their own, for example, attending birthday parties, which inevitably presented sensory and social challenges. Before becoming mothers, they would have avoided social group activities, preferring to spend time alone on their focused interests. This prioritisation of their children’s needs was described by the mothers in Sutcliffe-Khan et al. (2024) and Talcer et al. (2021) as mentally and physically exhausting, increasing executive dysfunction and symptoms of anxiety and depression as a result. The mothers in Talcer et al. (2021) continued to breastfeed despite experiencing high

levels of pain and discomfort, therefore sacrificing their own needs in the best interests of their children.

The participants would often compare themselves unfavourably against neurotypical mothers. In Talcer et al. (2021), some reported feeling guilty as they believed that they were not carrying out their motherly duties as well as neurotypical mothers. Some felt ashamed because they had not immediately developed an emotional bond with their baby after childbirth and felt that their connection had been delayed in comparison to other non-autistic mothers. As their children developed and their behaviour changed, the mothers in Sutcliffe-Khan et al. (2024) started to doubt their ability to meet their needs and worried about the judgment of others.

Strategies

Mothers described the strategies they used to cope with the stresses inherent in parenting, which included: asking for advice and support from other autistic mothers online, as well as from partners, close family, and friends; and having some downtime on their own (Sutcliffe-Khan et al., 2024). Participants in Talcer et al. (2021) explained that, after becoming mothers, they could no longer rely on their most helpful coping strategy – taking some time-out to recharge and reduce sensory overwhelm. However, as their children grew older and started school, there were more opportunities for downtime. Most reported that, if they were unable to get any respite, they would avoid attending any social events to prevent becoming overwhelmed. Social interactions with other parents and children were a particularly challenging aspect of being an autistic mother (Winnard et al., 2021).

In Sutcliffe-Khan et al. (2024), the mothers found stimming beneficial, and some revealed that they had deliberately self-harmed as a means to alleviate stress, such as picking their skin or hitting themselves. Small strategies and adaptations to their home environment helped improve the well-being of the whole family, such as playing calming music, keeping the living area tidy, and using low lighting. Autistic working mothers, as described in Gore et al. (2024), reported that their work provided them with a sense of purpose, which in turn supported their mental well-being and financial independence. Occasionally, they would need to negotiate with their partners for

support when conflicts arose between their work and caring responsibilities. However, these negotiations often led to disputes over “who’s busier today?” (p. 52).

Accessing support

The professionals that the mothers were in contact with seemed to have had minimal autism training and often criticised their abilities, making it difficult to get support for their parenting or their children (Talcer et al., 2021). The participants in Radev et al. (2024b) felt judged and stigmatised due to the language professionals had used, which they believed was an indication of their outdated understanding of autism as a result of their poor training. They did not appear to contemplate the fact that the parents of autistic children may also be autistic, putting the responsibility on the mothers to educate them, while attempting to advocate for themselves or their children. They felt that the wider system was the problem rather than those individual professionals, and services could be improved through better training, which participants believed should be developed and run by autistic adults (Radev et al., 2024b).

In Sutcliffe-Khan et al. (2024), the participants described occasions when they were not believed or taken seriously by professionals regarding the health or education of their children, so in subsequent appointments, they attended armed with all the facts and the latest research. When autistic working mothers in Gore et al. (2024) disclosed their diagnosis to their employers, some were not believed. Their managers had assumed they were able to cope without support, as they had previously juggled their employment and parenting responsibilities (p. 1). As they lacked knowledge about autism, the managers were unaware that the participants had been masking their difficulties.

In Radev et al. (2024b), the mothers described their experiences of feeling judged and stigmatised while interacting with statutory services regarding their autistic children. Previous experiences of stigma dissuaded many participants from disclosing their autism when attempting to access support, either for themselves or their children. They were often fearful of being ‘othered’ or labelled as a bad parent (Gore et al., 2024; Radev et al., 2024b; Sutcliffe-Khan et al., 2024). Mothers in Talcer et al. (2021) were worried that they would be thought of as being ‘a risk’ to their family. In contrast, some felt that disclosing was an essential part of spreading awareness

and thought that they had received a lot more credibility from professionals by doing so, making them feel “empowered” (Radev et al., 2024b, p. 1400).

Autistic mothers were motivated to get the support their children needed at school and to make sure they were treated fairly by professionals (Sutcliffe-Khan et al., 2024). However, in Radev et al. (2024b), Winnard et al. (2021), and Sutcliffe-Khan et al. (2024), participants felt they had to fight to obtain the proper support for their children, which increased their stress and frustration. They were sometimes misunderstood and accused by professionals of being demanding. Some participants in Radev et al. (2024b) described a lack of communication between services, which resulted in delays in receiving support for their children. Others mentioned promises made by services that were not kept, which left them feeling let down by the system. For some families, rules laid down in legislation had not been followed, and they felt a sense of injustice at not being provided with the support that they were entitled to. These circumstances had negatively impacted their mental health and self-confidence (Radev et al., 2024b). The process of demanding accommodation for their children, with some having to attend special educational needs tribunals, was perceived as unfair by participants. They believed that those who could easily navigate the system, were willing to battle these institutions, and had the money to pay lawyers’ fees, were more likely to receive the support their children needed.

Discussion

This review revealed that the number of articles on autistic motherhood had increased in the last few years, although it still remained limited, with most research focusing on pregnancy, childbirth, and caring for newborn children and considerably less on parenting children from infancy to adulthood (Hernández González et al., 2024).

The five articles that were identified described high levels of empathy, commitment to their children’s well-being, and positive parent–child relationships among autistic mothers (Dugdale et al., 2021). Those who were undiagnosed before becoming mothers often referred to their diagnosis as beneficial, as it had increased their self-confidence and self-understanding, although they felt that a period of adjustment was necessary (Edwards et al., 2025; Sutcliffe-Khan et al., 2024; Talcer et al., 2021). They believed they possessed several distinct autistic strengths, such

as their intense interest in researching parenting (Sandra Thom-Jones et al., 2024). As they had studied this subject extensively, it enabled them to make informed decisions regarding their parenting style (S. Hampton et al., 2022; Sutcliffe-Khan et al., 2024). The focused research they conducted on raising their children, whether autistic or non-autistic, was likely to be a beneficial consequence of their monotropic neurotype (Patrick Dwyer et al., 2024) (see Chapter 2, Social and Historical Context, pages 14-15). They made a concerted effort to create a warm and supportive home environment for their children (Dugdale et al., 2021; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Winnard et al., 2021). Autistic mothers reported experiencing joy, a deep connection, and a good understanding of their children's interests and support needs (Dugdale et al., 2021; Radev et al., 2024b; Smit & Hopper, 2023; Sutcliffe-Khan et al., 2024; Winnard et al., 2021).

However, the changes experienced and adjustments required when becoming a new mother naturally entailed some disruption to the participants' daily routines, and revisions to their schedules continued to occur as their children grew and developed (Hernández González et al., 2024). Intolerance of uncertainty is frequently more pronounced in autistic individuals, which may explain the increased anxiety experienced by autistic mothers during this transition (Bird et al., 2024; Sutcliffe-Khan et al., 2024; Winnard et al., 2021). The autistic mothers also faced significant stress and sensory overload when their autistic children exhibited behaviours that conflicted with their own sensory processing differences (Hampton et al., 2021) (see Chapter 2, Social and Historical Context, pages 23-25). These hindered the mothers' ability to manage their parenting responsibilities effectively and impacted their mental health (Hernández González et al., 2024; Sutcliffe-Khan et al., 2024; Talcer et al., 2021; Winnard et al., 2021). Autistic mothers may require more respite from noisy situations to prevent sensory overload than those who are non-autistic (Poulsen et al., 2024). The autistic mothers reported tactile and olfactory challenges while preparing food or during messy play (Asaridou et al., 2024; Talcer et al., 2021). They also had sensory difficulties associated with breastfeeding, yet persevered in their attempts, despite experiencing high levels of pain and discomfort (Wilson & Andrassy, 2022). The mothers, therefore, sacrificed their own needs in the best interests of their children (Pohl et al., 2020; Talcer et al., 2021).

The participants' hypersensitivities caused stress, anxiety, and physical pain for them and, hence, impacted their psychological well-being and mental health (Jurkevithz et al., 2020). Focusing on their children's support needs, but not their own, and having to advocate for them was described as exhausting. The participants tended to compare themselves unfavourably with mothers that they met who were neurotypical (Gore et al., 2024; Pohl et al., 2020; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Talcer et al., 2021). Some doubted their parenting ability and worried about the judgment of others (Turnock et al., 2022). Those autistic mothers who were working outside the home expressed high levels of guilt and anxiety as they tried to juggle work and childcare responsibilities (Heyworth et al., 2023). However, their employers showed a lack of understanding of the challenges they faced (Gore et al., 2024; Szechy et al., 2023). The autistic mothers in the studies seemed to have contributed more to caregiving than their partners, a position that may have stemmed from societal gendered expectations (Craddock, 2024). This seemed to create additional pressure for these working autistic mothers and contributed to their lower levels of subjective well-being (Gore et al., 2024; Lindsay et al., 2021).

Following their diagnosis, participants employed several valuable strategies to lessen the effects of their sensory processing difficulties, including taking breaks, asking for support, stimming, linking up online with other autistic mothers, and adapting their home environment (Crane, Lui, et al., 2021; Smith & Sharp, 2013; Sutcliffe-Khan et al., 2024; Talcer et al., 2021). Although downtime was the most effective method of reducing sensory over-reactivity, as primary caregivers for their children, it was not always possible for them to escape from overwhelming stimuli (Poulsen et al., 2024; Talcer et al., 2021). Instead, they deliberately avoided or withdrew from social commitments to reduce potential over-stimulation and burnout (Jones et al., 2021; Talcer et al., 2021). Contact with online autistic groups was an important strategy for autistic mothers to access a supportive community (Crompton et al., 2022; Sutcliffe-Khan et al., 2024). Worryingly, some of the participants reported the use of deliberate self-harm to alleviate stress, for example, picking at their skin or hitting themselves (Licence et al., 2020; Talcer et al., 2021).

Lack of support had a significant effect on reducing well-being and quality of life for the mothers in the five studies (Browne et al., 2024). They struggled to communicate their needs to healthcare and educational professionals regarding themselves and their children, which heightened their

stress levels and lowered their self-confidence (McVey et al., 2023; Sutcliffe-Khan et al., 2024; Winnard et al., 2021). Access to support sometimes seemed to depend on the mothers' knowledge about autism, and their willingness to educate the professionals they were in contact with (Milosevic et al., 2022; Radev et al., 2024b). The participants often felt that they knew more about autism than they did (Bury et al., 2024). Even so, their concerns were not taken seriously, and they felt misunderstood and disregarded (Mason et al., 2021; Sutcliffe-Khan et al., 2024). While it is possible that these difficulties may also occur for non-autistic mothers of autistic children, the mothers in the studies reported their specific experiences of feeling judged and stigmatised (Dugdale et al., 2021; Radev et al., 2024b; Sutcliffe-Khan et al., 2024). They feared being considered less capable of parenting their children and were often reluctant to share their autism identity due to perceived stigmatisation from children's services (Hampton et al., 2021; Radev et al., 2024b; Talcer et al., 2021). These fears may have stemmed from previous negative interactions, but also from professionals' unfavourable views regarding the abilities of autistic mothers (Dai et al., 2024; Sutcliffe-Khan et al., 2024).

The autistic mothers in the studies felt misunderstood and unsupported by education and health professionals, and often worried that they would question their ability to raise their children (Hwang & Heslop, 2023; Talcer et al., 2021). Participants also talked about an imbalance in the system, with some families being at an advantage when accessing support due to having more time, money, and legal knowledge (Keville et al., 2024; Radev et al., 2024b).

Conclusions

Until a few years ago, qualitative studies had only focused on the early experiences of autistic motherhood, specifically the postnatal period, which revealed a gap in the research on autistic mothering between infancy and early adulthood (Talcer et al., 2021). Currently, there have only been a handful of qualitative studies conducted on autistic mothering throughout childhood (Sandra Thom-Jones et al., 2024). An encouraging feature of four of the five studies identified was that they included neurodivergent research team members, and three studies had asked the autistic community to review the recruitment and interview materials (Gore et al., 2024; Pellicano et al., 2021; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Talcer et al., 2021). However, there were no qualitative studies on the experience of motherhood by more diverse and marginalised

autistic groups, such as ethnic minorities and gender-diverse individuals (Sandra Thom-Jones et al., 2024).

The five qualitative studies on autistic motherhood indicated that there were specific differences in autistic mothers' experiences compared with those of non-autistic mothers (Pohl et al., 2020). However, specific demographic data that would likely have impacted their parenting experiences were missing; for example, three articles did not provide information on ethnicity (Sutcliffe-Khan et al., 2024; Talcer et al., 2021; Sandra Thom-Jones et al., 2024; Winnard et al., 2021). The incomplete ethnicity data suggested that the participants likely had limited cultural diversity (Kandeh et al., 2020). The amount of support provided by partners and other family members was also not reported (Garcia-Molina & Cortes-Calvo, 2025). This may have influenced the mothers' perceptions of their roles and responsibilities, providing further context to the data (de la Cuesta Benjumea, 2024). In the articles, all autistic mothers identified their gender as women (Putnam et al., 2023). Hence, the authors were unable to report on experiences that may have been specific to gender-diverse individuals (Mittertreiner et al., 2024). The intersection of neurodiversity and gender-diversity is likely to be more complex, so research should extend beyond a binary understanding of gender (Pellicano et al., 2014; Sutcliffe-Khan et al., 2024; Warrier et al., 2020).

My review of the academic literature revealed only five qualitative studies on autistic females' experiences of motherhood, even though becoming a mother entails a significant period of adjustment (Dugdale et al., 2021). The results of the five studies on autistic mothers' strengths and difficulties showed a need for more research on maternal and child diagnoses, official and informal support, and maternal self-efficacy (Camus et al., 2024). The autistic women in all five studies felt misunderstood, judged, and stigmatised by healthcare and education professionals (Mullally & Connolly, 2025). This may have affected their perception of their maternal abilities and been a barrier to acquiring support for them and their children (Rabba et al., 2025). Participants considered existing training for healthcare and education professionals to be outdated and ableist (Chown et al., 2023). They felt that more up-to-date training programmes needed to be co-produced to raise awareness of autism, particularly in women and gender-diverse individuals

(Suhrheinrich et al., 2024). Crucially, professionals must consider the possibility that parents of autistic children may also be autistic (Heyworth et al., 2023).

While the findings from the five reviewed studies offer valuable insights, a more in-depth understanding of the experiences of autistic mothers is required (Pagnier & Moualla, 2024). Further research in this area is necessary to understand the difficulties late-diagnosed mothers may encounter (Sandra Thom-Jones et al., 2024). This knowledge may inform the development of personalised support and interventions to improve the well-being and quality of life of autistic mothers and their children (Hwang & Heslop, 2023).

Many autistic females receive a late diagnosis when they have already started a family and, therefore, have to negotiate new motherhood with either little support or by navigating the advice from generic parenting programmes (Garcia-Molina & Cortes-Calvo, 2025). Therefore, I was interested in studying the maternal experiences of autistic women and gender-diverse individuals who transitioned into new motherhood before they were diagnosed and whether the self-understanding gained from their diagnoses impacted their maternal self-efficacy and relationships with their families (Hernández González et al., 2024).

CHAPTER 4 METHODOLOGY

Research questions

Building on the evidence gaps identified, the purpose of this research was to address the following four research questions:

- What challenges do undiagnosed autistic mothers experience when transitioning to new motherhood?
- How does receiving a late diagnosis of autism impact a mother's maternal self-efficacy?
- How do family members respond to an autistic mother's disclosure of their diagnosis?
- What are the perceived benefits of living in an 'authentically autistic' family home?

By answering these questions, the research sought to provide new insights that could shape health and social care policy and support for autistic people of all genders.

Ontology and epistemology

I conducted my research using a critical realist philosophical approach, an integration of a realist ontology and constructivist epistemology (Bhaskar, 1978). Traditionally, when considering theories in social science, epistemological concerns are privileged over ontological ones, but critical realism focuses on 'what exists' rather than 'how we know it exists', while trying not to lose touch with epistemological matters (Pocock, 2024). Critical realism proposes that we exist in a reality that often operates independently from our knowledge of it, so our experiences will only ever consist of partial facts from our perception (Van Ingen et al., 2020). This partial understanding of reality is situated within our historical, social, and cultural context (Botha, 2025) (see Chapter 2, Social and Historical Context). Individuals have different standpoints, drawn from a variety of interests and lifestyles, which influence the type of partial knowledge they perceive (Van Ingen et al., 2020). Yet this knowledge may be transformed by newly acquired understanding or awareness, which, in some cases, may have the potential to transform and challenge dominant viewpoints (Kourti, 2021a).

Within medical literature, autism is often described in terms of 'deficits', and autistic behaviour is understood as 'disordered' or 'deviating' from what is generally considered as 'normal', which gives an impression of 'suffering' and in need of 'correction' (Zaks, 2023). This understanding is rooted in positivistic thought that views knowledge as observable, discrete 'facts', and events that can be understood in an objective, empirical way (Glynne-Owen, 2010). In contrast to this positivist approach, interpretivist scholars view autism as socially constructed and based on social values and culture (S. Mo et al., 2021). However, critical realists contextualise both objective aspects and intersubjective constructs from the social world to understand the mechanisms that affect autistic people's lives (Kourti, 2021a). On a positivist-interpretivist continuum, critical realism occupies the middle ground between these two extremes (Botha, 2025).

Critical realism recognises that context and values are embedded in research, unlike positivism, which seeks to identify de-contextualised laws and facts (Botha, 2025). Critical realists emphasise the significance of objective, tangible, and measurable effects, as well as the subjective, socially constructed dimensions of reality (Burr, 2015). This understanding echoes my personal view on the nature of autism, which is: a) a naturally occurring, epigenetically-based, and mainly hereditary neurotype that affects how individuals perceive, understand, communicate and experience the world; and b) a diagnostic category that was socially constructed, although its representation has been periodically modified during the last eighty years, according to the shifting political, social, and economic climate (Kourti, 2021a).

Reality is differentiated and stratified, and properties exist simultaneously and interact by enabling, constraining, and otherwise affecting each other (Bhaskar & Danermark, 2006). A person cannot be described as only 'physical', 'chemical', 'biological', 'psychological', or 'social', since they cannot be assigned to a single level of reality (Van Ingen et al., 2020). There are, nevertheless, generative mechanisms that give rise to emergent properties (Kourti, 2021a). Social capital may result from becoming a member of a community group (Botha, 2025). In some respects, these generative mechanisms may appear similar to assumptions of causality found in positivism; however, they are often multifaceted and extremely complex, and may not necessarily be visible or quantifiable (Collier, 1998). The social world is an 'open system' that operates on

multiple levels, with numerous events occurring simultaneously, making it impossible to predict relationships between cause and effect (Nichol, 2025). Some academics believe that human society is less stable than nature, as it can rapidly change and adapt its organisation (Pilgrim, 2014).

Interpretative phenomenological analysis (IPA)

Whether examining subjective phenomena or objectively measuring the physical world, an appropriate methodology must be used (Bannister-Tyrrell & Meiqari, 2020). IPA represents an idiographic approach to inquiry, shaped by the insights of Heidegger's hermeneutics and phenomenology (Cuthbertson et al., 2020). I chose this methodology because it is grounded in critical realism and recognises that participants' accounts may provide insights into their lived experiences and interpretations of events (Nichol, 2025). However, both critical realism and IPA maintain that a researcher cannot access a participant's 'real' experience, only their interpretation of it (Jeong & Othman, 2016). Therefore, insights gained through interpretation cannot uncover the underlying 'truth'; a person's comprehension can only ever be partial (Fletcher, 2017).

The three main theoretical approaches that underlie IPA methodology are: phenomenology, hermeneutics, and idiography (Cuthbertson et al., 2020). Phenomenology is an approach to studying experience that is used to interpret phenomena and explore their significance for participants (Heidegger, 1962). It focuses on participants' recollections and interpretations of experiences, as they attempt to acquire meaning and insight from them (Smith, 2004). I examined my participants' experiences in detail, focusing on how these were perceived by the participants, rather than trying to develop a purely objective statement about the events (Merleau-Ponty, 2012).

Another theoretical approach underlying IPA methodology is hermeneutics, which refers to the theory and practice of interpretation (Packer & Addison, 1989). Eatough and Smith (2008) propose that interpretations may be "rich experiential descriptions" or more analytical "in ways which participants might be unwilling or unable to do themselves" (p.189). IPA employs both stances, helping to develop a rich, broad analysis by extracting the meaning and complexity of each person's experiences (Smith et al., 2012). The participants and I engaged in a 'double

hermeneutic', where I sought to interpret how they interpreted their experiences (Smith & Osborn, 2015). IPA calls on researchers to employ the 'hermeneutic circle' to assist in this sense-making process (Smith, 2018). This iterative method requires shifting between broader and subtler levels of meaning, or between the parts and the whole of the phenomena or experiences being studied (Smith et al., 2012).

The third theoretical approach underpinning IPA is idiography, which requires the researcher to provide detailed, nuanced interpretations of each participant's personal experiences (Shinebourne, 2011). The aim of this approach is not to formulate laws or produce generalised results from the data (Smith et al., 2012). IPA conceptualises each participant as a cognitive, affective, and physical being, whose perception of life will have been shaped by their thoughts and emotions (Smith & Osborn, 2015). People are self-interpretative beings who reflect on issues when they attempt to comprehend events or experiences (Wilson et al., 2023). A person's interpretations are constrained by their existing knowledge and the cultural, social, and historical context of their lives (Heidegger, 1962). However, these interpretations may sometimes need to be updated when new knowledge is acquired or cultural and social attitudes change (Lilley et al., 2023). I was particularly interested in the reflections of the autistic mothers in this study, as they attempted to make sense of their lived experiences both before and after their diagnoses (Giddens, 1991).

Howard et al. (2019) considered the IPA methodology to be extremely suitable for autism research. It promotes reflexivity, views people as 'experts by experience', and ensures 'equality of voice' (Dowley, 2016). I also deemed IPA to be suitable for my research since it emphasises each participant's viewpoints, interpretations, individuality, and their social and cultural context (Creswell & Poth, 2016). I was also attracted to this methodology due to its focus on empowering those with 'insider' knowledge to take an active and dynamic role in research (Larkin et al., 2006). As I also had received my late autism diagnosis after becoming a new mother to an autistic child, this gave me 'insider experience' of the phenomenon I was researching (Dwyer et al., 2021).

Throughout the study, the participants and I engaged in a process of sense-making, becoming producers of knowledge rather than simply conveyors and recipients (Frost, 2011). I developed

an understanding of my assumptions and beliefs, and used them to enhance my interpretations (Smith et al., 2012). Qualitative research should not treat participants as mere data subjects; instead, it should be a reciprocal process focused on inclusion and dialogue. I believe that my 'insider knowledge' was beneficial in building rapport with my interviewees, understanding and interpreting their lived experience, and reducing the likelihood of misunderstandings resulting from the double empathy problem (Milton et al., 2022).. (see Chapter 2, Social and Historical Context, pages 22-23)

Positionality

Throughout my life, I had always felt 'different' and was called 'a weirdo' and 'a freak' by my peers at school, although I could never work out why they had targeted me in particular. I assumed it was because I had a traumatic upbringing and was quite a serious child. By the age of 11, I had already attempted suicide (which was very nearly successful), stopped attending school, and attended twice-weekly sessions of psychoanalysis at the Royal Free Hospital in London. My analyst found me challenging because I was so withdrawn. I found it difficult to open up to her, as she was a colleague of my mother, who was also a psychoanalyst and was one of the causes of my childhood trauma.

At 17 years old, life began to improve when I met my husband. He encouraged me to talk and express my feelings for the first time. In the years that followed, I was determined to make up for not progressing academically as expected by my family by studying for a part-time undergraduate degree course with the Open University (OU), while working full-time. I found the OU's method of distance learning suited me as I could work without interruption in my own space and in my own time. I was very determined and, after six years, I completed my honours degree in Biology, which was followed by a part-time master's degree in Medical Microbiology, which I also completed while working full-time. I currently work as a senior scientist at the UK Health Security Agency. I am still married to my husband after 42 years, and we have a bright and happy 16-year-old son. I have to admit that, through the years, I have had occasional bouts of depression and anxiety, and as a consequence, I have been on antidepressant medication for many years.

Shortly after my son started in the nursery class (the year before reception) of a mainstream primary school, I began receiving regular phone calls at work, halfway through the day, asking me to immediately come to collect him and take him home, as he was being 'challenging'. At that time, I was unaware that these requests would be classified as 'informal exclusions' (Blackwell, 2025). It is unlawful for schools to repeatedly send a child home 'to cool off' because of their apparent 'difficult behaviour', especially if they may have special needs (DoE, 2023; IPSEA, 2025). I was extremely concerned and upset by the negative feedback I received from the school, and my colleagues and manager at work showed little understanding of my situation and the stress I was under.

I found this phase of my life extremely traumatic as I was given a verbal warning about my disruptive, anxious behaviour, the number of private phone calls I was receiving, and my unexpected departures from the office. The situation at the school began to improve after my son received his autism and attention deficit hyperactivity disorder (ADHD) diagnoses from Great Ormond Street Hospital at only four years old. He then received a statement of special educational needs (now replaced by the Education, Health, and Care Plan or EHCP in 2014) which specified that he must be provided with a full-time one-to-one teaching assistant (TA) to enable him to access the curriculum successfully. The school were given extra funding from the local authority to pay for a TA's salary. Finally, those upsetting and demanding phone calls from the school stopped.

After my son was diagnosed, I became passionate about finding out as much as I could about autism and neurodiversity. I decided to enrol in a Post-graduate Certificate in Autism and Asperger syndrome (AS) at Sheffield Hallam University. While listening to Dr Luke Beardon talk about late diagnoses and adult autism, particularly in mature females, I suddenly realised that, not only was my son's 'challenging' behaviour similar to my behaviour as a child, but his strengths and difficulties mirrored my own. I realised I needed support to avoid becoming overwhelmed at work or during my studies, so that I would not experience any more depressive episodes. I also wanted to tell my son that "mummy's brain is wired differently as well". Luckily, my GP supported my request for a referral to be assessed for AS at the Adult ASD/ADHD Service at the South London and Maudsley NHS Foundation Trust. My assessment was undertaken in a small room

at the Maudsley Hospital, with the sound of roadworks coming through an open window. The clinician who conducted my assessment appeared unfamiliar with the female presentation of AS. During the interview, she rapidly ‘fired’ questions at me, and, at one point, I started to panic. The clinician suggested that “although we could take a break for a while, we still have a lot to cover”. So, I tried hard to compose myself until the assessment was completed.

After my assessment, I was instructed to wait in the canteen for approximately an hour. Then I was given my results by a Consultant Psychiatrist, not the clinician who conducted the assessment. I was told that, without a developmental history, generally a “higher burden of proof” was necessary to confirm a diagnosis, especially for females of above-average intelligence like me. I had provided no evidence of my developmental history from a relative who knew me during my childhood, as my mother had died a few years earlier, and I had minimal contact with my father, as he had left the family home when I was very young. The psychiatrist explained that, as I made good eye contact, could converse, used non-verbal body language, and was successful in my job, I did not meet the criteria for a diagnosis. However, she found evidence of ADHD, social anxiety, obsessive-compulsive disorder, and generalised anxiety disorder, to add to my collection of diagnoses I already had (Dr C Murphy, 2015, personal communication).

Two months later, I received the assessment report and, after reading it thoroughly, I realised I had actually scored over the threshold for ASD on the Autism Diagnostic Observation Schedule (ADOS). This instrument is the ‘gold standard’ tool for ASD diagnoses, even though it was developed for use with children. The ADOS module 4 (ADOS-4) was a version adapted for assessing adults, with the main difference being that information about social-communication is not acquired through interactive play with toys, but through a conversational interview (Lord et al., 2000). I must have been given the children’s version, as I was presented with a big box of toys to play with.

However, the report stated that the score had related to a “present state assessment without developmental history”, so there was no evidence of behaviours that met the criteria which “had been present since early years” (Dr C Murphy, 2015, personal communication). Therefore, “on the balance of probabilities, but not beyond doubt”, I did not meet the criteria for ASD, according

to the International Classification of Diseases, 10th Revision (ICD-10) (WHO, 1992). However, I was confused by the conclusions made, as my GP had referred me for an AS assessment, but the report referred to ASD, which was not categorised in the ICD-10 version of the diagnostic manual. At first, I thought they might have used the DSM-5 classification system instead, which does not include AS, but does include ASD. However, this was not the case (APA, 2013). They had used ICD-10, but instead of diagnosing me with the criteria code for AS (F84.5), they had assessed me for 'childhood autism' (F84.0) (WHO, 1992). Obviously, I was unable to meet the criteria for childhood autism, as I would have needed to prove the presence of abnormal or impaired development that manifested before the age of three years old. This was not required for a diagnosis of AS, as it differs from childhood autism primarily by the lack of any general delay or retardation in language or cognitive development in childhood.

Following this disappointment, I asked my GP for a second referral, specifically to Dr Judith Gould at the Lorna Wing Centre, who specialised in the diagnosis of autistic females (Gould, 2017). During this second assessment, she used the Diagnostic Interview for Social and Communication Disorders (DISCO) tool for my diagnosis, which consisted of a detailed semi-structured interview which provided a picture of my life from my early years to the time of the interview. This tool used a dimensional approach, rather than arbitrary cut-off points (Billstedt et al., 2007). She said she considered me a reliable informant, as I had a good long-term memory and could comment on my early life. I could also elaborate on my strengths and difficulties (Dr J Gould, 2017, personal communication).

Dr Gould explained that specific areas of functioning were key to enabling a diagnosis, even without detailed information from very early development. She considered that my pattern of behaviour and the way I see the world fitted into the characteristics described by Hans Asperger (Asperger, 1944/1991). My traits were typical of a female presentation of AS, and I had been masking my 'atypical' behaviours throughout my life. She recognised the likely genetic factors associated with my case, as my son had already received his diagnosis. Dr Gould was not surprised that I had been having mental health problems, considering the anxiety and stress I experienced daily due to my difficulties with social interaction and communication (Dr J Gould, 2017, personal communication). The diagnosis that I received, at 51 years of age, confirmed my

assumptions and explained many of the strengths and problems that I had experienced during my life, particularly during adolescence.

I conducted this study and wrote this dissertation as an autistic autism researcher (Grant & Kara, 2021). My interpretations of the participants' experiences were situated and shaped by my previous experiences (Haraway, 1988). I believe that being an 'expert by experience' helped me to connect with the mothers during their interviews, as well as to interpret and convey the experiences and emotions they described (Fletcher-Watson et al., 2019). I drew my lead from feminist researchers who support 'insider research' and urge other researchers to employ positionality and reflexivity when interpreting lived experiences (Fletcher-Watson, 2024a). They criticise positivist methodologies that traditionally emphasise objectivity, impartiality, and detachment, and believe that preserving a totally objective attitude towards research is not achievable or suitable (Willig, 2013). Qualitative research necessitates researchers to immerse themselves in their research data (Bleiker et al., 2019). Therefore, I felt that, for me to produce any meaningful insight into the lived experiences of autistic mothers, my research should not be conducted in a depersonalised and impartial manner (Madill et al., 2000). I used my experience as a mother who had received a late autism diagnosis to enrich my analysis, rather than considering my experiential knowledge a bias that needed to be disregarded (Frost, 2016). On the other hand, I was also determined that a substantial 'voice' would be given to the autistic mother's experiences (Peat et al., 2019).

Reflexivity

Phenomenological research frequently employs a technique known as 'bracketing' to maintain data objectivity and scientific rigour (Kelly et al., 2024). This method requires the researcher to temporarily set aside their preconceptions, expectations, and perceptions of their surroundings (Barker et al., 2016). Recently, academics using the IPA methodology have stressed that subjectivity is an inherent aspect of qualitative research and have suggested that "the researcher does not bracket preconceptions or theories but uses reflexivity to be fully aware of his meanings of the real world and his existence in the world of study" (Ugiagbe et al., 2025, p. 4).

Reflexivity is a critical consideration of how a person perceives society and recognises the interactions between content, context, and the consequences of knowledge that may arise from research: “Reflexivity is not just about the ability to think about our actions—that is called reflection—but an examination of the foundations of frameworks of thought themselves” (May & Perry, 2017, p. 3). Throughout my research, I maintained a continuous process of reflexivity by considering how my standpoint, values, understandings, and motivations for carrying out this study may have affected and influenced the analysis of my findings (Frost, 2016). I also contemplated how the social context of the last 100 years had influenced the construction of autism, which provided me with a greater appreciation of the complexities of this subject area and enhanced the quality of my dissertation (Mailick et al., 2025) (see Chapter 2, Social and Historical Context). Milton (2012) brought to our attention how a person’s starting point for questions about autism may bias their conclusions. As an example, he explained that by framing autism within cognitive neuroscience or psychology, the interpretations made usually lead to a deficit-based understanding of autism. “The claim that autistic people lack a theory of mind pervades psychology”, yet it is “empirically questionable and societally harmful” (Gernsbacher & Yergeau, 2019, p. 102).

A consideration of how my assumptions and viewpoints related to my research interpretations helped sharpen and focus my decisions and choices (Frost, 2016). Simply stepping ‘outside’ of the research was impossible for me, as my interest in autism had guided my decision-making and choice of subject matter, even before I started this research (Bhaskar, 1998). Instead, I wrote reflexive notes after each interview and throughout my analysis to record my deliberations, issues, judgments, questions answered, and critical themes that I identified (Finley, 2002). Keeping a detailed record of these helped me write this dissertation by making my interpretations clearer and more descriptive (Frost, 2016). My writing was also thoroughly read and commented on by my two neurotypical supervisors. Our meetings enabled a diversity of perspectives to be brought to the interpretation of the findings, ensuring a degree of critical dialogue occurred. In addition, I made sure that the experiences and emotions of the mothers in my study were accurately conveyed, thereby reducing the possibility of bias (Fennell & Johnson, 2022).

Theoretical framework

This section describes the two theoretical approaches of neurodiversity and intersectionality, which have shaped my understanding of autism and formed the theoretical framework for my research. During the process of data interpretation, I found it helpful to situate my findings within this framework of understanding (Samra & Hankivsky, 2021). As the core theoretical foundation of the concept of neurodiversity is the social-relational model of disability, this section starts by providing some background information on the medical, social, and social-relational models, before describing the two approaches used in my research (Chapman, 2021).

The medical, social, and social-relational models

Scientific knowledge and standards of 'normality' within society form the basis of the medical model of disability (Pellicano & den Houting, 2022). It establishes a general understanding of the term disability, referring to physical, sensory, and intellectual injuries or dysfunctions, but typically overlooks the involvement of social, cultural, and environmental factors (Waltz, 2023). From a medical model perspective, disability is understood to be an individual's impairment, so the disabled person should be rehabilitated to reach, as far as possible, an acceptable standard of normality (Zaks, 2023). This narrative creates an impression of deviant bodies and minds, and ultimately legitimises inequitable divisions of resources and power (Samra & Hankivsky, 2021). Most clinicians use the medical model as a basis for diagnoses; however, their understanding of autism is often based on stereotypical and outdated concepts (Pearson & Rose, 2023).

Autism research that still uses the medical model generally addresses themes such as causality, underlying mechanisms, 'symptoms', and prevalence (Pellicano & den Houting, 2022). Interventions of different kinds are disseminated, and studies tend to focus on methods such as behavioural therapy and pharmacological treatment (Vivanti & Messinger, 2021). Research funding organisations still invest most of their money on the aetiology, screening, and treatment of autism, while paying less attention to the social and cultural aspects that impact the daily lives and well-being of autistic individuals (Bottema-Beutel, 2024).

In the 1970s, the Disabled People's Movement criticised the medical model, and the negative impact it had on the lived experience and well-being of disabled people, particularly its biological

and reductionist views (Oliver, 1996). The social model proposes an alternative way of viewing disability, shifting away from considering deficits in the functional, physiological, and cognitive abilities observed in disabled individuals (Lee et al., 2024). Instead, it concerns itself with the ability of society to oppress and discriminate against disabled people systematically and the negative social attitudes they encounter throughout their everyday lives (Gibbs et al., 2023). The issue of social exclusion experienced by disabled people is seen to be the responsibility of society; it is not just the inevitable result of a person's physical or mental characteristics (Mansour et al., 2025). Disability is understood as a social construct that limits the full participation of people with disabilities in society (Thomas, 1999). The social model's primary focus of analysis is along materialist lines, focusing on accessibility to employment, education and the built environment (Lee et al., 2024). Historically, however, there was a lack of consideration given to 'non-productive' labour in disability studies, such as caregiving, and women's concerns were neglected, including motherhood (Wendell, 1996).

According to the social model, eliminating barriers that hinder the lives of individuals with disabilities should enable them to gain greater independence. In the 1990s, feminist disability theorists critically examined this assertion (Morris, 1996). They argued that people may have specific impairments that cause significant distress and pain, which may be disabling for them, regardless of the social context (Anderson-Chavarria, 2021). Autistic people experience disability with their communicative challenges in social interaction with non-autistic people within a society where they are in the minority (Thomas, 2004). However, they also experience disability through distinct features that are inherent to being autistic that may be difficult to alleviate fully, even with societal accommodation, for example, sensory sensitivities (Mantzalas et al., 2022).

The foundation of the social-relational model's understanding of disability is the important conceptual distinction that is drawn between impairment and disability, as described by the Union of the Physically Impaired Against Segregation in 1976: "Impairment [is] lacking part of or all of a limb, or having a defective limb, organ, or mechanism of the body" and "Disability [is] the disadvantage or restriction of activity caused by contemporary organisations, which takes no or little account of people who have physical impairments, and thus excludes them from the mainstream of social activities" (UPIAS, 1976)

Being autistic may include having both inherently disabling features, such as sensory distress that may be difficult to reduce, and socially disabling factors, such as a lack of consideration and accessibility in the external environment (Mantzalas et al., 2022). A social-relational model considers these individual challenges, as well as structural and societal barriers, and it can help frame autistic experiences (Thomas, 2004). It also considers gender diversity, caring responsibilities, interdependence, and lived experience to be central themes (Garland-Thomson, 2002). The social-relational model has deepened the understanding of disability as constituted in intersectionality with identities that include gender, ethnicity, class, and religion (Davis et al., 2022).

Neurodiversity

The neurodiversity paradigm is an emancipatory perspective that promotes a value-neutral understanding of neurodivergence, which is defined as a deviation from an assumed normative standard of functioning, i.e., neurotypicality (Walker, 2021). It is a concept that provides space to explore all variations in human development, including neurotypicality, without attaching value to the most prevalent (Hens & Van Goidsenhoven, 2023). Singer (1999), an Australian autistic social scientist, described the concept of neurodiversity as a category for analysis within an intersectionality framework (Botha & Gillespie-Lynch, 2021). It stems from the concept of biodiversity, which emphasises the importance of supporting a diverse range of life within an ecosystem (Blume, 1997; Singer, 1999). By using their alternative form of mental processing to contribute complementary and valuable skills, neurodivergent people fill their own 'ecological niche' within society (Chapman, 2020).

The 'normal' human, or 'normate', represents an idealised, able-bodied, and able-minded individual who typically possesses qualities such as independence and self-sufficiency (Pellicano & den Houting, 2022). The normate is often contrasted with those who are 'disabled' or 'deviant' and lack those embodied qualities (Garland-Thomson, 2017). Ableism positions particular individuals as undesirable and broken, and who, therefore, need to be 'treated' and 'normalised' through scientific, cultural, and social practices (Cowell, 2024). Botha (2021) considered the dehumanising nature of comparing human diversity and difference to an assumed 'ideal' to be inherently flawed. Dehumanisation relies on the tendency of an 'ingroup' to attribute more agency,

emotionality, and distinctly human features to fellow 'ingroup' members rather than to 'outgroup' members (Kteily & Landry, 2022). I consider the idea of having a 'normal' brain to be as inappropriate as claiming the existence of a 'normal' ethnic group or religion (Walker, 2014).

The neurodiversity movement contributes to the pursuit of social justice by acknowledging the power inequalities between people of different neurotypes, comparable to other social stratifications such as class, gender, and ethnicity (Bernard et al., 2023). Autistic strengths and differences are unique and fundamental to a person's identity and sense of self (Alle et al., 2025). In contrast to the medical or 'deficit' model, autistic activists argue that autism is an identity that does not need to be treated as a tragedy or cured like a 'disease' (Lamash et al., 2025). The term 'disorder', in the diagnostic category of 'autism spectrum disorder', implies that some 'natural order' is not working, and that the person's underlying cognition is dysfunctional (APA, 2013; WHO, 2018). Yet, the biology of autism shows no evidence of dysfunction, either genetically, functionally, cognitively, or behaviourally; it only shows proof of difference (Turowetz et al., 2024). The autistic community promotes a form of diagnosis that is less pathologised and more affirmative (Bernard et al., 2023). For autistic individuals, a diagnosis may still be required to access the necessary support to enable them to lead fulfilling lives in a society where they are marginalised and face social oppression (K. J. Benson, 2023).

Neurodiversity advocates challenge the funding of research that is primarily directed towards topics such as aetiology, treatment, and cure (Bernard et al., 2023). They advocate instead for more attention to be paid to improving autistic people's quality of life and to reducing healthcare disparities (Del Bianco et al., 2025). Studies with the potential to critically reveal the oppression that exists in society should not only focus on the ability to understand and describe phenomena, but also on the power for change (Patra et al., 2025). Individuals "are reflexive and therefore can accommodate, adapt, contest, or resist top-down endeavours to govern them if they so wish" (McKee, 2009, p. 20).

Intersectionality

In the 1980s, intersectionality was conceived as a method for analysing the complex oppression of black females in the US (Crenshaw, 2017). In the last few decades, it has evolved into a widely

used interdisciplinary theory for conceptualising multiple marginalised identities (Crenshaw, 1989). Intersectional theory states that when an individual belongs to multiple marginalised groups, these identities interact to create a distinct group that experiences its own unique form of oppression or privilege (King, 1988). Members may possess unique needs and face specific challenges that differ from those of the original groups, and should be recognised as having a distinct voice (Garland-Thomson, 2005).

Saxe (2017) maintained that the experiences of autistic females should be examined through an intersectional lens, as they are frequently overlooked due to the prevailing male-centric perspective in autism discourse. Using an intersectional lens for such studies should prevent the additive approach that Crenshaw warned about in her original publication, for example, when an autistic woman is perceived as 'autism + gender' and not as someone who has unique needs and specific challenges (Crenshaw, 1989). Instead, one should explore the person's gendered experience of growing up autistic, what this may look like to others, and how it has shaped the person's identity and behaviour (George & Stokes, 2017). Intersectional theory is compatible with both the social-relational model of disability and neurodiversity theory, although its inclusion within academic literature is still evolving (Strand, 2017). Many autistic people are marginalised in multiple ways, and this often shapes not only their identity and their experience of the world, but also their access to societal participation (Botha & Gillespie-Lynch, 2021). Historically, autistic women and gender-diverse individuals were almost absent from autism research, and even now, the number of studies of these groups is much lower in comparison to those that represent young males (Putnam et al., 2025). This disparity suggests that women and gender-diverse individuals may be at a disadvantage in our society.

In the past, identity politics plagued two activist movements: disability studies and feminism (Knoll, 2012). This had negative implications, such as the restriction and oppression of the study and conceptualisation of those with multiple intersecting identities (Malacrida, 2019). Traditionally, the identity of disabled females was not generally associated with success or capability, and they were typecast as lacking, incapable, and unfit (Kim et al., 2019). In contrast to non-disabled 'feminine' women, they were often considered undesirable, asexual, and unsuitable as parents (Garland-Thomson, 2005).

Fine and Asch (1988) alleged that disabled females were being excluded from feminist research to combat the stereotype of females as dependent. The foundation of feminism was traditionally based on the notion of female independence, and some felt that disabled females undermined those ideals (Simpson, 2019). In the 1990s, disabled females began to express their disapproval of the Disability Rights Movement's unwillingness to address gender issues and the feminist movement's inability to incorporate the standpoint of disabled females (Kallianes & Rubenfeld, 1997). When an individual possesses multiple identities but is overlooked by their respective identity groups, the phenomenon is referred to as 'intersectional invisibility' (Purdie-Vaughns & Eibach, 2008). Intersectional theory seeks to illuminate the unseen and explore the inequalities arising from the marginalisation of various groups (Smooth, 2013). Thankfully, since then, disability studies and feminism have converged to address gaps in their respective fields and are now an academic area known as 'feminist disability studies' (Bê, 2014).

Society's concept of motherhood naturalises women as caregivers, unpaid workers in the production of life, loving and tender, and biologically destined to be mothers (Daniels, 2019). For years, many feminists positioned this concept as being at the centre of female oppression (Clímaco, 2020). However, disabled females indicated that the patriarchal institution of motherhood challenged them in a different way (Malacrida, 2009). They are not obligated, but dissuaded, from reproducing and providing care, as they were perceived as being unfavourably situated in society's reproductive hierarchy (Daniels, 2019). In contrast, mothers of economically privileged, white, young, married females without disabilities were at the top of this hierarchy (Wignall, 2012). Historically, feminists struggled for females to have other roles, apart from being mothers, but this was not necessarily what disabled females wanted (Thomas, 1997). They viewed female reproductive rights as going beyond just the right to remain childless; they wanted to be recognised as sexual beings who were capable of motherhood (Morris, 1991).

Policies and supports have frequently underserved disabled mothers, and their experiences have been unexamined until recently, particularly within autism studies (Daniels, 2019). Whilst a very significant body of research on how an autistic child may affect the lives of non-autistic mothers has been conducted, research on autistic mothers was disregarded entirely until a few years ago (Pohl et al., 2020). Therefore, health and social care professionals may lack expertise on autistic

motherhood, and autistic mothers may not receive the support and understanding they require (S. Hampton et al., 2022). As a consequence, autistic mothers attempting to raise and retain custody of their children may be adversely affected (Malacrida, 2019).

The combination of neurodiversity and intersectionality provided an effective framework for me to explore the lived experience, marginalisation, oppression, and disablement of autistic mothers (Strand, 2017). This framework focused on the met and unmet needs of the participants and provided context for their shared experiences, without having to rely on the medical model (Pellicano & den Houting, 2022). Understanding the context within which autistic mothers are generally framed within our society enabled me to acquire greater insight to interpret the lived experiences of the autistic mothers beyond a pathological lens (Zaks, 2023). Hopefully, this study may go a small way to remedy the lack of intersectional recognition within autism research (Mallipeddi & VanDaalen, 2021). Currently, intersectional perspectives have remained relatively underexplored in autism studies (Cascio et al., 2021).

Methods

Recruitment of participants

Before recruiting my participants, I had sought feedback on my draft interview questions, participant information leaflet, and poster invitation from my supervisors and a few autistic academics, who were also autistic mothers and members of one of two private Facebook autism groups. The feedback I received was very positive, with only minor amendments needed in the text. This interaction with the autistic community proved to be helpful later, when I was attempting to recruit participants to the study. I was able to acquire the necessary permissions to display my study invitation from the administrators of the two private Facebook groups mentioned earlier (Appendix C). As a member of both groups, I was pleased that my 'insider' positionality had helped expedite my requests. Permission from both groups was granted straight away, so my invitation was posted on their respective sites later that day. As only autistic people were able to access these sites, the posting of my invitation clearly demonstrated that I was autistic as well. I also stated that I was an autistic autism researcher on the poster invitation itself.

The inclusion criteria used to recruit the participants stipulated that they had to be English-speaking mothers, living in the UK, and had received an autism diagnosis after the age of 18 years. Interested participants were asked to contact me by email, and I received around 100 responses within 24 hours, which was a total surprise. I had been quite worried that there would be a poor response, as many autistic mothers are undiagnosed or self-diagnosed. I replied to the first 30 people who had contacted me, attaching the participant information sheet (Appendix D) and consent form (Appendix E) (Howard et al., 2019). I was reasonably confident that I would be able to recruit ten autistic mothers who would meet the inclusion criteria from the initial 30 respondents. I also replied by email to all the other people who had responded to the invitation, in which I gave my apologies and explained that the response received had been far greater than anticipated. I thanked them for responding to the invitation and for their interest in participating in the study. I did not receive any complaints from my reply.

I selected the first ten applicants who had met the inclusion criteria and had returned a completed consent form by email. I informed the remaining applicants in a similar manner to the previous replies I had sent to those who were not recruited. In addition, I also explained how I had selected the participants for the study. Again, I did not receive any complaints from my reply. I chose to recruit ten participants, as it is typical in IPA research to have relatively small sample sizes, although the interviews are generally lengthy and reflective, so that the findings generated are detailed and insightful (Pietkiewicz, 2014).

Demographic data was requested by email from the ten participants, which included their age, age at diagnosis, gender identity, preferred pronouns, how they wished to be referred to (identity-first or person-first), ethnicity, number of children, children's ages, children's gender, children's autism diagnosis status (diagnosed, awaiting an assessment, or non-autistic), highest level of education, and employment status. This data was saved in NVivo 14 for Windows. I used password-protected emails in my communication with the participants and those who responded to my invitation. I stored all the data I collected from my research in password-protected files, which were securely saved on OneDrive, in accordance with the General Data Protection Regulation (ICO, 2018).

Interviews

I employed semi-structured, in-depth interviews for this study, as this data collection method is recommended for IPA research due to its effectiveness in gathering detailed data from participants (Frost, 2011; Smith et al., 2012). I used MS Teams meetings to conduct the interviews due to social distancing restrictions during the COVID-19 pandemic. None of the recruited applicants were unwilling to participate in an online interview. The interviews took place between 5th and 16th March 2021, approximately two weeks after I recruited the ten participants. At that time, the third national lockdown in England was coming to an end.

One benefit of conducting the interviews online was that the mothers could choose a comfortable environment, such as their bedroom or garden. Carrying out interviews online may have enabled a “greater connection through participants’ increased sense of ease with the setting” (Weller, 2015, p. 625). Some autistic people can become very anxious about travelling to new environments (Winn, 2015). Therefore, online interviewing enabled the study to be accessible to participants from both urban and rural locations throughout the UK, as they would not need to travel anywhere or meet in an unfamiliar place. It was also more practical for those mothers with caring responsibilities. Each interview took place on a date and time that was convenient for the participant.

Although online interviewing may have potential disadvantages, such as network connection issues or a more impersonal feel, neither factor occurred in any of the interviews in this study. Another researcher at the University of Hertfordshire also interviewed her autistic participants online during the COVID-19 pandemic. She used the online platform Skype, although now believes that either Zoom or MS Teams may have been a better option, as people have become more familiar with these packages, and they also produce much higher quality sound and vision (Turner, 2023).

Szulc (2023) stated that interviewees may have specific needs that may require accommodations that would enable them to contribute to the research more effectively. According to Das et al. (2021) the video backgrounds on applications like MS Teams or Zoom may be distracting for some autistic people, especially if bright or animated; therefore, I chose a plain background. Szulc

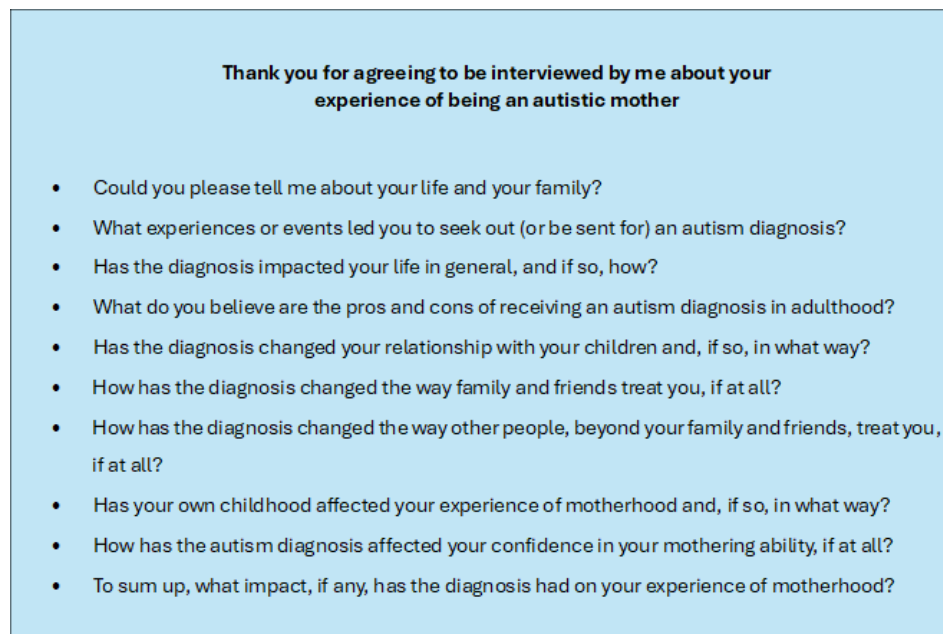
(2023) recommended that researchers ask participants for their specific preferences before their interview, for example, whether they would prefer the video facility on or off. I emailed the participants a few days before their interviews to ask what adjustments or modifications they needed to facilitate their participation in the research. A couple of participants preferred the video function to be turned off; some requested that there be no background noise; one wished to see the interview questions before the interview; and another, who was deaf, needed a good view of my face to lip-read. All these requests were carried out.

Before starting each interview, I described the research to the participant, including the research questions. I explained that, although the interview would probably last approximately an hour, there was no strict time limit. I informed each participant that they could stop the interview at any time, and, upon request, I would delete their data, provided it was before the findings were published. I assured them that none of the questions had definitive answers, and what truly mattered was their personal views and opinions. This reassurance was intended to convey the importance of their viewpoints, to make them feel comfortable enough to discuss their experiences openly, and to inspire future involvement in other social research studies (Moser & Kalton, 1985). Participants were informed that the study's findings would be included in my doctoral dissertation, subsequent oral and poster presentations, and published articles. I explained to each participant that I would be using a small audio-recording device to capture the interview and that, after the interview, the audio file would be promptly transferred onto a password-protected laptop and securely stored on OneDrive in compliance with GDPR (ICO, 2018). I assured them that I would maintain their confidentiality and anonymity. Finally, I asked each participant if they had any queries about the process, and then answered them as clearly as possible. The first participant interview functioned as a pilot for the data collection process, although no modifications to the process were required for the remaining interviews.

In the interviews, I used broad, open, and expansive questions to encourage the participants to give in-depth descriptions of their experiences, including any uncertain or conflicted feelings they may have had about them. The interview questions started with a general, informative question to build rapport and enable the participants to describe their family situation to me. I asked questions that involved more reflection later in the interview (Whyte, 1985). I used an interview

schedule as an aide-memoire, as is standard practice in IPA studies (Figure 2). However, I did not necessarily stick to the order of the questions precisely, as I felt it was more important to follow the participant's dialogue and explore novel areas (Braun & Clarke, 2013, 2024; Frost, 2011). Smith et al. (2012) explained that "... unexpected turns are often the most valuable aspects of interviewing ... because they arise unprompted, they may well be of particular importance to the participant" (p. 58). At times, I had to request further clarification and elaboration on specific answers the participants provided. A probe would sometimes act as a catalyst, allowing the participant to make connections with a previous response. There may be some parallels here to the idea of 'retrospective–prospective interpretation' (Garfinkel, 1987).

Figure 2 Interview schedule



**Thank you for agreeing to be interviewed by me about your
experience of being an autistic mother**

- Could you please tell me about your life and your family?
- What experiences or events led you to seek out (or be sent for) an autism diagnosis?
- Has the diagnosis impacted your life in general, and if so, how?
- What do you believe are the pros and cons of receiving an autism diagnosis in adulthood?
- Has the diagnosis changed your relationship with your children and, if so, in what way?
- How has the diagnosis changed the way family and friends treat you, if at all?
- How has the diagnosis changed the way other people, beyond your family and friends, treat you, if at all?
- Has your own childhood affected your experience of motherhood and, if so, in what way?
- How has the autism diagnosis affected your confidence in your mothering ability, if at all?
- To sum up, what impact, if any, has the diagnosis had on your experience of motherhood?

I aimed to build a rapport with the participants so that they would feel comfortable describing their lives within their frame of reference, and to allow them to express their feelings and emotions (Pajo, 2018). The process of data collection that produced the rich data required meant establishing an empathetic relationship with them (Creswell & Poth, 2016). Feminist research had influenced me, as it had suggested 'dialogic retrospection' and portrayed an ideal interview as "an open and active exchange between the researcher and participant in a partnership of co-

research” (Humm, 1995, p. 63). To foster an environment where participants felt relaxed and secure enough to share their experiences, I questioned them in a casual, conversational manner. However, I carefully monitored each participant to assess how their interview was affecting them emotionally (Creswell & Poth, 2016). As the interviews involved emotional reflection, I had previously ensured that support services were available to the participants through the National Autistic Society (NAS) helpline. The participants all reported feeling perfectly fine at the end of the interview, and many stated that they had found it enjoyable and therapeutic. Throughout my doctoral studies, I have been supported by a specialist autism mentor.

Transcription

I transcribed the interviews verbatim from the audio recordings as soon as possible after each session to enhance my engagement with the data (Braun & Clarke, 2013). Transcriptions for IPA studies typically only record the spoken words, along with any false starts (Smith & Osborn, 2015). Even so, I believed that features like pauses and laughter warranted reporting, as these may indicate emotional reactions by participants. I made a note whenever either the participant or I talked over each other. I reviewed the recordings several times to ensure the transcriptions were accurate and had captured all the speech and significant sounds. This level of detail proved helpful for indicating moments when a participant may have been struggling to articulate their thoughts or feelings (Braun & Clarke, 2013, 2024).

During transcription, I anonymised any data that could be potentially identifiable, not just in isolation but also cumulatively. I replaced participant names with pseudonyms. I also substituted family member names, place names, and other potentially identifiable information with generic descriptions in square brackets, as combinations of such data may reveal a person’s identity through deductive disclosure. After the audio recordings were transcribed, I deleted the audio files under secure conditions. The anonymised transcripts were password-protected and stored securely on OneDrive, where they will be kept for five years, in accordance with the GDPR (ICO, 2018). This should provide plenty of time for me to generate any reports or publications related to the research. After this period, I will ensure the secure disposal of the data.

Data analysis

I was guided by IPA rules for my data analysis, which involved the step-by-step staged process described in Smith et al. (2012). Key IPA principles include a commitment to understanding the participant's lived experience and the adoption of a psychological focus on personal meaning-making in specific contexts. As an IPA researcher, I was engaged in a 'double hermeneutic', aiming to make sense of the participants, who were trying to make sense of their experiences (Smith, 2011, 2015). My relationship with the data was not linear but shifted according to a 'hermeneutic circle'; it moved back and forth as I thought about different levels of my interpretation, for example, looking at the broader context of an event and then examining a specific emotion felt by a participant about that event (Gadamer, 2013; Heidegger, 1962).

IPA is a methodology that aims to understand and elucidate the conscious lived experience of phenomena, while also analysing participants' meaning-making and hermeneutic interpretations. Therefore, I needed to rely on knowledge and descriptions of my participants' explicit and conscious behaviours, including their masking. However, in previous studies, autistic participants, although aware of some aspects of their masking, had described it as being multifaceted and not always under conscious control (Pearson & Rose, 2021; Pearson & Rose, 2023). Therefore, my participants' understanding and descriptions of their behavioural strategies and the underlying drivers of their masking may have been only partial. This is consistent with critical realism's proposal that we exist in a reality that sometimes operates independently from our knowledge, so our experiences can only ever be partial and from our perspective (Van Ingen et al., 2020). (see Chapter 4, Methodology, page 60)

I employed NVivo, a content management software, which enabled my exploration of the data, facilitated category comparison, and allowed links and patterns to be discerned and stored. The key benefits of NVivo were its efficiency compared to a manual system and its transparent audit trail: codes were easily traced back to their source data within the transcripts. When writing up this dissertation, I evidenced my interpretive claims with quotes (Shenton, 2004). I password-protected and saved my NVivo project file on OneDrive, in accordance with GDPR (ICO, 2018).

In Table 6, I outlined the analytical process that I applied, and the way my coding and categorisation of nodes (codes) in NVivo tied back to the theoretical approach of IPA (Smith et al., 2012). Figure 3 is a screenshot of this study in NVivo, illustrating how the package looks for those unfamiliar with the software. On the left-hand side of the large white area of the screen, you can see my coding. In the middle, it shows how many of the ten participants had quotes for that code. On the right-hand side, it shows the total number of quotes provided by all participants for that code. In Table 7, I produced a matrix coding table that indicates the total number of quotes provided by each participant for all the superordinate themes and subthemes.

Ethics committee approval

As this study included human participants, ethics approval was sought and received from the University of Hertfordshire Ethics Committee (Designated Authority: Health and Human Sciences) (Appendix F). The research was conducted in accordance with the Declaration of Helsinki and its later amendments, as well as the UK Policy Framework for Health and Social Care Research (HRA, 2017; WMA, 2013). This study did not involve NHS premises, patients, or staff; therefore, it did not require submission to a Health Research Authority Research Ethics Committee or approval from local NHS Research and Development Committees.

Autistic community involvement

The National Institute for Health Research stated that public involvement in a study is “research being carried out with or by members of the public rather than to, about, or for them” (NIHR, 2019). Public involvement can range significantly, from simple participation to user-led research, as demonstrated in this study, at the highest level (Amstein, 1969; Autistica, 2018; Kelly et al., 2024). I asked for and received feedback on my draft interview questions, participant information document, and poster invitation from some autistic academics, a couple of whom were also autistic mothers, on private Facebook groups. I am grateful for the feedback and helpful advice received from the autistic community.

Table 6 Outline of the theoretical approach of IPA, and my analytical process using NVivo

IPA analytical focus (Smith et al., 2012)	NVivo Process
Steps 1 & 2: Reading and initial noting Involves complete immersion in the original data and initial noting. Attend to the participant and focus on the sense and meanings they make about their experiences – if possible, moving from the broad and general to specific details about events. Initial noting examines “semantic content and language use on a very exploratory level” (Smith et al., 2012, p. 83) and how the participant addresses issues relevant to the research questions. The aim is to produce detailed, comprehensive descriptive notes and exploratory comments on the data, rather than seeking meaning units at this stage. Three primary processes are involved: 1. Descriptive comments on the content of the transcript 2. Linguistic comments on how the participant has used language 3. Conceptual comments, both interrogative and reflexive, to start interpreting the text.	Open coding I created open codes (called ‘nodes’ in NVivo) to make a first pass at reducing the original data to descriptive phrases and notes. This process was iterative – I went through the participant’s transcript several times to code and re-code and add comments, both interrogative and reflexive, as follows: 1. I captured a summary description of the content in the node name 2. I included rich, descriptive comments to provide coding transparency in the node description 3. I referred to my reflexive and conceptual comments in my journal, which had arisen from the interview, to interpret the text (Finley, 2002)
Step 3: Developing emerging themes The researcher attempts to reduce the volume of data by summarising while retaining its complexity by looking for patterns and connections. The hermeneutic circle (Gadamer, 2013; Heidegger, 1962) refers to the process of interpreting a part of the transcript in relation to the whole and vice versa. Themes should be “a synergistic process of description and interpretation” (Smith et al., 2012, p.92), reflecting both the participant’s original words and thoughts and the researcher’s interpretation, which should feel like they have “captured and reflect an understanding” (ibid.).	Category creation As the first step in data reduction, I created a new ‘Category’ folder for the participant’s transcript in NVivo, which held a copy of the set of open nodes. Then, I reviewed each node in the Category folder, reordered them into broad categories (nodes were added to other nodes, either as parent or, more usually, as child nodes), merged, and re-labelled them, while ensuring that the new labels accurately reflected coded content and facilitated a more in-depth understanding of the participant’s lifeworld.

Table 6 (continued) Outline of the theoretical approach of IPA, and my analytical process using NVivo

Step 4: Searching for connections across themes This step maps how the themes fit together. Several strategies may be helpful: <u>Abstraction</u>: development of a 'super-ordinate' theme for theme clusters. <u>Subsumption</u>: An emergent theme may naturally become a superordinate theme. <u>Polarisation</u>: Looking for differences and similarities – oppositional relationships <u>Contextualisation</u>: Identifying narrative/contextual elements: organising into explicit temporal, cultural, and narrative themes can highlight patterns. <u>Numeration</u>: An indication of the frequency with which themes appear. <u>Function</u>: e.g., positive and negative meanings (language/discourse analysis).	Category development I employed IPA strategies to create superordinate themes for the clusters of nodes. My first step was to consider how categories might be linked or further reduced into emergent themes. Then, I created new names for the superordinate themes, which reflected both the descriptive and the interpretative. I aimed to consolidate the nodes into a more abstract framework and to reduce the original data down to between three and six themes that were relevant to the research question.
Step 5: Moving to the next case Repeating all the previous steps for each participant, without, as far as possible, referencing the other transcripts, as IPA has a commitment to idiographic analysis.	Next transcript I created a new 'Open Nodes' folder in NVivo, where I stored the new nodes created for the next participant's transcript, separate from the other transcripts. Therefore, I treated each transcript as a new analysis, and I repeated the previous steps for each participant. I produced a fully worked-up analysis for the first participant before proceeding with the next one, and so on (Smith et al., 2012).
Step 6: Looking for patterns across cases This step involves examining the themes across participants to detect patterns and look for connections - do themes from one case illuminate those in another? Which themes are the most potent? This process can lead to a more theoretical level of analysis, as individual themes or superordinate themes may also reflect higher-order concepts shared across all cases. Also, the recurrence of themes across cases is considered. For a superordinate theme to be classified as recurrent, it must be present in at least half of the cases and, ideally, across all participant interviews.	Consolidation I copied the emergent themes from all the transcripts into a standard 'Themes' folder, where they were merged for the first time. I consolidated the superordinate themes within the Themes folder. I utilised a specific type of query in NVivo called Matrix Coding, which produced a table showing participants in columns and themes in rows (Table 7). From this table, I was able to examine the themes, both between and within participants, and then provide further interpretations to gain a broader understanding for my final analyses. These interpretations highlighted similarities among participants, while also demonstrating disjunctures between their experiences that required analytical attention. I studied my reflexive journal and field notes, drew on higher-level theories and insights, and related the findings to existing literature to further explore the data (Howard et al., 2019).

Figure 3 Print screen of my NVivo project file

Codes

Name	Files	References
1. Transition to new motherhood	10	452
1.a. Challenges	10	142
1.a.a. Sensory sensitivities	9	49
1.a.b. Executive functioning and social interaction	7	31
1.a.c. Additional exacerbating challenges	10	61
1.b. Responsibilities	10	165
1.b.a. Assuming responsibility	9	70
1.b.b. Comparing maternal ability	8	44
1.b.c. Negative evaluation and stigma	10	51
1.c. Pressure to be a 'good mother'	10	145
1.c.a. Maternal self-efficacy	10	69
1.c.b. Meltdowns and shutdowns	8	32
1.c.c. Impact on mental health and well-being	10	44
2. Autistic identity development	10	426
2.a. Receiving an autism diagnosis	10	149
2.a.a. Typically autistic behaviours	10	61
2.a.b. Diagnostic journeys	10	50
2.a.c. Personal reactions	10	38
2.b. Identifying as autistic	10	125
2.b.a. Research and the autistic community	10	43
2.b.b. Authentic autistic nature	10	43
2.b.c. Assessing whether others are autistic	9	30

1.a.b. Executive functioning and social interaction

Reference 2 - 0.46% Coverage

It's been hard, it's been hard for my mental health and my sister lives a long way, so when my parents were vulnerable, she was divorced, had to work full time to keep the house going. So, it made sense for my mum and dad to come here, not to her, because I was already not able to work much on account of my younger kid, whose needs are too big for me to go off and do work. She's off school too much. So, yeah.

Reference 3 - 0.45% Coverage

I've had a lot of anxiety. And in the course of last year, I've realised that, actually, quite a lot of these physical symptoms over the years were probably only partly due to anxiety. Some of it was down to my autistic traits, and I have not yet got to the bottom of it; I'm not fully used to it. I've accommodated myself, worked around them, and learn to cope with them to fit into the world.

Reference 4 - 0.58% Coverage

And she wasn't sleeping properly. She was an awful, awful sleeps. And I left her there for two further occasions before the message drops that she can't do this. As much as I needed the time in the house to think, I couldn't do this to my child. And I woke up one morning and I must have been grinding my teeth at night because when my jaw opened, I got only a bit of banana in my mouth and it wouldn't go in for me. So, I had to go and have that looked at by the osteopaths and the medics as well.

Reference 5 - 0.49% Coverage

Unfortunately, the backdrop was that I was getting really stressed, and she's had this playgroup experience and he was suicidal. So, it went badly. She'd stick her fingers in her ears, and she'd lose it, and then I'd lose it, and I physically put her outside. I put her out the back door and said, 'You can wait out there, I can't be dealing with this', which is horrible. Then I came into the front room and bashed cushions.

Reference 6 - 0.26% Coverage

when I have been bad to them or got it wrong, I've always apologised and said, 'I've got to be calmed down. Look, I'm really sorry. I lost it there,' and 'I was cross about something else, which wasn't anything to do with you.'

Reference 7 - 1.10% Coverage

CM 52 Items Files: 7 References: 31 Unfiltered

Table 7 Matrix coding table, showing the number of NVivo nodes (codes or “quotes”) in all superordinate and subthemes for each participant

	A : Anna	B : Bridget	C : Chayana	D : Diane	E : Eva	F : Fiona	G : Georgia	H : Hannah	I : Ivy	J : Jo
1. Transition to new motherhood	44	20	20	18	22	9	19	30	24	14
1.a. Challenges	31	4	7	8	13	2	8	14	8	11
1.b. Responsibilities	23	9	13	17	15	3	11	23	19	4
1.c. Pressure to be a 'good mother'	24	16	13	11	8	4	4	18	11	5
2. Autistic identity development	46	30	34	28	30	15	20	16	11	18
2.a. Receiving an autism diagnosis	20	18	20	15	16	10	11	7	5	10
2.b. Identifying as autistic	23	6	10	14	18	5	7	14	8	10
2.c. Impact on experience of motherhood	9	15	14	9	19	6	11	4	10	11
3. Diagnostic disclosure	45	33	25	22	26	18	19	19	16	17
3.a. Family	11	14	1	6	8	7	1	7	6	9
3.b. Friends, work, and education	18	11	15	9	21	11	8	11	11	5
3.c. 'Caring' professionals	31	20	15	14	10	8	13	6	10	10
4. An authentically autistic family	55	36	30	23	23	13	21	25	21	18
4.a. Undiagnosed lived experience	43	18	27	10	14	6	15	13	17	13
4.b. Shielding the children	31	14	3	8	12	7	8	16	12	1
4.c. Benefits of an authentically autistic family	14	12	6	14	14	4	8	10	10	8

Having disclosed a shared identity with the participants meant that trust and rapport between us were more easily established during the interviews (Foster et al., 2024; Milton, 2014). My lived experience helped me to understand and relate to some of the experiences and emotions that the autistic mothers described. This connection led to the open and descriptive accounts about their lived experiences that have been portrayed in this dissertation (Turner & Beresford, 2005).

I am a member of the Participatory Autism Research Collective (PARC), an autistic-led academic network aimed at increasing the involvement of autistic individuals in autism research (Fletcher-Watson et al., 2019; Kelly et al., 2024). I am a member of the Autistic Autism Researchers, a private Facebook group offering support and guidance to autistic adults engaged in autism research. I am also a member of the Discover autism research network and the Autism Insight group, both run by Autistica, a leading autism research charity (Autistica, 2018; Kelly et al., 2024).

CHAPTER 5 PARTICIPANT DEMOGRAPHICS AND OVERVIEW OF THEMES

In this chapter, I present demographic data on the ten autistic mothers who participated in this study. In addition, I have provided a brief overview of the four superordinate themes and their related subthemes that I identified from the data. I also prepared brief biographies of each participant (Appendix G).

Participants demographics

The participants' names referred to in this dissertation are pseudonyms to protect their confidentiality (Table 8). The mothers in this study were aged between 28 and 54 years (mean age = 39 years). All lived in the UK, eight identified as White British, one as White Roma (Ivy), and one as Asian Indian (Chayana). Seven identified as women, one as gender fluid (Georgia), one as non-binary (Ivy), and one as gender questioning (Hannah). Four of the mothers were employed, two were self-employed, three were full-time students, and two were full-time parents. All participants were well qualified, with the minimum qualification level being a BTEC National Diploma. Seven mothers had an undergraduate qualification, four had a postgraduate degree, and one was currently doing a PhD. Seven of the mothers were married, one was living with a partner (Georgia), one was married for the second time and their husband was the stepfather of two out of their three children and father to the third (Hannah), and one was divorced; her ex-husband had transitioned, becoming a second mother to her child, and they both had joint custody (Bridget). Apart from receiving some assistance from partners and older children, most participants received little to no regular familial support, except for Diane and Fiona. Nine mothers were relatively recently diagnosed, between one and four years ago (mean = two years), although one mother had been diagnosed 15 years ago (Chayana).

All of the participants had been diagnosed as autistic after becoming mothers. The number of years they had spent as an undiagnosed mother varied between two and 19 years (mean = eight years). Only one participant had given birth as a diagnosed mother, as her youngest son was born two years after receiving her diagnosis (Jo). Eight mothers had children who were diagnosed with autism, and two had children who were assumed to be autistic and were awaiting an assessment (Fiona and Jo). Their assessments were delayed due to the COVID-19 pandemic

Table 8 Demographic information on the ten participants in the study

Pseudonym	Age	Age diagnosed	Years since diagnosed	Age first child born	Years as an undiagnosed mother	No. of children	Children's gender, age and neurotype	Gender Identity	Ethnicity	Education	Employment	Marital status	Local family support
Anna	54	52	2	33	19	2	Female 21 years and female 16 years, both diagnosed	Woman	White British	BA History, postgraduate qualifications in librarianship and reflexology	Normally reflexologist but part-time shop assistant due to COVID	Married	None
Bridget	34	30	4	26	4	1	Male 8 years, diagnosed	Woman	White British	Currently doing a BSc	Full-time student and part-time waitress	Divorced. Ex-husband is transexual and both mothers share custody	Mother
Chayana	48	33	15	23	10	2	Male 25 years and male 20 years, both diagnosed	Woman	Asian Indian	BTEC Public Administration	Part-time nanny	Married	None
Diane	28	26	2	24	2	1	Male 4 years, diagnosed	Woman	White British	Dropped out of a PGCE as bullied in placement and no support from disability services	Full-time mum, recently made redundant from job as content editor for a parenting website	Married	Parents, mother-in-law and father-in-law
Eva	36	34	2	31	3	1	Female 5 years, diagnosed	Woman	White British	PGCE, currently doing a MSc	Full-time student	Married	Sister
Fiona	40	36	4	34	2	2	Female 6 years, awaiting assessment and Male 4 years, neurotypical	Woman	White British	PGCE	Part-time pioneer missionary	Married	Parents
Georgia	38	35	3	30	5	1	Male 8 years, diagnosed	Gender fluid	White British	MSc, currently doing a PhD	Student/doctoral researcher	Living with partner	Mother (although they have issues)
Hannah	47	45	2	29	16	3	Non-binary 18 years, awaiting assessment, Male 16 years, diagnosed and Female 9 years, awaiting assessment	Woman, although exploring non-binary	White British	BA (Hons)	Part-time self-employed business	Married, although husband is not the father of their first two children. He also has two neurotypical children who live with their mother.	None
Ivy	33	32	1	17	15	3	Male 16 years, neurotypical, Male 11 years, diagnosed and Male 5 years, diagnosed	Non-binary	White Roma	BTEC	Full-time mum	Married	None (mother visits every few months)
Jo	35	33	2	30	3	3	Female 5 years, awaiting assessment, Male 3 years, and Male 0 years	Woman	White British	BA Psychology	Part-time self-employed writer	Married	Mother (although she doesn't agree with diagnosis)

restrictions. Most mothers received their diagnosis after their autistic children had received theirs (Anna, Bridget, Chayana, Georgia, Hannah, and Ivy). The age of the mothers when their first child was born varied between 17 and 34 years (mean = 28 years). Four mothers had one child, three had two children, and three had three children. The age of the children at the time of the interviews varied between zero and 25 years (mean = 11 years). The autistic children included six daughters, eight sons and one non-binary teenager. Two of the mothers had a neurotypical son, as well as at least one autistic child (Fiona and Ivy). Seven of the mothers had been diagnosed with additional neurodevelopmental, mental health, or physical health conditions, which had mainly been present before they were diagnosed as autistic. Three of the seven mothers felt that these were misdiagnoses, and that the difficulties that had been attributed to these conditions had developed as a consequence of having been an undiagnosed autistic person living in a predominantly non-autistic world (Bridget, Georgia, and Jo).

An overview of the superordinate themes and subthemes

From my data analysis, four superordinate themes emerged, encapsulating the experiences of all ten participants within each (Table 9).

Table 9: Superordinate themes and subthemes

Superordinate themes	Subordinate themes
Transition to new motherhood	Challenges
	Responsibilities
	Pressure to be a 'good mother'
Autistic identity development	Receiving an autism diagnosis
	Identifying as autistic
	Impact on the mothers' maternal self-efficacy
Diagnostic disclosure	Family
	Friends, work, and education
	Health and social care professionals
An 'authentically autistic' family	Undiagnosed lived experiences
	Shielding the children
	Perceived benefits of an 'authentically autistic' family

CHAPTER 6 THEME ONE – TRANSITION TO NEW MOTHERHOOD

Findings of Theme One - Transition to new motherhood

This chapter begins with the findings of the first subordinate theme, which portrays how the mothers described their experiences of transitioning to new motherhood without knowing they were autistic. The findings reveal the challenges they faced during their transition, how they coped with their new child-rearing responsibilities, and the pressure they felt to be ‘good mothers’. The discussion of these findings follows directly afterwards, in the second half of this chapter. This arrangement will be repeated in the following three superordinate themes, and hopefully, will make it easier for you to recall the findings of the theme whilst reading the corresponding discussion immediately after.

Challenges

All ten mothers were undiagnosed at the time of the birth of their first child, so they had to manage their differences during the transition to new motherhood without understanding why certain aspects of their daily life seemed so problematic. The participants in this study were diagnosed, on average, eight years after the birth of their first child (range: 2-19 years) (Table 8). All ten of the autistic mothers had at least one autistic child, ranging in number from one to three, and only two of the mothers also had a neurotypical child (Fiona’s youngest 4-year-old son and Ivy’s eldest 16-year-old son). Four mothers (Anna, Chayana, Hannah, and Ivy) recognised their own autistic traits whilst researching autism for their autistic children (Garcia-Molina & Cortes-Calvo, 2025).

When the ten participants were asked about the main challenges they had faced as new mothers, nine talked specifically about their over-reactivity to sensory stimuli. Following the birth of their first child, some parents experienced tactile sensitivities, mainly due to breastfeeding or chestfeeding. Anna and Eva highlighted that breastfeeding was initially overwhelming and very painful. Anna found being physically close to her child difficult at first and felt extremely uncomfortable when her midwife tried to help her baby latch on. However, they were aware that breastfeeding was beneficial for their child, so both Anna and Eva persevered with breastfeeding for approximately three years.

I'd be making lunch holding her and she'd be asleep on my shoulder. I made lunch and everything with one hand for the first two years, I would say, and I breastfed her until

she was nearly three. She wouldn't take a bottle, and it didn't matter what we did. It didn't matter what we tried. If I had left her like they told me to, she would cry until she was sick. (Eva)

The most challenging sensory sensitivity of all, according to the mothers, was auditory, such as the sound of their baby crying, noisy toys, and children's television. The participants explained that, before becoming mothers, their most effective coping strategy for reducing sensory overwhelm was to withdraw to a quiet place without any social interaction. However, as they were the primary caregivers for their children, the auditory stimuli were constant and felt impossible to withdraw from.

It was why I'd been struggling with motherhood, the transition and all of the different challenges. I realised that I'd unconsciously built in these coping mechanisms into my life, pre-parenthood, and was able to manage but I couldn't build those in anymore, because I was in a different situation (Eva).

Being unable to escape from stimuli created a perception of it as threatening, which in turn caused a higher stress response.

It's the sensory aspects of it, and when they're very small, that was the hardest. Newborn cries make me want to top myself; I can't bear them. I always interpret it as 'Danger, danger, danger'. It just makes my whole body recoil; I just hate it. I can't bear it. (Jo)

When the mothers described their relationship with their autistic children, a few recalled that, even when they were very young, their babies did not like to be separated from them.

I felt really, really, like no-one was taking me seriously. They thought I was being a hypochondriac mother. I was a stressed-out mother; that was the label. But I knew in my heart of hearts that something wasn't right, and I realised this soon after my son was born. In the hospital, he was the only child that was crying his eyes out, and I could not settle him. (Chayana).

The advice given to Anna by her health visitors was to leave her baby to “cry it out” until she settled to sleep. However, Anna’s baby went beyond crying to “panicking”, so she stopped using that strategy because she felt that it was too traumatic for her daughter. The guidance provided by the health visitor may have been effective for some families, but Anna felt that her children were unique and had different needs. She was able to evaluate the best course of action for her situation.

Co-sleeping with my children meant that we all got some sleep, and that was a thing that otherwise, if I'd have been a very usual parent, I might have said, ‘No, because the baby book says that, by a specific amount of time, she’s supposed to do such and such.’ Sod that for a lark! I was willing to accept they were very different children who have very different needs, and I did what I thought that child needed; not what some book had told me to do. (Anna)

Diane stated that, before she had started co-sleeping with her baby, the lack of sleep had affected her emotional control. Co-sleeping had helped her baby stay happy and made her feel less exhausted and overwhelmed by the noise of her baby's cries. Although all mothers may experience some challenges adjusting to new motherhood, a great deal of the participants’ difficulties in settling their children may have been related to their children’s autistic traits. Having an autistic child may have resulted in exceptional challenges and parental stress, in addition to those experienced by mothers of non-autistic children. Many of the participants had experienced chronic sleep deprivation, very little time to themselves, and needed to make significant lifestyle changes, such as giving up work.

My son was the first to be diagnosed, and that was way back when he was [age], because he was challenging. It was kind of obvious there was something. He (pause) didn't find it very easy when me and his dad split up. It all kicked off horribly. He had quite violent behaviour that took a long time to control. (Hannah)

Seven of the ten mothers in the study described having significant challenges with their executive functioning. Executive functioning is the cognitive processes that help a person regulate, control, and manage their thoughts and actions. It encompasses a broad array of cognitive skills, including planning, time management, impulse control, and the initiation and monitoring of actions.

Managing multiple, often unpredictable parenting tasks alongside their other demands was a specific difficulty for the mothers.

It was after my daughter was born, that I struggled to cope with a lot of things that I'd previously been able to cope with; the additional executive functioning difficulties, planning, organisation, the sensory challenges of having a baby that screams and cries a lot and wants to be attached to you all the time. I couldn't leave her with anybody, so I couldn't have a break. (Eva)

The transition into motherhood involved a considerable lifestyle change, with new routines and additional responsibilities, which the autistic mothers found difficult to manage. Cognitive inflexibility, also known as "black and white thinking" (Chayana), is a prominent characteristic of autism, which manifests as having difficulties shifting thoughts or perspectives.

It made sense why I needed it [a diagnosis], because the world doesn't behave the way it's meant to behave. I tend to have a set of rules in my head. When the world doesn't do what it's meant to do, that stumps me a wee bit. (Fiona).

Responsibilities

Nine out of ten participants reported assuming a high proportion of responsibility for the child-rearing duties in their families. They felt that there was an onus on them to provide a settled, loving, and secure home life, particularly as most mothers recalled their childhood as being insecure or having lacked much affection. These mothers were determined to provide a better life for their children, so they would not have to experience the same type of trauma.

A lot of the time, people would call me stupid, so I really assumed, growing up, that I was stupid, and I never really had any affirmation or love when I was growing up. So, when I became a mum, it was really extremely important for me that we had stability, and I guard that precious. Also, I made sure that I always was affectionate to my children. I always tell them, 'I love you,' probably more than most, and I'm always affirming them, 'You're wonderful, you're beautiful, you're smart, you're intelligent, you're fantastic, you can do anything in this world' (Ivy).

Although many of the mothers researched extensively about the best ways to care for their children, ultimately their decisions often resulted from using a combination of their instinct and understanding of their children's needs: "I can't do things in the conventional way, just because that's the way everyone else does it. I have to think about whether it's the right way. Like home educating." (Hannah) The mothers were highly responsive to their children, ensuring they were happy and well cared for. However, Diane felt that this responsive parenting style had made her feel very tense, as she was constantly waiting for her baby to cry and need attention, and therefore was unable to relax around her.

The participants became very selective about the people who could or could not be given access and influence over their children. Ivy was particularly unwavering about the type of people who would be welcomed into their home.

I guard the stability of our home preciously, so anybody who comes into our home who doesn't necessarily agree with how we're doing things or wants to say offensive things, I'm like, 'Out. No, you're not coming in. You're not being a part of our lives.' (Ivy)

Even though Anna desperately needed support when she was caring for her two autistic daughters as well as her elderly parents, she decided to stop getting assistance from her mother-in-law as she had been upsetting one of her children: "And also, mother-in-law is such hard work that I thought, no, she was actually rubbing my younger one up the wrong way a lot and that was causing trouble, and so I just thought that's it, let's leave it." Similarly, Hannah found that the support received from their parents had made their life more problematic, as their parents had difficulties managing their autistic son. Eva also decided to limit the influence that her father had on her daughter's life, as he was so unreliable and unstable.

On the other hand, some mothers actively sought out other mothers in their area to befriend, as they realised that it may prove beneficial to have a social network nearby as support. Anna was able to call on mothers in her neighbourhood to take part in group activities when her children were being home-schooled, and they also helped with childcare when she was unwell. Unfortunately for Eva, her husband could not understand the advantage of being part of the local community.

That, negotiating the social stuff as well, my husband would not make friends with any parents. If it was up to him, he would never go to birthday parties, and I said to him, 'It's important for our daughter, because she will be invited to these things, and she might want to go, and it's important that she has this network. It's useful. There's a purpose. There's a point to it. I don't do it for fun. I don't do it because I enjoy it. I do it because these relationships are important and useful. It would be isolating her from other people and that community if I didn't do that. (Eva)

Having autistic children also meant coping with the extra pressure of getting them diagnosed and applying for the educational support they will need. Ivy was the first person to notice the “red flags” in their middle child’s behaviour at primary school, so they approached their son’s teacher and their GP, and they were referred to a paediatrician. However, in the late 1990s, Chayana had much more difficulty persuading health professionals to assess her son for autism.

The professionals weren’t forthcoming with giving a diagnosis. They were trying to do all these things, but they didn't want to give him a diagnosis. That's what was frustrating. They send me to parenting classes, they sent him to speech therapy, but nobody wanted to give him an official diagnosis, but I was a fighter. (Chayana)

The mothers had to deal with endless appointments, fill in stacks of paperwork and forms, and fight a constant battle for services and support for their children.

I'd been disenfranchised as a parent, invalidated as a parent, made completely, they weren't listening at all, and I had a point of view, my kid was suffering ... and it was traumatic. It was absolutely horrible (Anna).

Furthermore, some of the mothers had tried to strike a balance between responsibilities at work and at home but found themselves shouldering a disproportionate amount in both settings. Some reached a point when they had to decide between whether to continue working or homeschooling their children. Anna was unable to work as her youngest daughter was not attending school while they waited for funding from the local authority to enrol in a suitable independent special school. Hannah home-schooled all three of their children as they did not believe they would have coped with mainstream school.

It's really the grind of the responsibility that really gets me down. Being the one that plans the curriculum, sorts out the hospital appointments, researches all the issues that come up and deals with the constant, 'Ouch, I banged this.' 'Oh, my little finger has been feeling weird.' 'Should my knee be that colour?' ... I have to produce the meals for everybody; taking into account everyone's nutritional needs but also everyone's textural issues and taste issues, and then try and incorporate that into some kind of menu that means that I don't end out cooking five separate meals every day for every meal, while also keeping it vaguely healthy, and trying to actually eat something myself after that ... No one bloody sleeps; they're awake until God knows when, and then someone's always up from God knows when. I'm always available and interruptible, and I'm always the one that they'll come to, to find about this, that or the other. (Hannah).

One of the most significant responsibilities the mothers believed they had was to prepare their children for adulthood and to help them find their place in the outside world. When children have additional support needs, that responsibility may seem daunting.

I can't just set them adrift into the world and then watch them burn out, like I did. I need to find them that niche and then settle them into it. Then I'd feel like I could relax about them (Hannah).

Pressure to be a 'good mother'

Eight out of the ten participants, without prompting, made comparisons with other mothers in their local communities who seemed to be managing far better than they were. Their tendency to set impossibly high standards for themselves sometimes made the mothers feel like failures for not knowing exactly how to respond to every given situation. Hannah was unsure whether they had been setting the correct ground rules for their children: "They say, 'Oh, my friends aren't allowed to do X, Y, and Z,' and I think, 'Shit, was I not supposed to allow them to do that?'" The mothers had put themselves under a lot of pressure to do everything perfectly, and this had become overwhelming at times.

Your voice saying, 'How come you can't do that, because look at [neighbour's name] next door, who has five children, two of whom are autistic? She's very organised and

plans everything ahead.’ And I thought, ‘I don’t know how you can do that. I don’t know where the energy comes from.’ And then my mother-in-law said, ‘Normally, you just cope when you’re a mother. You just cope.’ ‘Well, you might, but I don’t know where this energy comes from. I don’t have that amount of energy, thank you (Anna).

The mothers found it hard to relate to neurotypical mothers who had tried to give them advice and helpful tips, but did not seem to have the same issues with their children as they did. This had made them feel isolated and alienated within their local community.

I found that there weren't any other parents who understood my experience, whoever I talked to. They just couldn't connect with what I was saying. They were like, ‘Why don't you just leave her to cry?’ (Eva)

At various stages during their interviews, all participants reflected on their lack of maternal self-efficacy before they had received their autism diagnosis. Bridget’s anxiety became more extreme during her transition to motherhood: “I catastrophised like crazy, and when he was a baby, it was a nightmare; I would overthink absolutely everything.” Chayana was diagnosed with postnatal depression and questioned whether she had any maternal instincts: “I struggled with being a mum. That's when I felt that I was a failure. My maternal thing wasn’t there; it did not come. You know, when babies are born, everybody loves their babies automatically. That didn't come straightaway.” When Chayana looked back on that period of her life, she remembered how uncertain she had felt about how to care for her newborn, and she still feels tremendously guilty about it.

There were things which I did; I just didn't understand. I really regret it. You know, I really feel guilty. I'm going to put my hands up; I just didn't know how to look after a baby. I didn't put in a routine; the things I know now. No, I didn't know anything. For all I knew, some people just got it and knew how to do it. (Chayana).

Eva felt that there is a tremendous amount of pressure from society to be a ‘perfect mother’ who only cares for others and not themselves.

To fit into a mould, and to do everything and be everything, and it's almost like not having any needs yourself, is the goal. It seems that's the aspiration; an ideal of perfect motherhood is to have no needs yourself and to put everybody else's needs first. (Eva)

This pressure was felt even more acutely by Ivy, who had been brought up in the Roma culture.

The women in my family have the view that life is supposed to be hard and, as a woman, you should be saintly in your struggle. So, it's like a badge of honour to constantly struggle and wait on everybody else. That's the image; that's what a woman should do. A woman is about juggling, putting herself last in the pecking order and going to bed exhausted at the end of the night. If you're not like that, you're looked down upon. (Ivy)

Eight of the participants talked about how overwhelmed they felt when they became mothers. This feeling occurred when they lacked the support they needed, and their mental, emotional, and physical resources were depleted: "He would come home from work some days and both baby and I would be bawling our heads off, because she had evening colic from [month]". (Anna) The autistic mothers, however, were so devoted and determined that their children's needs would always come first, even if they were experiencing difficulties and their energy levels had diminished.

I can't stand those repetitive whining noises, which again leads to me having to be ultra, ultra-responsive. This puts so much pressure on me. The alternative is I get overwhelmed by the noise. If I'm responsive, I won't get overwhelmed by the noise, but I'll get overwhelmed by the responses. So, I can't win either way, and you know, I just have to do what makes [child's name] happy at the end of the day. (Diane)

Due to the perceived pressure felt by the participants to be 'perfect mothers', they tended to ruminate over every mistake they made, however small, which increased their anxiety levels:

The constant level of anxiety, the constant background chatter in my head, the fact that I'm thinking about ten things all at the same time, and I'm trying to plan for absolutely any eventuality that can possibly happen from even the most minor

situations. This is just how I think; this is just my general reality. I never knew anyone was any different. (Hannah)

Meltdowns and shutdowns are, respectively, emotional explosions and implosions that are natural reactions for an overwhelmed autistic person, and once started, they cannot be controlled.

I just cried and cried and screamed and screamed. The neighbours heard me and, oh my God, luckily, they didn't report me to anyone. They came and had a chat with me. They're like, 'Are you okay?' and I'm like, 'No, I'm really struggling.' Luckily, they've got an autistic child, so they get it. I think the lack of sleep really impacted on me. (Diane)

All of the participants felt that the pressure to be a 'good mother' had impacted their mental health and well-being. Many of them commented on how their anxiety had caused them to become hypervigilant and to have sleepless nights.

I've had a lot of anxiety. And in the course of last year, I've realised that, actually, quite a lot of these physical symptoms over the years were probably only partly due to anxiety. Some of it was down to my autistic traits, and I have not yet got to the bottom of it; I'm not fully used to it. I've accommodated myself, worked around them, and learn to cope with them to fit into the world (Anna).

Unfortunately, some of the mothers still had ongoing issues with their mental well-being at the time of their interview. "To be honest, I'm so burnt out; I'm struggling to come up with positives about anything right now." (Hannah). Depression often presents in autistic people who are diagnosed very late in life and are not given the support they need.

I do feel isolated. This is probably why I suffer from depression every once in a while, as I don't have that network of support and family. Furthermore, in my culture, I'm a stranger because I'm not following my culture, and I have issues with my cultural identity. (Chayana).

Discussion of Theme One - Transition to new motherhood

Challenges

Nine out of ten mothers in this study had mentioned in their interviews that they had experienced heightened sensory reactivity, particularly to auditory stimuli such as the crying of their newborn babies, noisy toys, and children's television programmes, as well as to tactile stimuli, particularly breastfeeding or chestfeeding (Hampton et al., 2023) (see Chapter 2, Social and Historical Context, pages 23-25). While all females and gender-diverse individuals may experience stress and anxiety during early parenthood, autistic mothers with sensory processing differences may exhibit more pronounced and pervasive difficulties that impact their maternal experience (Sutcliffe-Khan et al., 2024; Talcer et al., 2021) (see Chapter 3, Thematic Synthesis, page 51). Previous studies have discovered that the hyper- and hypo-sensitivities experienced by most autistic individuals are often the causal factors of heightened stress and anxiety (Smith & Sharp, 2013; Talcer et al., 2021). However, increased anxiety may also contribute to intensified sensory sensitivity, so it is likely to be a bidirectional relationship (Talcer et al., 2021).

Most of the participants (Anna, Bridget, Chayana, Diane, Eva, Georgia, and Ivy) had unhappy childhood experiences, and studies have suggested that trauma survivors may demonstrate hypervigilance, often resulting in more intense sensory sensitivities (Dell'Osso et al., 2024). Researchers have theorised that the sensory issues in autistic individuals may be, at least in part, caused by the anxiety and hypervigilance they experience due to living in a world that does not readily understand or accommodate their needs, and often treats them with hostility (Gara et al., 2020) (see Chapter 4, Methodology, page 73).

Many autistic people have a complicated sensory profile, which may be exacerbated by conditions such as hyperacusis, an intolerance of everyday sounds that causes them significant distress and may affect their day-to-day activities (Z. J. Williams, E. Suzman, et al., 2021). For those who are hypersensitive to auditory stimuli, sounds are perceived as significantly louder, causing annoyance, distraction, fear, distress, or even pain (Poulsen et al., 2025). When an autistic person becomes overwhelmed by unpleasant sensory stimuli, they may experience a meltdown or shutdown (Lewis & Stevens, 2023) (see Chapter 2, Social and Historical Context, pages 27-28). Unfortunately, autistic individuals are often perceived by others as being deliberately difficult, dramatic, or uncooperative when they are actually feeling overwhelmed (Donovan et al., 2023).

Jo explained how the cries of her newborn child had been so incredibly stressful for her, and she would often feel a need to escape because the noise felt so unbearable, but she felt unable to do so (Poulsen et al., 2025). The perceived inability to escape from this type of sensory ordeal may have contributed to her feeling that she was unable to cope (Beardon, 2008; Reuben et al., 2021). The sensory avalanche theory, proposed by Smith and Sharp (2013), explained how autistic people become more sensitive to sensory stimuli if they perceive it as alarming but are unable to escape it; thereby creating a vicious cycle of over-reactivity (Talcer et al., 2021) (see Chapter 3, Thematic Synthesis, page 55). Moreover, sensory overload would exacerbate difficulties in executive functioning and emotional regulation (Fernandez-Prieto et al., 2021).

Breastfeeding or chestfeeding success largely depends upon the guidance and support mothers receive in the early postnatal period, and this is especially important for autistic individuals (Wilson & Andrassy, 2022). However, this period of transition to new motherhood may have been a difficult time for the participants to learn this new skill, especially while still in the hospital environment. They may have felt pressured by the urgency and importance of the task, as well as been overwhelmed by the sounds of a busy maternity unit (Brown et al., 2023). Research conducted by Grant et al. (2022) found that the sensory differences and pain felt by autistic mothers were exacerbated due to a lack of support, making breastfeeding or chestfeeding incredibly challenging (Talcer et al., 2021) (see Chapter 3, Thematic Synthesis, page 51). They stated that “maternity and infant feeding services were built on a lack of understanding of autistic needs and were often inaccessible at a time when autistic mothers already felt a loss of control and lack of social support” (Grant et al., 2022, p. 1). Of course, in this study, the mothers were unaware that they were autistic during this transition period, so they were unable to ask for autism-specific support (Eidelman, 2022).

Anna and Eva described their initial discomfort while breastfeeding their newborn babies, and how they felt overstimulated and overwhelmed (Eidelman, 2022). For Anna, her initial experience was made worse when her midwife tried to help her baby latch on to her nipple without previously asking for permission to touch her (Wilson & Andrassy, 2022). Healthcare professionals must be aware that some autistic women and gender-diverse individuals, whether diagnosed, self-diagnosed, or undiagnosed, may experience hypersensitivity to touch, experience heightened pain, and should only be touched with a patient’s consent (Ujiie & Takahashi, 2022).

Both Anna and Eva described their focused determination to breastfeed, as they knew it was the healthiest option for their child (Wilson & Andrassy, 2022). They were aware of the feeding guidance for mothers, which recommends exclusive breastfeeding or chestfeeding for the first six months, followed by human milk in addition to solid food (UNICEF/NHS, 2022). Their determination enabled them to breastfeed for nearly three years (Grant, Griffiths, et al., 2024; Wilson & Andrassy, 2022). Eva described her intense attachment to her baby daughter and her reluctance to take formula milk from a bottle (Campbell et al., 2025). In studies by Gardner et al. (2016) and Pohl et al. (2020) autistic mothers had reported finding the initial sensation of breastfeeding or chestfeeding unpleasant, but, in a similar way to Anna and Eva, they persevered as they knew it was in the best interest of their babies. Despite the initial challenges they faced, Anna and Eva ultimately found breastfeeding a positive experience (Grant, Griffiths, et al., 2024). Studies have shown that oxytocin, the hormone that triggers the 'let-down reflex' that releases milk from the breast, has a calming effect on both mother and baby by blocking cortisol, also known as the 'stress hormone' (Ljubicic et al., 2025). Therefore, breastfeeding may have provided some relief from the sensory overload and stress that the mothers were feeling (Mehta, 2025).

During their transition to new motherhood, the mothers struggled with sleep deprivation and exhaustion (Hampton et al., 2021). Approximately 80% of autistic adults, whether parents or not, experience some form of sleep disturbance (Summer & Adavadar, 2023). Autistic individuals have different circadian rhythms and significantly different melatonin levels throughout the day and night in comparison to non-autistic people (Kotagal et al., 2024). For this reason, their sleep-wake cycles differ considerably from those of non-autistic people, and many have insomnia and other sleep disorders in daily life (Dai et al., 2025). The additional lack of uninterrupted sleep, caused by their babies waking in the night, would inevitably have reduced the mothers' emotional control during this critical transition period (Page et al., 2025). Unfortunately, studies suggest that autistic individuals require more sleep than non-autistic people, due to the extra cognitive effort they expend living in the majority neurotypical world (Rasmussen, 2023).

Up to 84% of autistic people experience anxiety, which is often a contributing factor to sleep difficulties (Richdale et al., 2023). Ruminating thoughts are characteristic of autism, ADHD (a co-occurring diagnosis for Chayana, Diane, and Eva) and anxiety (a co-occurring diagnosis for Bridget and Hannah), so it may have made it harder for these five mothers to wind down and fall asleep (Henderson et al., 2023). Furthermore, for both autistic adults and children, being anxious

during the day may contribute to having restless sleep, vivid dreams, nightmares, or night terrors (Berenguer et al., 2024). Bridget described how she “catastrophises and overthinks” everything due to her anxiety (Charlton et al., 2023). The potential effects of sleep problems on autistic people include: an increase in repetitive behaviours, more social and communication challenges, daytime fatigue, irritability, and difficulties with learning and memory (McLean et al., 2021).

Executive functioning may be significantly impaired by a lack of sleep, which may negatively impact the family unit as a whole (Lenker et al., 2025) (Chapter 2, Social and Historical Context, page 25). Executive functioning refers to a set of cognitive processes that occur in the frontal lobe of the brain, enabling us to think, plan, focus, control impulses, regulate emotions, prioritise, and organise activities required in daily life (Kiep et al., 2025). It directs and controls many mental skills that may be beneficial for new mothers, such as being able to adapt to change, ‘switch gears’, cope with interruptions, and manage time (St John et al., 2022). However, executive functioning ability is not static: it is affected by stress, depression, anxiety, lack of sleep, and other external factors (Conner et al., 2023). For the participants, impaired executive functioning may have affected their ability to control their impulses, focus attention, stay organised, and follow instructions, which may have been perceived by others as laziness, having a ‘bad attitude’, or ‘bad parenting’ (St John et al., 2022). This stigma may have become internalised, causing the mothers to feel guilty and ashamed, impacting their self-esteem and overall mental well-being (Han et al., 2023).

All the autistic mothers in this study had at least one autistic child who had been born while their mother was still undiagnosed. Fiona and Jo’s two autistic children were still waiting for an autism assessment; it had been delayed due to COVID-19 restrictions (Spain et al., 2022). It was unclear whether the difficulties that the participants had faced during their transition to new motherhood were impacted by their being, or their children being, autistic; I believe it was a combination of both (Winnard et al., 2021). A large number of studies have indicated that parenting autistic children results in increased challenges and stress for caregivers (Gong et al., 2015; Shishehfar et al., 2024). It has been shown to impact maternal well-being and mental health more profoundly than caring for non-autistic children (Liang et al., 2025). Trying to ensure all of an autistic child’s needs are met may often be challenging for mothers (Lee & Barger, 2024). When the autistic participants’ children got slightly older, they may have struggled to regulate their emotions and been prone to sudden and explosive meltdowns in noisy, crowded, and unfamiliar environments,

such as supermarkets (Eaton, 2024). Grey et al. (2021) outlined how neurotypical perceptions of the behaviour of autistic children may impact families via courtesy stigma. This leads mothers, in particular, to feel judged and morally inept due to these often verbalised opinions of their children's differences (Oz et al., 2020).

Chayana recalled that, after giving birth, she realised that her newborn baby was different from the rest of the babies on the maternity ward, as he was the only one who would not settle and continuously cried when left alone in his cot (Musetti et al., 2024). Anna and Eva also mentioned that their autistic babies would cry when separated from them, and Eva believed her baby was only content when in her arms (Narvekar et al., 2024). Six of the mothers (Anna, Chayana, Diane, Eva, Hannah, and Ivy) felt extremely 'attached' to their children and would continually hold their babies or carry them in a sling, even while doing housework (Mehta, 2025). However, the guidance Anna received from her health visitor, as well as from parenting books and the internet, suggested that mums should get their babies used to sleeping on their own by leaving them to 'cry it out' (Lee et al., 2025). Anna was unwilling to do this as she recognised how traumatic it would have been for her daughter (Cronshaw & Midouhas, 2024). She was instinctively aware that her child had high support needs, long before she was diagnosed, and therefore made the decision to co-sleep with her child (Page et al., 2025). Diane also believed that her baby was more content sleeping alongside her. She had also benefited from this arrangement, as she was not overwhelmed by the noise of her baby crying at night, so, consequently felt less exhausted the next day (Mannion & Leader, 2023). Eva also found it incredibly difficult to settle her daughter unless they co-slept together; it was only then that the household was able to sleep soundly (Mannion et al., 2024).

Responsibilities

Within their families, all the autistic mothers in the study had taken on the primary responsibility for caring for their children. In this country, mothers are typically viewed as being responsible for childcare due to the unequal distribution of labour in a typical household (Andrew et al., 2024; Oakley, 1979). Although fathers play a more active role in domestic life than they did in the past, mothers still tend to be the primary family member responsible for child-rearing and other household tasks (Chanfreau, 2023). All the participants described how they had struggled in their new mothering role and wondered why their parental responsibilities seemed to be so much harder for them than for the other mothers they knew (Miller et al., 2021). As they were

undiagnosed, they had to negotiate motherhood without any autism-specific support (Garcia-Molina & Cortes-Calvo, 2025). They had sought advice from generic parenting programmes and literature that included cultural ideals about how a ‘good mother’ ought to act (K. J. Benson, 2023).

Upon becoming mothers, the participants intentionally chose to raise their children in a different style from the way they had been brought up (Sedgewick et al., 2022). They drew on their own childhood experiences as they developed strategies and parenting styles, which they believed would ensure their children’s lives had meaning and purpose and would allow them to thrive and find happiness (ibid.). Every autistic mother in this study dedicated themselves entirely to making certain that their children felt loved and valued, and to always being a reliable source of support for their needs (Sedgewick & Douglas, 2023). The mothers’ comfort was often sacrificed for the best interests of their children, thus demonstrating empathy and their ability to see things from their children’s perspective (Talcer et al., 2021). For example, they attended parent and baby/toddler groups with their children, even though they found them difficult to cope with due to their anxiety, social differences, and sensory sensitivities (Poulsen et al., 2025). Eva chose to accompany her daughter to birthday parties, which were often held at very autism-unfriendly venues, such as bowling alleys or soft-play centres (Talcer et al., 2021). The mothers did everything they assumed was expected of them, but overlooked their own needs, and it left little room for them to experience peace, relaxation, and the straightforward enjoyment of motherhood (Sedgewick & Douglas, 2023). Previous research has also indicated that autistic mothers often put their child’s needs before their own (Talcer et al., 2021) (see Chapter 3, Thematic Synthesis, pages 51-52).

A prominent characteristic of autism is the tendency to thrive and feel more comfortable and secure when life is predictable and structured (Hwang et al., 2020). For all people, the transition to new parenthood brings many changes, but coping with this alteration to their lifestyle and changes to their daily routine was particularly challenging for the autistic mothers in this study, especially Anna, Chayana, Diane, Eva, Fiona, and Hannah (Smit & Hopper, 2023) (see Chapter 3, Thematic Synthesis, pages 51-52). Developing a daily schedule by setting reminders using apps such as iCalendar, Google Calendar, or Outlook on a computer, smartphone, or tablet may have helped plan tasks like feeding, sleep patterns, and bath times (Pagnier & Moualla, 2024). Chayana had regretted not initiating a routine when her first son was born. At her interview, 25 years later, she still felt guilty about her lack of childcare knowledge, despite being only 23 years

old at the time (Fletcher-Randle, 2022). Unfortunately, her parents had passed away, and she had fallen out with her extended family, who lived in India, so she had no family support network to call upon at that time (Smit & Hopper, 2023). When she was a child, her relatives continuously told her that she was “dumb” and “stupid,” and often unfavourably compared her to her sister (Andrzejewski & McDonnell, 2025) (see Chapter 2, Social and Historical Context, page 27). Therefore, it was no surprise that she did not wish to ask for advice or support from her extended family in India (Deniz & Toseeb, 2023).

Many of the autistic mothers gradually became aware of the similarities in personality and behaviour between themselves and their autistic children, which created a strong bond and exceptional understanding between them (Winnard et al., 2021) (see Chapter 3, Thematic Synthesis, page 50). Both Anna and Hannah felt that they instinctively knew, even when their babies were relatively young, if they were struggling, what had triggered them, how to accommodate them, and what support strategies to implement (Murphy, 2021). They were also aware that some of these strategies may have been perceived as controversial and unconventional, such as co-sleeping and home-schooling, but these solutions had worked for their family (Woodgate et al., 2015). Before implementing any of their parenting strategies, the mothers would research the topic extensively and carefully monitor the impact on their children, and adapt them when necessary (Pagnier & Moualla, 2024).

Self-care is vitally important for autistic people, especially at times when they find life problematic or become hypersensitive to their environment (Cai et al., 2023). Before becoming mothers, the participants’ most effective strategy for managing overwhelming sensory stimuli or prolonged social interaction was to remove themselves from that situation (Ghanouni & Quirke, 2023) (see Chapter 3, Thematic Synthesis, pages 52 and 56). They would find a comfortable, safe space where they could have some downtime to unmask and stim (Morris et al., 2025). Some autistic people require privacy and peace to carry out their vestibular and proprioceptive stims, which may include pacing up and down, jumping, skipping, throwing their arms around, spinning, and other similar movements, as well as verbal stims such as repeating words, phrases, or noises (Charlton et al., 2021). Eva explained how she had relied on this type of downtime over the years to regulate her emotions and recover from sensory overwhelm (Charlton et al., 2021; Kapp et al., 2019). However, when they became mothers, the participants believed they needed to be attentive to their children at all times, so they did not take regular breaks when they needed them (Nemati et

al., 2024). Not taking enough time to recover and recharge may have negatively affected their executive functioning and emotional regulation and increased the likelihood of developing mental health problems such as anxiety and depression (J. Galvin et al., 2024).

When an autistic mother has a supportive partner within the household, sharing childcare duties may be an effective way to manage them, ensuring both parents are able to get some time alone to rest (Sekulowicz et al., 2022). A few of the mothers had close relatives living nearby who were able to support them when they needed some downtime (Lin et al., 2025). Otherwise, developing support networks with other parents, where playdates could be ‘traded’ and the children would be able to socialise, may have offered some well-needed respite (Easler et al., 2022). If the mothers had been diagnosed as autistic before having their children, they may have been eligible for direct payments from their local authority, which would have provided funding for support and respite care (DoH, 2015; Taylor, 2021). However, applying for this funding would have entailed having their support needs formally assessed by social services (Norris et al., 2024). This would not be something many autistic mothers would be willing to do, as those asking for support are often perceived as being incapable and may risk attracting the surveillance of the safeguarding team (Gullon-Scott & Long, 2022). These fears are a common barrier for autistic mothers, preventing access to the support they need (Pohl et al., 2020) (see Chapter 3, Thematic Synthesis, page 53).

The participants, especially Anna, Hannah, Eva, and Ivy, explained that they had made a concerted effort to ensure their home was as peaceful, calm, and serene as possible for their children. Diane had tried so hard to be a ‘responsive parent’ and to have a perfect home for her child that she became more anxious about her mothering capabilities and was unable to relax around her new baby (Dugdale et al., 2021). For Ivy, even letting people into their ‘safe space’ sometimes proved a challenge, particularly if they did not fully respect their family’s principles and values.

Many of the autistic mothers felt that their challenges had been minimised by their families and health professionals, and Chayana was called both a “hypochondriac mother” and a “stressed-out mother”, which negatively affected her maternal self-efficacy (Lim et al., 2022). Being invalidated, especially by family members, led the mothers to mask their difficulties as a protective measure to avoid being perceived as a ‘bad mother’ (Miller et al., 2021). Some of the mothers

had family members who offered to help with caring for the children, although this was not always successful and sometimes their ‘support’ had to be discontinued (Anna, Hannah, and Eva). The relatives obviously were unaware that they were undiagnosed autistic children, of whom they had no previous experience, so they found the childcare more challenging than anticipated. Incredulity and disbelief had occurred, followed by microaggressions, and finally, hostility (Li et al., 2025).

The mothers found certain aspects of their children’s school life challenging, such as sports days, coffee mornings, school plays, and having to navigate the ‘social politics’ at the school gates (Winnard et al., 2021) (see Chapter 3, Thematic Synthesis, page 51). Anna socialised with the other mothers, even though it entailed having to mask her autistic traits, and she attempted to keep up with all the local gossip, small talk, and the many different personalities within the group (Bolis et al., 2021). Nevertheless, developing this local social network was beneficial for Anna’s children, as they were still invited to group activities while they were being home-schooled (Galan-Vera et al., 2025). Mothers from her neighbourhood also supported the family with childcare on occasions when Anna or her husband were unwell or working (Dira et al., 2024). However, this ‘networking’ caused her well-being to deteriorate due to the considerable amount of autistic masking she was performing and the constant fear of ‘getting it wrong’ (Pearson et al., 2023).

Cultural values and practices influence expectations of parenting performance, as well as societal and inter-generational attitudes as to what constitutes ‘good and bad parenting’ or an ‘ideal’ family (Chayana and Ivy) (Porter et al., 2025). If a mother requires support to manage basic childcare and domestic duties, others may judge them as being ‘bad mothers’ or as being irresponsible, incapable, or lazy (Douglas et al., 2021). Neoliberal framings of worth often focus on self-reliance and independence and are evaluated based on their impact on economic growth or efficiency (Fine & Glendinning, 2005; Ghanouni et al., 2024). Our society devalues interdependence in favour of a view of ‘thriving’ that is fundamentally linked to a person’s independence, as it prioritises market-based values and individual economic contribution as primary determinants of worth (Chapman & Carel, 2022). However, nobody is solely reliant on themselves throughout their whole life, for example, during childhood and old age, and our identities and self-understanding are shaped by systems much broader than just the individual (Li et al., 2025). The concept of interdependence acknowledges the benefits of people relying on one another by both requesting and providing support (Moser et al., 2024) (see Chapter 4, Methodology, page 72). Traditional conceptions of childcare need to be questioned to reframe it as emerging out of

interdependencies between people, such as within families, and as an essential aspect of citizenship (Greenlee et al., 2022).

As all of the participants grew up and attended school without any autism-specific support or understanding, they were determined that their children would be respected and valued for their differences and would not struggle in the same way (Cleary, West, & McLean, 2023) (see Chapter 3, Thematic Synthesis, page 49). The mothers wished to pass on to their children the skills, experiences, and coping strategies they had acquired throughout their lives (Crane, Lui, et al., 2021). Although autistic people process and experience life differently from those who are non-autistic, they have to spend the vast majority of their lives in environments designed for non-autistic individuals (Lee et al., 2025). For an autistic child to lead a fulfilling life in a world organised around the needs of a predominantly non-autistic population, they will usually require support (Bureau & Clement, 2024). Failure to provide them with the appropriate support may have a negative impact by increasing the level of disability they experience (Crowson et al., 2024). Beardon (2018) proposed that 'Autism + Environment = Outcome', which suggests that the level of disability an autistic individual experiences is reduced within an appropriate environment.

The mothers, especially Anna and Chayana, were confronted with significant barriers in their attempt to access healthcare and educational support tailored to the needs of their autistic children (Doherty et al., 2020). They had ongoing battles with their local health services and local authorities regarding obtaining referrals to autism diagnostic assessment centres and obtaining EHCPs to implement appropriate educational support for their children (Keville et al., 2024) (see Chapter 3, Thematic Synthesis, page 54). In the UK, this type of battle has increasingly been waged by parents and carers of autistic children during the past decade due to various factors, including economic austerity and the COVID-19 pandemic (SMC, 2020). In particular, there have been significant issues regarding the lack of access to diagnoses for autistic children from ethnic minority groups (Tromans et al., 2021). They have often been dismissed as 'naughty' or coming from a 'problem family' with 'poor parenting' (Tromans et al., 2021). Racial, gender, and autism stereotypes may confuse the perceptions of GPs, who may find it hard to envisage, for example, an Asian autistic adolescent female without LD (Jones et al., 2020). This has been, and still is, a major issue, as GPs serve as gatekeepers to getting a diagnostic assessment, as they decide whether to refer a person for an autism assessment or not. Furthermore, an autism diagnosis is

imperative in order to access appropriate autism-specific educational support for an autistic child (Kandeh et al., 2020).

Autistic mothers experiencing multiple forms of discrimination, such as racial, gender, or cultural, including those who identify as gender-diverse (Georgia, Hannah, and Ivy) or those from ethnic minority groups (Chayana and Ivy), may be even more likely to mask their challenges and less likely to apply for services or support that they urgently need (Gratton et al., 2023; Kandeh et al., 2020). These barriers to support, as well as problematic constructions of motherhood, have together created distinct forms of maternal struggle (Koffer Miller et al., 2022) (see Chapter 4, Methodology, pages 75-76). When a child and/or mother has multiple marginalised identities, their challenges are intensified, leading to even more significant threats to their autonomy, dignity, respect, and ability to have a voice (Lopez, 2022).

Pressure to be a ‘good mother’

All ten participants reported that, after having their first child, coping with the demands of their newborn babies, not having the mental and physical space to unwind, and negotiating with their families and friends for support had put a significant amount of pressure on them (S. Hampton et al., 2022). Eva and Ivy felt that society placed high expectations on new mothers to live up to the ideal of being a ‘good mother’, but they also realised that they were placing incredibly high expectations on themselves (Williamson et al., 2023). For Ivy, the pressure was even more intense, having been brought up in the Roma culture where a person perceived as a woman was expected “to put herself last in the pecking order”, without complaint or expecting any support, as, after all, “life is supposed to be hard” (Afanasieva et al., 2020).

Even after 25 years, Chayana still felt incredibly guilty that she had not immediately bonded with her baby when he was born (Donovan et al., 2023). In those early days of being a new mother, she regarded herself as a ‘failure’ who lacked ‘normal’ maternal instincts and thought that she would never fully connect with her baby (Nakic Rados et al., 2024) (see Chapter 3, Thematic Synthesis, page 52). Having bonding issues with one’s baby immediately after birth may be viewed as a taboo subject, particularly in Asian culture (Garg & Garg, 2022). However, it is actually pretty common. A large-scale study by the National Childbirth Trust (NCT) revealed that a third of females struggled to bond after giving birth, and one in ten were embarrassed to discuss

their bonding issue with healthcare professionals, reflecting the sensitive nature of this subject (NCT, 2016).

All the autistic mothers in the study felt continuously judged according to normative standards that emphasised 'ideal or intensive mothering' (Pohl et al., 2020). This ideology expects mothers to be powerful role models, offering warm and loving support, providing stability and close supervision at all times, and to be nurturing and focused entirely on their children, without limit to their capacity to care (Meeussen & Van Laar, 2018; Winnard et al., 2021). Yet eight of the ten participants, in particular Anna and Hannah, had unfavourably compared their mothering abilities with other mothers who seemed more organised, energetic, and able to cope (Dugdale et al., 2021) (see Chapter 3, Thematic Synthesis, page 52). Some neurotypical mothers had given Eva some parenting advice, but their approach and concerns seemed alien to her, making her feel isolated and misunderstood (Trunk et al., 2024).

Due to the social discourse around intensive mothering, the undiagnosed autistic mothers felt very guilty whenever they felt that they had failed to live up to their own and society's high, and often unattainable, expectations, and subsequently experienced social isolation and depression (Donovan et al., 2023) (see Chapter 3, Thematic Synthesis, pages 51-52). A comparative study by Pohl et al. (2020), looked at both autistic and non-autistic females' experiences of motherhood, and found that, during the postnatal period, autistic mothers were more likely to experience mental ill-health and to struggle with stress due to the perceived pressure to be a 'perfect mother'.

Autistic people tend to be perfectionists and may try hard to avoid rejection or criticism from others. The autistic mother's anxiety and stress regarding their new maternal role may have appeared 'over the top' to other non-autistic mothers, who may have thought that they were 'catastrophising' or 'being irrational' (Dupuis et al., 2022). Autistic people often engage in 'internal conversations' and may ruminate for hours about how they could improve their performance (Archer, 2003; Cooper & Russell, 2025). Researchers have shown that the brains of autistic people are 42% more active at rest than their non-autistic peers, and have speculated that they may have a more active 'inner life', which may account for people's impression that they are 'lost in their own world' (Perez Velazquez & Galan, 2013). Bridget's ruminations and anxiety increased after having her child, mainly due to the pressure she felt to be a 'perfect mother' and her wish to be able to cope 'naturally' (Z. J. Williams, E. E. McKenney, et al., 2021). The amount of cognitive

effort the mothers spent ruminating meant they were missing out on precious relaxation time while they forensically examined their past actions and conversations (Cooper & Russell, 2025). All this “background chatter” was exhausting for Hannah and significantly increased their anxiety level while lowering their maternal self-efficacy (Hampton et al., 2021).

The mothers believed that they were less capable than other mothers and should ‘try harder’, and these feelings of self-blame were internalised as self-stigma (Riebel et al., 2025). Perhaps their disproportionate level of self-blame may have been a consequence of being repeatedly told that they were ‘weird’ or there was something ‘wrong’ with them during their lives (Turnock et al., 2022) (see Chapter 2, Social and Historical Context, page 36). Some mothers were reluctant to seek support due to the abuse they had received from others in the past, whom they had considered trustworthy, which included family members as well as healthcare and social care professionals (Han et al., 2022). Although the mothers experienced sensory processing issues and anxiety when they had their children, they felt they had to mask their discomfort as effectively as possible to ‘not stand out’ or reveal themselves as markedly different to the other mothers they met (Pearson & Rose, 2023). To achieve this, they attempted to disguise their sensory sensitivities, created scripts to use while socialising, and suppressed their ‘stims’ (Sweetmore, 2022).

It would take a significant amount of cognitive energy for the mothers to mask their differences while they continued to be attentive to their children. Even at times of emotional upheaval, such as during a divorce or bereavement, they would still need to keep up their performance (Chapman et al., 2022). Anna’s prolonged masking during a period when she was caring for her daughters, as well as her elderly parents before they passed away, had negatively impacted her anxiety levels (Leedham et al., 2020). In Pearson et al. (2023), participants highlighted how masking to avoid stigma and abuse had caused them to have meltdowns and, when the masking was prolonged, autistic burnouts that were harder to recover from. When Diane was struggling with sleep deprivation and anxiety, she had a meltdown at home, which manifested itself as a massive emotional outburst, which led the neighbours to check up on her well-being (Phung et al., 2021). After a meltdown, a person often feels ashamed, remorseful, and totally exhausted (Lewis & Stevens, 2023). A meltdown may not always happen publicly, as the person would be in no doubt how socially unacceptable it would appear to others, so would try to leave the situation or try hard to suppress it until they had some privacy (Price, 2022). However, suppressing it may result in emotional ‘pressure’ building up, creating an autistic burnout instead, especially if the original

trigger persisted (Raymaker et al., 2020) (see Chapter 2, Social and Historical Context, pages 26-27).

Burnouts were first discussed in the late 1970s, specifically concerning high-flying professionals who were so overworked that they had reached a stage when they could no longer work effectively (Freudenberger, 1977). However, an autistic burnout occurs when an autistic person tries too hard to fit into the neurotypical world by masking intensively over a long period without support. This prolonged masking may deplete their coping ability, as was the case for Anna when her baby had evening colic (Higgins et al., 2021). She had been pretending to cope, but was exhausted, overwhelmed, and, as the trigger persisted, she became incapable of functioning any longer without having some recovery time (Bradley et al., 2021). Autistic burnout was recently defined in Higgins et al. (2021) as a “highly debilitating condition characterised by exhaustion, withdrawal, executive function problems, and generally reduced functioning, with increased manifestation of autistic traits ... distinct from depression and neurotypical burnout.” Autistic burnout may be long-term, as in Hannah’s case, or acute. Recovery would need to include support, social withdrawal, and a reduction in demands until the person’s energy reserves are restored (S. R. Arnold et al., 2023). Extensive research has highlighted the role that masking plays in the development of autistic burnout (Mantzas et al., 2022). Ironically, while experiencing an autistic burnout, masking becomes impossible to sustain, as it places such a high demand on cognitive resources that have been depleted (Mantzas et al., 2022).

Autistic burnout may present in a similar way to a major depressive episode, although its occurrence is primarily the result of masking, social interaction demands, and/or sensory overload over a prolonged period (Mantzas et al., 2022). Consequently, autistic people without a diagnosis who have become new mothers and experience autistic burnout may often get diagnosed with postnatal depression, as in Chayana’s case (S. R. C. Arnold et al., 2023). Their executive functioning deteriorates, and they stop taking care of themselves properly regarding their eating, washing, and dressing, among other regular tasks (Higgins et al., 2021). They also may have difficulties logically breaking down more complex activities into smaller, manageable steps (Demetriou et al., 2021). When an autistic person attempts to reflect on a past burnout, they often cannot recall specific events that occurred during that period (Raymaker et al., 2020).

Having spent the first few weeks with their baby, a mother's potential source of support and advice would be their health visitor, which may be especially valuable for mothers like Chayana who have no supportive family network in this country (Grant, Griffiths, et al., 2024). Unfortunately, some of the participants felt that their health visitor had dismissed their concerns, or the advice offered did not address the specific support needs of either themselves or their baby (Milosevic et al., 2022) (see Chapter 3, Thematic Synthesis, page 53). They felt judged, misunderstood, patronised, and stigmatised, and the experience contributed to their internalised belief that they were not 'good mothers' (S. Hampton et al., 2022). Dugdale et al. (2021) also showed that autistic mothers felt criticised and dismissed by health professionals and, consequently, found the support they needed harder to access. Training for health visitors should raise awareness of autistic mothers and/or infants to improve the support they provide, as recommended by the National Institute for Health and Care Excellence (NICE, 2017).

Despite the participants in our study finding motherhood rewarding and prioritising the needs of their children above their own, they were concerned about others judging their parenting abilities. They particularly feared losing their children to child protection services (Clements & Aiello, 2023) (see Chapter 3, Thematic Synthesis, page 53). In a study by Pohl et al. (2020), autistic mothers had struggled to communicate with health professionals due to their anxiety, selective mutism, and not feeling sure whether it was safe to share information about their parenting difficulties. Many autistic mothers feel unable to discuss their challenges with health and social care professionals for fear of being stigmatised as 'bad mothers', and potentially stirring up misconceptions about their parenting ability (Clements & Aiello, 2021). Regrettably, this fear is not irrational, as autistic mothers with autistic children have had their rights infringed after simply asking for support, as described in a UK Human Rights Committee report by Blakemore (2015), which outlines countless human rights violations that have occurred.

Autistic children are, in general, significantly more challenging to care for than non-autistic children, due to their additional emotional and behavioural difficulties; higher rates of sleep, feeding, and social interaction issues; and the caregivers' constant battle to obtain appropriate support for their education (Sommers et al., 2025; St John & Ausderau, 2024) (see Chapter 3, Thematic Synthesis, page 50). For any mother, endeavouring to meet all the support needs of a young autistic child is difficult; they often lack a basic sense of danger so are prone to impulsive actions such as running away from their caregiver, struggle to regulate their emotions and are

prone to sudden and explosive meltdowns, and avoid social interaction with others (Northrup et al., 2024). Their sensory processing issues may significantly impact their ability to attend to their basic hygiene and dental needs; for example, they may not tolerate toothbrushing or having their hair cut (Mahabala et al., 2025). Autistic children may also be incredibly selective about what food they are willing to eat (Farag et al., 2022). Even when they get older, they may continue to be extremely fussy eaters and often still have an intense fear of hairdressers and dentists (Sherriff et al., 2023). Therefore, ‘mother blaming’ is not helpful (Hollingworth et al., 2023).

Healthcare and social work practitioners are often not sufficiently well-informed about the complexities of caring for an autistic child, and rarely consider the fact that both mother and child may be autistic, although unaware of this fact (K. J. Benson, 2023). It is relatively easy to see how autistic traits and behavioural difficulties may be misinterpreted as “evidence of Fabricated or Induced Illness (FII)” when one reads the alerting signs described in the guidance from the Royal College of Paediatrics and Child Health (RCPCH) (RCPCH, 2020, 2021). They may easily be misconstrued as a result of a parent’s inability or unwillingness to impose appropriate boundaries (RCPCH, 2021) (see Chapter 3, Thematic Synthesis, pages 53-54). Social work practitioners have highlighted children’s emotional and behavioural difficulties and their concerns with sleep and feeding as examples of ‘significant issues’ that they have regarded as safeguarding matters, including cases where the mother and child were autistic but undiagnosed (Eaton, 2024; RCPCH, 2021).

While the current landscape has begun to embrace the concept of neurodiversity, there still appears to be a lack of support available for autistic mothers (Whiteley et al., 2021) (see Chapter 5, Methodology, pages 72-73). The transition to motherhood is arguably one of the most momentous periods that a woman or gender-diverse individual will experience during their life (S. Thom-Jones et al., 2024). The fact that autistic people tend to struggle with change has been well-documented, so it is regrettable that the transition to new motherhood, made by the participants in this study, was so challenging for them (Hwang & Heslop, 2023).

To sum up, this first superordinate theme illustrated the participants’ transition to new motherhood and their lived experience of being a mother before they received their diagnosis of autism. Without the knowledge that they were autistic, they struggled to understand their strengths and challenges. They found it difficult to adapt their previously successful coping strategies to their

new situation. Many participants mentioned in their interviews how they had struggled with the impact of their new responsibilities, due to their problems with executive functioning, such as planning and multitasking, as well as their sensory sensitivities and sleep disturbances. Most of the mothers compared themselves with new neurotypical mothers in their neighbourhood, who they believed were coping far better than they were. They felt a tremendous pressure to be 'good mothers' and set extremely high standards for themselves. They sometimes chose to 'do things differently', but felt judged for using parenting methods that fell outside of 'the norm' (Williamson et al., 2023). However, following their autism diagnosis, the mothers used their new self-understanding to develop new autistic identities, as will be described in Theme Two (Lilley et al., 2023). They began to embrace their autistic strengths and felt more confident to face their challenges by finding strategies that worked for their whole family. They were then able to concentrate on providing their children with the support and love they needed to grow and thrive (Taylor et al., 2023).

CHAPTER 7 THEME TWO – AUTISTIC IDENTITY DEVELOPMENT

Findings from Theme Two - Autistic identity development

This second superordinate theme describes how the mothers developed their autistic identity. It explores the mothers' lived experiences of seeking out, or being sent for, a diagnosis, how they developed their new autistic identity, and the impact of their diagnosis on their experience of motherhood. The discussion of these findings follows directly afterwards in the second half of this chapter.

Receiving an autism diagnosis

All ten mothers described the lifelong behaviours which they believed were 'typically autistic'. They had only become aware of the significance of these 'autistic traits' after they had recognised their neurodivergence. Throughout their lives, the mothers had all felt "different ... on the outside edge, on the periphery of normal" (Anna). Diane revealed that she had always been "a bit airy-fairy ... away in the clouds, in my own world." They described how they would need to stim to self-regulate their emotions and to process their sensory environment and the events of the day. Many of their stims were "socially acceptable" (Eva), such as gesticulating, pacing, tapping feet, and fiddling with hair, so their significance had not been initially recognised. Many also described having an "internal dialogue" (Chayana), ruminations, or internal conversations that continually went through their minds. In addition, they all tended to become hyper-fixated on their intense interests, which they researched extensively.

All the participants had difficulties 'fitting in' and being socially accepted during their lives and were often bullied at school. At times, they tried to act like their peers to gain more popularity. However, they found it hard to sustain their performance continually: "I tried my best to fit in, but I just couldn't maintain it, if you know what I mean. I wondered whether they thought I was being two-faced or fake." (Chayana) The mothers described themselves as being shy or lacking in confidence when they were young. They found social 'chit-chat' particularly difficult due to the mundane and uninteresting subjects that were discussed by others. Many described feeling misunderstood by their peers because their unusual and inappropriate behaviour was often mistaken for deliberate rudeness or ignorance. After attending a large or formal social occasion, they would need to be alone for a couple of days, as they would be "socially drained" (Diane)

All ten mothers described their journeys towards receiving their autism diagnosis. Nine of the mothers sought their diagnosis after they had realised they were autistic. Fiona was the only mother who had been advised to get an assessment by her psychiatrist. For Anna, Chayana, Hannah and Ivy, the revelation that they were autistic occurred after investigating the subject on behalf of their newly diagnosed children. They all recognised similar behaviours in themselves, particularly during their childhood.

So younger one, first diagnosed ... I started looking at it and looking at what are the indicators if you are a girl and you're autistic ... and I said to my elder daughter, I said 'What do you think about that?' And we both went, 'Yeh'. Blatantly, we both of us ticked those boxes as well. (Anna)

Bridget, Georgia, and Jo believed that their mental health diagnoses that they had received before their autism was identified, which had included depression, bipolar disorder, and borderline personality disorder (BPD), were misdiagnoses or secondary conditions acquired as a result of unknowingly being autistic in a world shaped around the needs of neurotypical people. From a teenager, Diane had suspected that she was autistic and had Ehlers-Danlos syndrome (EDS), both of which are commonly co-occurring conditions. When her school recommended that Diane pursue an autism diagnosis, her mother had been reluctant in case the label ruined her career prospects. Diane eventually received a diagnosis of EDS when she was a young adult. Years later, after meeting two fellow autistic women with EDS, she was persuaded to go for an autism assessment.

Eva had been working as a teacher with a young autistic girl in a special education unit. She became aware that this girl had similar behaviour to hers when she was a child. This occurred after Eva's daughter had been born, when she had been struggling to cope with planning and sensory challenges, so she decided to ask her GP to refer her for an autism assessment.

The GP said to me, 'Well, why do you want a diagnosis? What's the point? You're successful, you've got family, you've got a job, you've got a degree. Why? What are you going to get out of it? Why do you need to know this? Let's say, even if you are autistic, what do you have to benefit? Why? What's the point?' and he said, 'I don't think you are, because you can do all of these things and you're here, sat with me,

talking to me, making eye contact.' ... So, the reason I gave was for my self-understanding; to be able to frame my experiences through the appropriate lens. I don't want to be framing them through the lens of depression or anxiety when it isn't depression or anxiety that's the underlying problem ... if I know that I'm autistic, then I know what I can do about it, how I can help myself, how I can support myself and be able to access support at work and in education. (Eva)

Eva eventually persuaded him to refer her, and she was subsequently diagnosed as autistic. Unfortunately, Bridget and Chayana were not given a diagnosis at their initial autism assessment. Bridget had a short consultation with a trainee psychiatrist at her local hospital and was told that she was not autistic. However, a consultant from the psychology department at the same hospital referred her to a specialist team that was more experienced in diagnosing women. They were extremely thorough, took a developmental history from her mother, and finally, Bridget received her diagnosis. Chayana also had to get a second opinion from a consultant who specialised in diagnosing females.

The first time, they were not experienced; they were these young doctors or nurses that weren't very helpful or supportive. Maybe it was because I came across as a very confident person, because I was masking. So, I didn't get the diagnosis ... they thought that there was nothing wrong with me ... they didn't do any tests or anything ... they were not autism specialists. (Chayana)

All the participants reacted positively to receiving their diagnosis. Diane stated that "it was the best thing that I ever did", Ivy also declared "it's the best thing that ever happened to me", and Jo announced that "it was the most incredible thing ever". After receiving her diagnosis, Bridget's psychologist had asked her how she felt, to which she replied: "Relieved. Finally, I can admit I'm not a freak. You know, there's actually people like me out there!" For the mothers, the diagnosis provided confirmation and proof so others would stop assuming they were making it up or acting like a "hypochondriac" (Diane).

I couldn't quite justify telling anybody this about myself unless I had an official diagnosis to back it up ... It's important to have some validation, partly because everyone that I spoke to about it just immediately questioned it. (Hannah)

For the mothers, receiving their diagnosis led to a period of self-discovery, which reframed their experiences in light of their new knowledge and helped to explain many of the problems they had been having as new parents. “People often say, ‘Oh, why do you want to label yourself?’ I don’t see it as a label; I see it as a diagnosis that answers questions. Things like weird, nasty, strange; they’re labels.” (Diane) Once they received their “official identification of having a legally recognised disability” (Georgia), they felt more confident about meeting other autistic people and accessing support in healthcare, work, and education. “I am able to say, ‘Well, I need this because I’m autistic,’ makes it much easier to get reasonable adjustments because you have a good reason for it and you have a piece of paper that says, ‘I’m autistic.’” (Jo)

Identifying as autistic

Following their diagnoses, all ten mothers spent time researching the subject by reading books about autism, watching videos, searching for information online, and contacting the autism community. By sharing the information from one of her reference books on autism, Jo had explained to her husband how autism may present differently in females and how her behaviour matched the autism criteria.

I think initially he thought, when I decided that I was autistic, that it was a product of me being mentally unwell, until he was able to look at a list of stuff that Tania Marshall produced in her book. I said to him, ‘Okay, put all of these things into a spreadsheet and tick off the ones that you agree add up to what I’m like and let’s see what you think then.’ (Jo)

The participants used social media to engage with the autistic community. They felt able to discuss their diagnostic journeys with other newly diagnosed women and gender-diverse individuals in private Facebook groups, whom they found easier to communicate with. It was a revelation for them to discover that similar-minded people existed who understood them.

That’s when I got into the autistic community and, suddenly, they were talking as if they were in my brain. They were verbalising everything that’s ever been in my brain, my whole entire life, and I was like, ‘Oh my God, these people are like me.’ Before, when I tried to explain things to people, they just didn’t get it, and I felt weird. (Ivy)

Ivy discovered strategies to help themselves from other autistic people. This support had been more helpful than any advice they had received from healthcare professionals. By joining local autism social and support groups, some of the mothers had also befriended other autistic people:

I remember going to [support group] that's in [town], and they were amazing, and I remember sitting there and explaining everything to her and being like, 'Oh my God, this is a journey.' She was like, 'Well, talking to you, I can tell you a hundred per cent that you belong here.' (Bridget)

Following their diagnoses, all the mothers felt more able to express their authentic autistic nature, instead of masking to create a more 'socially acceptable' persona. Ivy believed that they had gone through their whole life trying to be accepted and believing that they were 'abnormal', so, after their diagnosis, they were surprised to suddenly realise that they were a "perfectly normal autistic person". Chayana felt that, as a child, her culture had "brainwashed" her to act in specific ways. She had felt like an actress and was unable to be herself.

I've made changes and I'm now really good with my authentic self. So yes, I allow myself to have more downtime. I'm allowed to be kind to myself, so that I don't feel overwhelmed. I'm not going along with the rat race that I had been doing for years. The reason why is that it left me in a very fragile state, and my mental health suffered as a result of all of that masking over the years. (Chayana)

Eva also did not wish to continue conforming to cultural norms just because it was expected of her. "As much as I might mask myself to be more socially acceptable or liked, I have never been able to, thankfully, squash my authenticity, my strength, or my opinions." Hannah particularly disliked gender norms that dictate how males and females should act within society. They believed the autism community were more accepting of diversity and felt more relaxed when they were amongst other autistic people, as they made fewer assumptions and did not expect a person to act in a particular way.

A small group of women who are a similar age to me and recently diagnosed, we were getting together to go for walks before lockdown. We keep in touch a bit. That was nice because it was just easy. We just meet up, and you can feel the shoulders dropping

and everyone says, 'Right, okay, you can say any old weird shit, and it doesn't matter.'
(Hannah)

Unfortunately for Eva, her husband had not been overly impressed with her newly acquired authenticity: "He has, since I've been diagnosed, been learning what is the mask and what is me. He is not entirely comfortable with some of the changes that have happened, because he met the masking me." In general, however, the mothers thought that being authentic and keeping in contact with the autistic community had given their family, particularly their autistic children, a sense of identity.

I talk to so many autistic people in this room in the way that we are, and it's all going in. He's going to pick up on it. I'm giving him a sense of community and I'm going to give him a positive sense of self. (Georgia)

During their interviews, nine of the ten participants had speculated whether their friends and relatives might or might not be autistic. Having received their diagnosis and researched the subject of autism extensively, the mothers believed they were able to tell whether others were neurodivergent.

I've got an 'adar', whether someone is diagnosed or not. I might have just met them, and I think, 'Yeah, you're one of me, you're the same, you're somewhere within this neurodivergent Venn diagram. You might not know it.' It's a feeling of connection and understanding that you don't get with other people. It's difficult to explain because it's ephemeral; it's not something you can quantify. I don't think it's something that observers from the outside would be able to see or notice. I don't have to worry about filtering with that person. (Eva)

Anna, Diane, and Hannah were convinced that their husbands were also autistic. Eva, Fiona, and Jo had used their knowledge of autism to determine that their children may be autistic and should be assessed:

I knew, before she was diagnosed, I knew that she was also autistic because I knew that we were the same. I understood why she didn't like going to baby groups. I

understood why she didn't like noise. I understood why she wanted to be carried all the time ... It wasn't any of the bollocks that people tell you about, 'Oh, it's separation anxiety. It's because you haven't left her. It's because you're too attached.' It wasn't that. It was sensory, and it was because the world, as an autistic baby, is terrifying. (Eva)

In addition, many of the participants had decided that their parents were autistic, as well as some of their siblings. Jo had realised that, because her mother was probably autistic, it explained why her autistic traits had never been recognised by her parents when she was a child. To her mother, Jo's behaviour was similar to her own, so not 'atypical'. "I suspect that my mum might be on the spectrum as well, so she couldn't see anything different in me because I was similar to her." (Jo)

Impact on the mothers' maternal self-efficacy

During their interviews, all the mothers explained how their diagnosis had been instrumental in helping them develop effective coping strategies, which significantly improved their quality of life and mental well-being. As they developed a better understanding of their difficulties and how to manage them, they became calmer and more confident parents, and in most cases, their relationships with their children improved as a result.

I actually finally feel settled; my mental health is so much better, and I'm being kinder to myself. I'm discovering, through being in the autism community, strategies to help myself. So, figuring out my sensory profile and what sensory things that I need to know and accepting my limitations, which has been a huge thing, I have been accepting myself instead of comparing myself to the neurotypical model. (Ivy)

The mothers had become more self-compassionate and willing to accept that they needed to look after themselves as well as their children. "With noise and tantrums, I find it all too much sometimes. I have to go and have a breather, but you know, it's all about balance and self-care really." (Diane) They were also more inclined to seek support from other family members or friends. "I get warning signs now, and I'm able to apportion responsibility for things that I find difficult to my husband. Yeah, and he knows; I don't have to ask him."

Some participants had made radical changes to aspects of their lifestyle that they felt had been negatively affecting their well-being, which subsequently created a more comfortable and fulfilling way of life. Chayana had found working in an office environment challenging because she constantly needed to mask and suppress her authentic self to fit in with her colleagues. However, she had never felt she belonged to the “clicky group”.

I've survived for so long; I don't care what people think now. I'm not dealing with office politics any more, as I'm not working in an office. My job now is as a nanny. So, no more dealing with people, and no, I haven't told my boss about it because it's not affecting my job, so there's no point. Children are innocent and naïve; they don't have these negative judgements about you or preconceived ideas ... so, I can be myself.
(Chayana)

All the participants felt that their new autistic identity, along with the knowledge they had acquired from the autistic community and their research, had helped them to understand the challenges faced by their children.

I feel like it makes me more understanding and more accommodating. Like, other parents might think ‘Oh, he's being so naughty,’ and I'm like, ‘No, he's not being naughty, he's having a meltdown.’ I don't want to let genuine bad behaviour go missed, but at the same time, as his mum and an autistic woman, I can tell whether the behaviour has been triggered by something, as opposed to [child's name] just pushing the boundaries. (Diane)

Anna and her two autistic daughters had openly discussed what situations or sensory sensitivities they could and could not cope with. “All three of us are a bit more understanding and accepting of the different ways in which each person might get overwhelmed or have a meltdown.” (Anna) The mothers felt a profound connection with their autistic children, no doubt due to their similar neurology. “We talk about it as if we have superpowers that other people don't have” (Bridget). Following both of their diagnoses, Chayana became aware that her relationship with her son had improved. “I think that the biggest thing is that my son and I are much closer now. He knows that I've got the best support for him.” In addition to having a strong bond with her daughter, Eva was

confident that she would be able to utilise her knowledge and lived experience to advocate for her daughter as she matured.

So, as she's developing and progressing and growing, I can help clear the path for her in a way that only I can do as her mother, as an autistic mother. It's a feeling that I can't put into words; that I can't quantify. The connection that we have is a connection that I don't have with anybody else. I've never experienced before, this connection with her. It's peace and unconditional love that I haven't experienced with anybody else. It's unlike anything else. You know, it's just a totally different kind of love and bond. (Eva)

Hannah used the knowledge they had acquired when they had realised that they were autistic to talk with their daughter about her neurodivergence. "Because I'm diagnosed, I can say, 'Right, this is what I'm like,' and 'Your brain works in a slightly different way compared to some people.' So, it's been a springboard to some conversations." Eva explained that her daughter would be able to witness firsthand the benefits of developing effective coping strategies as her mother would be able to model them.

Actually, having the diagnosis has really helped me understand what my needs are and how to meet them, and that makes me be a better parent. Then, by me being able to model that to my daughter, I can show her how to meet her own needs, how to understand what her needs are, how to take that time and how to deal with those things herself. To create coping strategies, appropriate neurodivergent, inclusive coping strategies, rather than suppressing them. (Eva)

Nine of the ten participants talked about how their self-confidence and self-esteem had improved since their autism diagnosis. The one exception was Hannah, who still felt particularly fragile due to the pressure of homeschooling their three autistic children throughout their school years and having taken on most of the responsibility for their welfare without receiving much support. On the other hand, the nine mothers had grown in confidence since their diagnosis and felt more empowered to express their needs and ask for support.

Before the diagnosis, I just thought everything was going pear-shaped; nothing was right. I was just comparing myself to an average neurotypical person, wasn't I? Now, I

don't do that at all. I've stopped doing that. I don't compare myself to anybody else, so that's a good thing. (Chayana)

Bridget had previously blamed herself for her son's difficulties, but since receiving her diagnosis, she had stopped viewing her mothering abilities so negatively. "It's made me a little bit more confident about the fact that I'm not doing something wrong, because that was always my biggest fear; that he's different because of me and that I'd done something wrong." Ivy also viewed their maternal self-efficacy in a more positive light:

I actually think it's made me more confident, because I realised, talking to other autistic adults, that actually I've been surviving and doing pretty well, and a lot of people ask me for advice now. I didn't even realise that I was doing such a good job. It's weird to have this feeling that you're constantly failing, and then someone saying, 'You're doing an amazing job.' (Ivy)

Bridget recognised that having a shared identity with her son was a significant asset and would be highly advantageous in the future when she would need to explain his neurodivergence. "I'm actually succeeding. He's a really awesome kid. Yes, he has certain difficulties, but everyone does. It's definitely made me understand how to support him in the best way, and how to explain things to him in the best way." Eva believed that her lived experiences provided her with the insider knowledge needed to successfully advocate for and protect her daughter. Consequently, she had become more secure in her parenting decisions and maternal self-efficacy.

A very positive experience. A very positive impact. I think it's made me feel more confident in my parenting and my parenting decisions. It's helped me to understand my daughter and to advocate for her as well. To explain what her experience is like to other people, to explain what her needs are, to be able to advocate for her from a position of being an autistic person myself. (Eva)

Discussion of Theme Two – Autistic identity development

Receiving an autism diagnosis

Throughout their lives, all ten mothers in the study had been aware of having certain 'atypical' behaviours that they had tried hard to suppress, as they wanted to be accepted by their peers

(Charlton et al., 2021) (see Chapter 2, Social and Historical Context, pages 26-27). Many autistic individuals, including the participants in this study, have been bullied both in childhood and adulthood and consequently carry a profound sense of social alienation and isolation (Jones et al., 2021). These experiences would have formed a type of social trauma, which the mothers would have felt as a result of being neurodivergent within a majority non-autistic society, whether they realised they were autistic or not (Wilson, 2024) (see Chapter 4, Methodology, pages 72-73). Similar to many others on the autism spectrum, they may have developed the habit of masking instinctively before even recognising their autistic traits (Sedgewick & Douglas, 2023). Masking is characterised as a reaction to a person's existence within a predominantly neurotypical society where there is a conventional grasp of cultural rules and norms that are harder for autistic individuals to comprehend (Pryke-Hobbes et al., 2023).

Each participant had specific factors that had led them to mask their 'atypical' behaviours, which included having been bullied, feeling pressured by societal norms to conform, wanting to fit in and be accepted by their peers, and not understanding why they were different and wanting to appear 'normal' (Kelly et al., 2024). During their life, the participants had experienced shyness and a lack of self-confidence due to receiving unfair treatment from others (Trundle et al., 2023). Autistic individuals are often singled out for the way that they interact and are typically the ones who get blamed for any misinterpretations or miscommunications that occur between themselves and neurotypical people (Spaeth & Pearson, 2023). To avoid negative judgments while socialising with their peers, the participants would attempt to script appropriate topics of conversation and rehearse potential interactions (Black et al., 2023). They would also reflect on conversations that had taken place in the past, which Chayana described as having an "internal dialogue" that would constantly ruminate in her mind (Z.J. Williams, E. E. McKenney, et al., 2021). Severe and pervasive difficulties in reciprocal communication are considered defining characteristics of autism spectrum disorder in the diagnostic manuals. This may manifest itself as the autistic person struggling to allow another person to speak when discussing their passions, interrupting, or not fully engaging in a conversation that they feel is meaningless (APA, 2013; WHO, 2018) (see Chapter 2, Social and Historical Context, pages 19-22).

Many autistic people attempt to adapt their behaviour, whether consciously or subconsciously, aiming to increase favourable social judgements and reduce negative ones (Rodríguez-Zafra & Garcia-Molina, 2025). Radulski (2022) drew upon the seminal work of Butler (1988) on

performativity to explain how autistic masking involves the performance of a constructed self, based on societal norms and accepted modes of being. Due to cultural expectations relating to gender norms, autistic individuals perceived to be women are more likely to make a greater effort to perfect their mask than autistic men (Beck et al., 2020) (see Chapter 2, Social and Historical Context, pages 28-29). Autistic girls often rote-learn conversational phrases or copy social behaviours they witness at school or on television (Hull et al., 2020) (see Chapter 2, Social and Historical Context, pages 26-28).

For the mothers, masking was often cognitively exhausting and would occasionally lead to others getting the wrong impression due to their lack of authenticity or attempting to show emotions that they did not feel (Alaghband-Rad et al., 2023) (see Chapter 2, Social and Historical Context, pages 27-28). Their peers would have been unaware of the intense effort they had been putting in to appear more socially confident, although they were quick to point out when the mothers had got it 'wrong' or made a 'faux pas' (Pryke-Hobbes et al., 2023). Sometimes, Chayana found it hard to sustain her elaborate performance, and worried that her mask would slip, and others to perceive her as untrustworthy or "two-faced."

Autistic individuals have a monotropic attention style, which enables them to develop intense interests, passions, or topics that they would happily hyperfocus on for hours and enjoy studying in depth (see Chapter 2, Social and Historical Context, pages 14-15). However, these intense interests may often seem 'restrictive' to neurotypical observers (Patrick Dwyer et al., 2024). Their monotropic characteristics should be viewed as potentially beneficial, as not only do they provide joy and comfort, but in some cases, they may lead to exciting careers and opportunities if channelled and encouraged during their education (Overland et al., 2024). Murray et al. (2005) suggested that the uneven skills or 'spiked' intellectual profile of many autistic people is due to "which interests have been fired into monotropic superdrive and which have been left unstimulated by any felt experience" (p. 143). On the other hand, the propensity for autistic individuals to hyperfocus on specific interests may sometimes cause difficulties in social situations, as they may become so animated in their descriptions and explanations that they often fail to realise when others have lost interest, or they misread the social appropriateness of the topic (Black et al., 2023). With reference to the double empathy theory, this type of miscommunication ought to be viewed and understood as a 'mismatch of salience', as opposed

to their interaction being 'wrong' or a 'deficit' in neurotypical social chit-chat or small-talk (Milton, 2017) (see Chapter 2, Social and Historical Context, pages 22-23).

Many of the participants would often feel misunderstood, for example, when their straightforward manner was mistaken for rudeness or a lack of empathy, their stims appeared strange or 'weird' to others, their attempts to describe their passions led to accusations of 'showing off' or 'lecturing', or their tone of voice was considered too loud or too demanding (Camus et al., 2022). Of course, as they were undiagnosed, they had no idea why they were so 'different' to their peers or why they had to try so hard to be accepted. Some of the mothers had been told that they looked too serious or bored because their facial expressions appeared different to those of neurotypical people (Canigual et al., 2021). To ingratiate themselves with a social group, they would make a conscious effort to smile, attempt to suppress or change their stims to more socially acceptable ones, such as hair twiddling, try to look more interested in the social chit-chat, and mimic the behavioural characteristics of the group (Price, 2022) (see Chapter 2, Social and Historical Context, pages 26-28).

The double empathy problem may have been even more pronounced for the gender-diverse participants in the study, Georgia, Ivy, and Hannah. The majority of people they would have met would not only have a different framework for understanding social interaction, but also a different framework for understanding gender (Greene et al., 2024) (see Chapter 2, Social and Historical Context, pages 22-23). They may have had to use considerable amounts of emotional and cognitive energy trying to navigate social situations that consisted of intersecting tensions (Adams & Liang, 2020). In a similar way to other marginalised groups, gender-diverse people struggle against a tide of incomprehension, and autistic people battle against an ableist social world (Kourti, 2021b) (see Chapter 2, Social and Historical Context, page 27).

Many autistic women and gender-diverse individuals can portray themselves as sociable, make eye contact, and suppress their stimming behaviours for brief periods while in company. However, after extended periods of social interaction, complete seclusion may be required to recharge, serving as a respite from the social world (Zhuang et al., 2023). Surviving the complexities of a demanding, predominantly neurotypical world by pretending to be 'normal' is mentally draining (Wala & Pawlik, 2024) (see Chapter 4, Methodology, pages 72-73). Long-term masking may negatively affect a person's sense of their authentic self and reduce their mental well-being

(Evans et al., 2023). In essence, protracted periods of masking may be detrimental to autistic women and gender-diverse individuals, as they may develop a lack of self-esteem and sense of identity (Seers & Hogg, 2022).

All the participants in this study received their diagnosis after they had become parents (Garcia-Molina & Cortes-Calvo, 2025). Following their transition to new motherhood, the complexity and demands of their circumstances had overwhelmed their ability to cope as well as they would have liked, particularly for those who experienced additional challenges, such as bereavement in their family, ill-health, or divorce (S. Thom-Jones et al., 2024). Nine of the ten participants had discovered for themselves that they were autistic and sought a diagnosis as confirmation; only Fiona had not considered that she was autistic until she was referred to an autism assessment centre by her psychiatrist (Trundle et al., 2025). Apart from Diane and Fiona, the mothers did not suspect that they were autistic when they were children or young adults. This may have been partly a result of hermeneutical injustice; they were not able to 'see' themselves in the descriptions of autism at that time, due to the stereotypical descriptions that were portrayed (Cage et al., 2024) (see Chapter 2, Social and Historical Context, pages 28-35).

Anna, Chayana, Hannah, and Ivy began to recognise their condition whilst researching autism on behalf of their children (Garcia-Molina & Cortes-Calvo, 2025) (see Chapter 1, Introduction, page 10). The mothers used informal checklists of typical autistic behaviours from reference books, as well as widely available screening tools, such as the Autism Quotient (AQ), for clarification (Taylor et al., 2020). Although they found that the AQ tool had verified their suspicions, there has been criticism regarding its application, as it exhibits a pronounced bias towards autistic male characteristics. For example, it asks whether the following statement is true: 'I like collecting information about categories of things, e.g., trains, cars' (Sedgewick & Douglas, 2023). Unlike the mothers in the study, some people may find that their results from these screening tests provide sufficient validation and are satisfied to remain self-diagnosed (Friedman et al., 2024). Others may decide against seeking a diagnosis due to concerns about being stigmatised or potentially having their parental rights questioned (K. J. Benson, 2023).

The main objectives the participants had for seeking a diagnosis were to understand themselves better and to acquire effective coping strategies from fellow autistic individuals who possessed first-hand experience (Crane, Hearst, et al., 2021). The mothers were also aware that to qualify

for reasonable adjustments or autism-specific support in their workplace or college, they needed to receive an official diagnosis (Fletcher-Watson, 2024b) (see Chapter 2, Social and Historical Context, page 36). However, when the participants approached their GPs for a referral to be assessed for autism, they were initially uncertain as they found it difficult to envisage the mothers as being autistic women or gender-diverse individuals (Chown et al., 2023). Even when they finally agreed that they could possibly be autistic, as in Eva's case, they still did not see the point of referring them because the mothers were successful and were "making eye contact" (Tien, Pearson, et al., 2025). The mothers felt disempowered when they received this type of reaction from their GPs. They had been masking their behaviour all their lives, had barely coped, and their difficulties were being questioned precisely because they had masked so effectively that they no longer matched a clinician's idea of a stereotypical autistic person (Lockwood Estrin et al., 2021).

As described on page 10 of this dissertation, autism used to be historically conceptualised as a 'disorder' that impacted males at a far higher rate than females (Harrop et al., 2024). This perception led to a cultural bias in clinical practice, where females were often not referred for assessment (Tien, Pearson, et al., 2025). Both autistic women and gender-diverse individuals are unlikely to meet the clinical male-gendered stereotype, so they tend to be diagnosed later in life than autistic men, if diagnosed at all (Kourti, 2021b) (see Chapter 4, Methodology, pages 74-76). Reducing autistic lives, experiences, and identities to this type of reductive set of stereotypical behaviours and personas does little to improve autism awareness, particularly for those who are not cisgender white males (McQuaid et al., 2024).

The extreme male brain (EMB) theory suggests that autism is an extreme variation of typical male cognitive traits, characterised by strong systemising skills and weaker empathising skills (see Chapter 2, Social and Historical Context, page 30). This theory has further compounded the underdiagnosis of autistic females, even though their empathetic, social-seeking behaviour would more likely be a result of cultural expectations, as described on page 28 (Brickhill et al., 2023). Screening, diagnostic tools, academic literature, and, consequently, clinicians' understanding of autism have evolved from studies on mainly autistic males. Therefore, autistic girls and women have often been missed or misdiagnosed, as well as those not fitting the binaries of gender or sexuality, those with other disabilities or co-occurring conditions, and those from other ethnicities, cultures, and socioeconomic backgrounds (Han et al., 2023). The intersectionality of autism and other marginalised groups has been overlooked, even though there has been a vast amount of

research indicating that autistic people often have co-occurring conditions and that they are much more likely to identify as gender-diverse in comparison to those who are non-autistic (Bungert et al., 2024) (see Chapter 4, Methodology, pages 72-74).

As an autistic individual matures, masking becomes a habit which becomes more difficult to break for those who have relied on this strategy for decades (Rodríguez-Zafra & Garcia-Molina, 2025). An autistic person may worry that their relatives and friends would be shocked if they met their 'unmasked' self. Many autistic females believe that, as they have been masking for so long, their authentic behaviour may be awkward for them to suddenly unveil in public (Cleary, West, Kornhaber, et al., 2023). Unfortunately, their mask also makes it harder for clinicians to diagnose them, as they generally expect to observe stereotypical behaviours that fulfil the criteria for autism (Cook et al., 2024) (see Chapter 2, Social and Historical Context, page 29). Autism diagnoses are based on a person's observable behaviours demonstrated during their assessment. If a person masks their authentic autistic impulses and characteristics, it may prevent the health professional from providing an accurate diagnosis (Gonçalves Garcia et al., 2025).

A diagnostician's clinical experience of adult autistic individuals of all genders, the diagnostic tools used, as well as many other factors, may impact the likelihood of a person obtaining a diagnosis (Eaton, 2024). If a diagnosis is denied after a person's assessment, as was the case for Bridget and Chayana, a second opinion may be sought, ideally from a clinician with extensive experience of how autism presents in their gender (Nayyar et al., 2024). Of course, some people may worry about being misunderstood again, so they avoid asking for a second opinion from another diagnostician, as experiencing another refusal would prove too painful and confusing (Eaton, 2024).

There is extensive evidence that females are not only being 'missed' but misdiagnosed, often with conditions such as depression, anxiety, borderline personality disorder (BPD), and bipolar disorder (Dell'Oso & Carpita, 2022) (see Chapter 2, Social and Historical Context, page 33). That is not to say that mental health conditions cannot coexist with autism; indeed, research suggests they often do (Yeung et al., 2023). After all, pregnancy itself increases the risk of developing a mental health issue by up to 20% in the general population of adult females, so it is likely to occur in autistic females as well (Shakespeare, 2015). Sometimes, however, these conditions are erroneously diagnosed, as Bridget, Georgia, and Jo suspected had occurred in

their cases (Cruz et al., 2025). A previous diagnosis of borderline personality disorder (BPD) may cause diagnostic overshadowing due to the similarity of some of the behavioural characteristics to autism, thus making it exceedingly difficult for some people to acquire an autism diagnosis (Cook et al., 2024). In Dudas et al. (2017), 68% of autistic people met the criteria for at least one personality disorder, and 15% of those with BPD also fulfilled the criteria for autism.

Receiving their autism diagnosis was a significant turning point in the mothers' lives, and their initial reaction was primarily one of elation and relief (Kelly et al., 2024) (see Chapter 2, Social and Historical Context, pages 36-37). However, they also had phases when they felt grief, confusion, and anger as they recalled the harm and invalidation they had endured during their lives, which they believed had damaged their sense of self (Gray et al., 2024). Many of the mothers contemplated whether their lives might have been easier if they had received an autism diagnosis in childhood (Smith et al., 2024). They considered whether, if diagnosed when they were young, they would have understood why they felt so different to their peers, would not have assumed something was wrong with them, would have been supported to make and keep friends, and would have been taught coping strategies to overcome their sensory sensitivities (Lai et al., 2023). However, the participants were children long before the concept of neurodiversity became widely known, so if they had received an autism diagnosis in childhood, it is doubtful that they would have been provided with the type of educational support currently available for autistic children today (Atherton et al., 2021) (see Chapter 4, Methodology, page 72).

The participants did not regret receiving confirmation that they were autistic, as it finally allowed them to understand their strengths and challenges, and this self-awareness proved useful, enriching their lives (Ferenc et al., 2023) (see Chapter 2, Social and Historical Context, page 37). They began to accept themselves more and embrace their individuality, rather than being ashamed of their 'atypical' behaviours (J. Davies et al., 2024). In a few studies, however, autistic people described their emotional reaction to being diagnosed as akin to 'grief' or a crisis of identity (Huang et al., 2023). Unfortunately, the availability of post-diagnostic counselling differs widely by local area, and is usually not routinely provided (Harmens et al., 2022). Then again, a diagnosis does enable some autistic people to obtain the support they need, such as reasonable adjustments at work or in adult education (Huang et al., 2024). Welfare benefits are also available for disabled neurodivergent individuals whose condition affects their ability to perform daily care tasks (Finch et al., 2022). The participants in this study were all relieved to have finally received

confirmation that they were autistic and were able to provide proof that they had challenges that needed support and understanding (Cage et al., 2024).

Identifying as autistic

Receiving an autism diagnosis in adulthood has been portrayed in several studies as a pivotal or life-changing event for autistic individuals and their families (Sedgewick et al., 2022). At their interviews, all ten mothers had come to terms with being autistic and were able to incorporate autism into their sense of identity (J. Davies et al., 2024). Receiving their diagnosis had led to a mission to reframe their experiences by viewing them from the perspective of having been an undiagnosed autistic person (Leedham et al., 2020) (see Chapter 2, Social and Historical Context, pages 36-37). They read books about autism, searched for information and the latest research online, and watched videos of other autistic adults who had been recently diagnosed (Gilmore et al., 2023). Jo was able to explain to her husband how she fitted the profile of an autistic woman by referring him to a checklist of behaviours typically observed in autistic females in one of her books on autism (Marshall, 2015). The participants adjusted their self-understanding and insight into their past experiences by integrating their new knowledge of their diagnosis and reconceptualising themselves as autistic (Lilley et al., 2023).

Contact with the online community became a key factor of each participant's diagnostic journey (Gilmore et al., 2023). They discussed their journeys in private social media groups for autistic individuals (Skafle et al., 2024). Within their communications, they learnt coping strategies and received advice that they described as being more constructive than anything provided by their health professionals (see Chapter 2, Social and Historical Context, page 37). The increasing appreciation of the neurodiversity paradigm among autistic people has contributed to the establishment of autism as an identity (Botha & Gillespie-Lynch, 2021) (see Chapter 4, Methodology, pages 72-73). Chapman (2021) outlined how autism, as a shared identity, can foster emancipation from pathologising conceptualisations, providing a sense of community amongst autistic people. Some people have likened the neurodiversity movement to the gay rights movement, as neurodivergent people have become increasingly empowered and have collectively developed a stronger voice (Singer, 1999). Often, individuals who are lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual or aromantic, and all other sexual orientations and gender identities (LGBTQIA+) may look for information on the internet before feeling able to disclose their identity to friends or family. Being part of a community may make

individuals feel accepted and more confident in sharing this personal information (McAuliffe et al., 2023). It is thought that this may also be true for individuals who believe they might be autistic (Sedgewick et al., 2022).

During the last decade or so, autistic individuals have been coming together, both in person and via social media, not only to accept but to celebrate their autistic identity, with self-advocacy being promoted and supported, including the creation of autistic pride events across the UK (Koteyko et al., 2024). The mothers had befriended other autistic parents by joining social groups in their local area; however, in the year before their interviews, face-to-face socialising had been restricted due to the lockdown measures for the COVID-19 pandemic (Stewart et al., 2023). Nevertheless, the mothers also enjoyed forming new connections with autistic individuals in forums, online support groups, blogs, and other social media platforms (Horton et al., 2024) (see Chapter 2, Social and Historical Context, page 37). Communicating online was a good opportunity for the mothers to be their 'authentic selves' in a lower-risk environment (Jedrzejewska & Dewey, 2022). By using their defining label of 'autistic', they were recognised and understood as part of the group, thus enabling their isolated life to become a connected one (Skafle et al., 2024). As social media has become more popular, autistic individuals have found this technology to be a positive influence in their lives, enabling them to discuss issues affecting them and to learn new strategies to support themselves (Lilley et al., 2023).

It was a revelation for the participants to realise that there were people who had similar thoughts, behaviours, and life experiences to themselves (Crompton, Hallett, et al., 2020). It gave them a sense of belonging and mutual understanding that Ivy and Bridget, in particular, had not experienced before (Botha et al., 2022). Knowing they were not alone and being able to contact other neurodivergent peers in person or online was incredibly uplifting (Garcia-Molina, 2024). The experience was empowering, helping to build their confidence and boost their mental health (Cooper et al., 2023). They had found a space which allowed them to be themselves and where they felt comfortable asking and giving advice and support (Han et al., 2022). The mothers were able to make sense of recent misunderstandings, develop strategies to increase their well-being, and acquire appropriate language to describe and derive meaning from events that had occurred during their lives (Kelly et al., 2024).

All of the mothers felt more able to express their authentic autistic selves following their diagnoses, rather than masking them as they had done most of their lives (Evans et al., 2023). This masking had begun in childhood as a natural response to conceal their discomfort or fear of ridicule when in stressful or risky situations (Sedgewick et al., 2022). Family and social situations were often uncomfortable and threatening, and they were not confident enough to show their authentic self (Seers & Hogg, 2022). Negative judgments, such as those Chayana received from her family as a child, were pervasive, even though others were unaware of their neurodivergence (Timmons et al., 2024). Snyder (1987) proposed that the underlying motivation to mask is usually driven by attempts to engage in strategic impression management to avoid negative social judgements and stigma. Goffman (1959) stated that a form of 'idealised performance' would consist of behaviours representing accepted cultural norms that would be integrated into social interaction (see Chapter 2, Social and Historical Context, pages 26-27).

Some of the mothers told us that they used to be described by others as 'weird' or 'different', but had no idea why they were portrayed in this way (Pearson et al., 2023). Others may stigmatise autistic people due to their perceived violations of social interaction behaviour (Gurbuz et al., 2024). When meeting someone for the first time, non-autistic people may often imagine that they are being perceived negatively, although this is usually incorrect. However, research has shown that non-autistic peers are more likely to perceive autistic people negatively on first impression (Belcher, Morein-Zamir, Mandy, et al., 2022). Through the years, stigmatising experiences may be gradually internalised into a person's self-concept (Hume & Burgess, 2020) (see Chapter 2, Social and Historical Context, pages 26-27).

The mothers experienced bullying and microaggressions throughout their lives, reflecting a generalised attitude that their embodied identity was 'spoiled' and, in some way, 'other' (Junttila et al., 2024). Goffman (1963) theorised that a person may attempt to manage social interactions if they possess either a visible or invisible 'spoiled identity' (Turnock et al., 2022). The participants' masking had been shaped by their traumatic experiences and confirmed a belief that their persona was 'wrong' and would lead to rejection (Sedgewick et al., 2022). Oyserman et al. (2007) outlined how unfair treatment arising from being a member of a marginalised and stigmatised group may lead to their self-regulatory focus being allocated towards harm reduction. Self-regulatory focus refers to the motivational orientation people use to achieve goals, as described by the regulatory focus theory (RFT) (Higgins, 2012). The pressure to avoid continual

stigmatisation meant that the participants felt compelled to conceal their true selves, so their real natures were essentially hidden from the world, unheard, unseen, and unknown (Zhuang et al., 2023). They believed that they could not express themselves meaningfully when they suspected it was not safe to do so (Cleary, West, Kornhaber, et al., 2023).

Although masking has the advantage of facilitating successful social interactions with non-autistic people, it requires heavy demands to be placed on a person's socioemotional cognition, which may have detrimental effects, particularly on mental health and daily functioning (Evans et al., 2023). For autistic people, masking often causes exhaustion, worry, and self-harm and may lead to mental health issues (Corden et al., 2021). Ross et al. (2023) found a relationship between masking and mental health conditions in autistic children and adolescents, suggesting that masking may start having a negative impact at an early age. In autistic adults, masking has been related to depression and both generalised and social anxiety (Hull et al., 2021) (see Chapter 2, Social and Historical Context, page 27). Autistic people are more likely to be diagnosed with depression and anxiety compared to their non-autistic peers (J. Galvin et al., 2024). They are also at a higher risk of suicidality and suicidal ideation, which may be partly driven by their social status and perceived 'difference' in comparison to the social majority (Linden et al., 2023).

Minority stress theory states that people with minority identities, such as those who are gender-diverse, gay, from ethnic minority groups, or neurodivergent, experience higher levels of stress than those from the cultural majority, such as those who are neurotypical, white, male, or heterosexual (Kung, 2024). Autistic people exist in a majority neurotypical world, a world with neurotypical environments, neurotypical expectations of communication and sensation, neurotypical cultural ideals, and so on (Wharmby, 2022). However, instead of the majority recognising the inherent diversity within our society and making adjustments, neurodivergent people are viewed as 'deviant' when they do not meet normative standards (Jellett & Muggleton, 2022) (see Chapter 4, Methodology, pages 72-73). Botha and Frost (2018) explored the impact of autistic marginalisation on well-being and psychological distress. Societal framings around autistic behaviour have contributed towards the broader stigma and dehumanisation of autistic people, which have affected their identity development, impression management, self-monitoring, mental health, and masking (Cage et al., 2019). Minority stressors associated with stigma, such as victimisation, concealment, shame, and expectations of rejection, have been associated with lower levels of well-being and heightened psychological distress (Pearson et al., 2023). Autistic

people experience adverse life events such as abuse and sexual violence at an alarmingly high rate (Gibbs & Pellicano, 2023) (see Chapter 2, Social and Historical Context, page 26).

Some of the autistic mothers in our study are members of multiple marginalised groups; for example, Ivy is autistic, non-binary, and with a Roma cultural background, so would have encountered even greater levels of stress, which may have impacted their mental health during their lives (Kung, 2024). Autistic people may face marginalisation in multiple ways, such as through racialised and gendered experiences, and this may lead to masking across complex, interacting aspects of their identities (Botha & Gillespie-Lynch, 2021) (see Chapter 2, Social and Historical Context, page 27). Trauma resulting from these experiences is an intersectional issue driven by prolonged exposure to living within an oppressive social system (Botha & Gillespie-Lynch, 2021) (see Chapter 4, Methodology, pages 74-76).

Claiming an autistic identity provides those who may have often felt excluded with an opportunity to participate in a community that they truly feel part of (Lilley et al., 2022). Community membership and having a strong autistic identity have been linked to better mental health, social connection, and quality of life (Camus et al., 2024). The participants' ties to the autistic community grew stronger as they recognised that there was a sense of togetherness and collective identity (Lilley et al., 2023) (see Chapter 2, Social and Historical Context, page 37). For some, this strong group identity encouraged them to move beyond passive acceptance of stereotypes and dehumanising rhetoric by finding ways to engage in autism advocacy (Leadbitter et al., 2021) (see Chapter 4, Methodology, page 73).

Another significant reason that autistic people tend to mask when interacting with non-autistic people is that it helps them to be understood (Rhodes & Seeley-Wait, 2025). As described on pages 22 and 23, the double empathy theory proposed by Milton (2012) suggested that misinterpretations may often arise between autistic and non-autistic people, resulting from bidirectional misunderstandings. In contrast, autistic individuals feel less of a need to mask their authentic selves in the company of other autistic people, as there would be less likelihood of misunderstandings between them (Sedgewick et al., 2022). The participants, particularly Eva, felt a sense of relational similarity to the other autistic individuals she had met, due to their shared sensory sensitivities and similar experiences (Bolis et al., 2021). Recent studies have demonstrated that autistic individuals socialise with each other and share information just as

efficiently as neurotypical people do with one another (ibid.). In contrast, in autistic-with-neurotypical dyads, information transfer selectively degrades in parallel with rapport (Foster et al., 2024). These findings have challenged the historical assumption that autistic people lack the skills to interact successfully (G. L. Williams et al., 2021).

In various studies, autistic adults expressed a wish to spend more time with fellow autistic individuals, as they recalled talking more openly about their thoughts and feelings in comparison to previous conversations with non-autistic adults (Bolis et al., 2021). They felt that socialising with non-autistic individuals required much more of a conscious cognitive effort because they would need to work out when to speak, when to move on, what subjects were appropriate, how it would come across, whether their opinion would offend people, the connotations of every word, whose turn it was to speak, whether the other person really meant what they were saying, and so on (Crompton, Hallett, et al., 2020). Spending time with other autistic individuals felt much less stressful. For the mothers in the study, the introduction to new autistic individuals was described as ‘finding their tribe’ (Lilley et al., 2023). Many autistic people believe true autism acceptance in society would require feeling safe enough to be able to express themselves and respond naturally (H. L. Moore et al., 2024). When autistic people socialise with each other, they generally feel relieved to ‘drop their mask’ (Belek, 2023). Eva perfectly described this observation by saying, “I don’t have to worry about filtering with that person.”

After they had received their diagnoses and had investigated the subject in depth, the mothers believed that they were able to identify which of their friends and family were autistic, or at least neurodivergent, a skill Eva called her “adar”. A similar phenomenon was reported in a study by DeBrabander et al. (2019), where autistic adults were able to recognise other autistic individuals without being explicitly told and instinctively felt a sense of connection with them. Conceivably, autistic people may have the ability to sense the relational similarity between themselves and other autistic individuals (Granieri et al., 2020). When meeting for the first time, autistic individuals tend to be more likely to speak their minds and form friendships based on their passions, while paying less attention to social norms and expectations (Cook et al., 2023). An autistic person may offer or exchange facts about a topic they love as a way of building rapport, while neurotypical people may be more likely to initiate small talk (D. R. Jones et al., 2023). For autistic individuals, long-lasting friendships usually begin by feeling comfortable in each other’s presence and then develops over time through the sharing of passions (Botha et al., 2022). Incredibly, Eva, Fiona

and Jo were able to use their 'adar', as well as the knowledge that they had acquired about autism, to recognise that their children were also autistic and needed to be assessed and given educational support. Most of the participants also believed that their parents or siblings were autistic. This presumption is not surprising, as autism is highly heritable (Cirnigliaro et al., 2023). Interestingly, none of the autistic mothers discussed their feelings about the possibility of their children having inheriting autism from them, suggesting either that they did not perceive their children's autism as an impairment or problem, or perhaps the subject may have been too sensitive to discuss or even contemplate. On the other hand, none of my interview questions had referred to this issue specifically, and all the mothers were undiagnosed when they had their autistic children.

Many autistic people share, or at least understand, each other's difficulties in social interaction, so there tends to be an atmosphere of respectful patience where friendships may be forged (Bolis et al., 2021). Having a shared communication style makes autistic individuals feel confident enough to reduce their masking and become more 'authentic' (Cook et al., 2021). The ability to be genuine was the main reason why the mothers preferred socialising with other autistic people, whom they felt understood them, provided positive identity role models, friendship, and support (Han et al., 2022) (see Chapter 2, Social and Historical Context, page 37). The mothers highlighted the importance of authentic expression and how forming relationships with autistic people had helped them to develop a sense of belonging (Botha et al., 2022).

Impact of the mothers' maternal self-efficacy

Following their diagnoses, all ten mothers began to recognise their strengths and challenges. They discovered effective coping strategies, became more self-compassionate, and developed an appreciation and understanding of their new autistic social identity (Lilley et al., 2023). They stopped comparing themselves and their parenting abilities with those of neurotypical mothers (see Chapter 3, Thematic Synthesis, pages 49 and 52). Ivy realised the benefits of being more aware and accepting of their limitations and valued the helpful advice they received from the autistic community (Gilmore et al., 2023).

Years spent learning social skills through imitation and pretending to care about activities that they had no interest in, such as shopping for clothes and clubbing, led to the mothers neglecting their goals and sense of identity (Camus et al., 2024). As their camouflaging continued into their

adulthood, they progressed from not only hiding their authentic autistic self from others but also from themselves (Evans et al., 2023). The expectations and needs of others took precedence, while their self-compassion and self-understanding were neglected (John Galvin et al., 2024). So, to develop their authentic autistic identity after their diagnoses, the mothers needed to recognise their autistic persona by gaining insight into their sensory and social needs (Cummins et al., 2020). The mothers' diagnoses had facilitated the development of self-awareness about their sensory sensitivities and the triggers that could cause them to become overwhelmed (Kiep et al., 2025). It provided an opportunity to obtain effective coping strategies from the autistic community without having to mask their discomfort or their stims while in company (Ghanouni & Quirke, 2023). Diane was more willing to request and accept support from her husband on the occasions when she became overwhelmed. She found that being able to take some downtime from caregiving significantly improved her quality of life (Lin et al., 2025).

Some autistic people carry out heightened compliance and fawning as a response to having lived in environments where boundaries were either not respected or where it was not safe to assert them (Gibbs et al., 2023). The development of self-insight and the ability to convey a more authentic self would require them to finally declare their limits by saying 'no' to unsuitable or unwanted requests in an effort to ensure their needs and wishes are being met (Losada-Puente et al., 2022). The mothers began to limit what they said 'yes' to, particularly when a situation could have potentially cause them unbearable stress and anxiety (John Galvin et al., 2024). For example, the participants allowed themselves to turn down social invitations if they did not feel up to attending them (Sunagawa, 2023). They stopped putting themselves in environments with too much sensory stimuli and asked for support if they accidentally found themselves in situations that would potentially overwhelm them and trigger a meltdown (Benson, 2020). As their children grew older and became more self-sufficient, some of the mothers were able to retreat to a quiet area of their house to relax or spend time pursuing their passions (Bohadana et al., 2021). Of course, this was not possible for mothers whose autistic children required constant supervision to keep them safe (S. Thom-Jones et al., 2024). In those cases, employing quiet, enjoyable activities for the children, such as reading them a story, drawing, or spending time in nature, provided some brief respite (Dugdale et al., 2021).

For the mothers, their habit of masking had felt like they had been denying or hiding their authentic selves, which had negatively affected their mental health (Chapman et al., 2022) (see Chapter 2,

Social and Historical Context, page 27). Other studies into the impact of a late autism diagnosis on individuals have emphasised the importance of self-understanding by becoming aware of their masking and developing agency and insight into their own needs (Sedgewick et al., 2022). In a paper by Raymaker et al. (2020), the authors discuss how ‘unmasking’ reduces the likelihood of autistic burnout and may be used as a burnout recovery strategy for autistic individuals. Following her diagnosis, Chayana felt that she had to radically change her working environment to achieve a better quality of life and to improve her mental health, so she gave up her office job in the civil service to work as a nanny. She described how her life had improved, as she no longer had to mask or deal with office politics and negative judgments from her colleagues. By working with children, she was able to be her ‘authentic self’ more easily.

Their diagnoses had given each of the mothers an explanation for why they felt so different during their lives (Kelly et al., 2024). They started to become aware of with their unmasked selves that had been hidden beneath countless layers of camouflage (Ridgway et al., 2024). Following their diagnoses, their relationships with their children became closer as they peeled off those layers, learnt to accept their limitations, and stopped comparing themselves to the neurotypical ideal of ‘the perfect mother’ (Dugdale et al., 2021). During their transition into new motherhood, their masking had influenced not only their well-being but also, to a certain degree, their ability to fully appreciate the joys of parenting (Field et al., 2024) (see Chapter 2, Social and Historical Context, pages 26-28).

All the mothers felt that, by researching and connecting with the autistic community while discovering their own autistic identity, they were better able to understand their children’s strengths and challenges (Sedgewick & Douglas, 2023) (see Chapter 3, Thematic Synthesis, page 50). Diane explained that the knowledge she had been acquiring had enabled her to distinguish between when her autistic child was having a meltdown triggered by sensory overload and when he was just being naughty or pushing boundaries.

The mothers’ own lived experiences enabled them to accept their autistic children’s ‘unusual’ behaviours and to value their neurodivergence (Maw et al., 2024). They assumed that they may be more understanding and accommodating than neurotypical mothers would be, as they considered their children’s behaviours, such as their stims, were part of who they were. They believed that they should not feel ashamed of them or try to hide them away, especially not in the

family home (Evans et al., 2023). Having experienced similar issues, the mothers were able to pass on their skills, experience, and positive outlook to their children (Crane, Lui, et al., 2021) (see Chapter 3, Thematic Synthesis, page 48). They thought that they were also more likely to perceive most of their children's autistic behaviours, which others may have referred to as 'problematic', as strengths or neutral. This was because their judgements were not based on neurotypical expectations of behaviour and etiquette (H. K. Schiltz et al., 2023) (see Chapter 4, Methodology, pages 72-73).

The mothers felt a deep connection with their autistic children, and Bridget and Chayana stated that their relationship with their children had significantly improved since their diagnosis. Anna and her daughters had regularly discussed their ability or inability to cope with various situations or sensory stimuli, so the family were aware of each other's triggers (S. Thom-Jones et al., 2024). They understood each other's challenges and were supportive when one of them had a meltdown (Winnard et al., 2021) (see Chapter 3, Thematic Synthesis, page 51). Many of the mothers talked about their determination to ensure that their autistic children were given the best support available and were committed to advocating for their needs in the future. Hannah and Eva, as well as many of the other mothers, were able to explain their diagnoses to them using their own lived experience to guide them, without needing professional support to do so (Crane, Lui, et al., 2021). They were able to communicate and share their emotions in an honest, open way (Dugdale et al., 2021). They spoke about how beneficial this type of open communication was, as it encouraged a greater understanding between the mothers and their children, enabling them to work together to support each other through their difficulties (S. Thom-Jones et al., 2024). Eva pointed out another advantage of this close connection; when the mothers became overwhelmed, they would be able to effectively model their coping skills to their children, who could subsequently use those skills themselves when required (Crane, Hearst, et al., 2021).

Following their diagnoses, the mothers began reducing their masking in some situations as they became more comfortable with their autistic identities (Pearson & Rose, 2023). Having a choice of whether or not to mask felt very different for them compared to feeling forced by the people or situations around them. It increased their self-confidence and self-esteem (Sedgewick et al., 2022). What was crucial to them was feeling in control of their mask; that is, they were able to use it as they wanted and take it off when they wanted (Pearson & Rose, 2023). They felt empowered and supported to act on those choices, either independently or interdependently with

support from family and friends (Price, 2022). Having this type of autonomy has been associated with obtaining a better quality of life and well-being (Alaghband-Rad et al., 2023). Reducing and controlling their mask made the mothers feel more empowered and increased their self-esteem (Evans et al., 2023). The development of agency and autonomy led to a sense of being able to manage themselves and their environment, created a feeling of security, and offered the opportunity for authenticity to come about (Cook et al., 2023). It was valuable for the mothers to feel that, when they were their authentic selves, they were valued, liked, and respected by the people around them (Belek, 2023; Lamash et al., 2024).

The participants described their enhanced self-awareness after realising they were autistic (Kelly et al., 2024). They were able to justify and explain their challenges to others, such as issues with socialising in large groups or interpreting subtle cues (Sedgewick et al., 2022). Their self-understanding significantly helped their confidence and ability to advocate for themselves (Riebel et al., 2025). The mothers felt more empowered to express their need for support from their family and friends (Hwang & Heslop, 2023). Recognition of their needs may also have helped them to start ameliorating the impact of internalised stigma and self-blame that had arisen before their diagnoses (Riebel et al., 2025). Bridget, Chayana, and Ivy confirmed that they had stopped comparing their maternal abilities with other mothers and blaming themselves for their children's differences (Muniandy et al., 2025).

The mother's growing self-esteem was accompanied by an increased acceptance from the people around them, which further reduced their need to mask (Love, Cai, et al., 2023). The mothers did not feel it was necessary to constantly mask in front of trusted friends, as requesting specific adjustments, such as turning off background music while talking, was less fraught with their friends, who knew that they were autistic (Cage & Troxell-Whitman, 2020). Reducing their masking may have helped the mothers feel more comfortable with their diagnoses and with asking for support from those around them (Perry et al., 2021).

In this second superordinate theme, the mothers shared their experiences navigating the diagnostic process and their emotional responses upon receiving their diagnoses. They discussed their exploration of autism, their engagement with the autistic community, the evolution of their new autistic identity, and how the diagnosis had increased their self-confidence and maternal self-efficacy. They believed that their autism diagnoses had a positive impact on their

experience of motherhood, made them more confident in their parenting decisions, and increased their understanding of themselves and their children. The mothers had been in contact with the autism community who had enabled them to express their 'authentically autistic' selves instead of continuously masking. In the next superordinate theme, the mothers describe the reactions received from family, friends, work, education, and health and social care professionals following their disclosure of their autism diagnoses.

CHAPTER 8 THEME THREE – Diagnostic disclosure

Findings from Theme Three – Diagnostic disclosure

This third superordinate theme describes the mothers' experiences of disclosing their new autism diagnosis to their close and extended families, friends, workplaces, and educational establishments, how these people reacted to this information, and the effect and impact this knowledge had on their relationships. Many of the mothers had fears around the potential consequences of disclosing their new diagnosis to healthcare and social care professionals, and they described the accusations and discrimination that they had encountered from these professionals after sharing that they were autistic and what post-diagnostic support had been available to them. The discussion of these findings will follow directly afterwards in the second half of this chapter.

Family

All the participants discussed the subject of disclosing their new autism identity to their families. All ten of the mothers' closest family members living in the family home were informed, including their partners and those children who were old enough to understand the significance of the diagnosis. The mothers of Bridget and Fiona were present at their daughters' autism assessment to provide the clinicians with their developmental history. Eva and Ivy were the only participants who told members of their extended family, beyond their parents and siblings.

So, all my family know, both my close family and my extended family, and my husband's family. I've been quite open with all of them about it. From the beginning, as soon as I found out, at the first opportunity, I said, 'By the way, I've just found this out, and I wanted to tell you.' ... I thought quite a lot of them might be on the spectrum themselves and not realise. So, by me being the first person to say, 'Oh, look, I'm autistic. I don't look like I would be autistic, but I am and here's why. This is what led me to get the diagnosis', then a lot of the culture started turning and people started thinking, 'Oh, oh, well maybe that explains your granddad, your' you know. (Eva)

In contrast, Chayana talked about her reluctance to tell any member of her family outside her home about her autistic identity: "If anything, they would have kicked me under the carpet,

because that would have been a taboo subject for them. They didn't want to have a relative who's got problems. Then no one is going to want to marry me." (Chayana)

The participants discussed the reactions they received from their families after disclosing their new identity. For some, the reaction was positive, so they experienced a strong sense of relief and felt supported and accepted. After the clinician had given Bridget her diagnosis, her mother said: "'I'm so glad she's getting this diagnosis ... At least now I know that you guys are there and, if anything happens, Bridget has got support'". (Bridget) Ivy was also pleasantly surprised that their mother was so understanding, although most of their extended family did not try to accommodate their needs or give them any assistance.

My mum is supportive, but she lives about [hours] away from us. When she does come to visit, maybe every three to four months, she is very supportive when she is around, very accepting, and we do talk regularly on the phone. She is very accepting, but I think she's suddenly discovered, with the diagnosis of myself and my children, the neurotypical parent community. She makes it all about her, but I really feel like she is trying, and she does listen when I educate her. (Ivy)

When a close family member refused to believe that the diagnosis was correct, was unsupportive, or did not understand its significance, the mothers found it incredibly upsetting, and it sometimes put a strain on their relationship. "My mum has never really been on board with the idea that I'm autistic, and I thought that maybe a diagnosis would make her see the truth of it, but it hasn't really." (Jo) Ivy was distraught because their neurotypical son was particularly blasé about his mother's diagnosis and did not seem to understand the difficulties that the rest of his household had with issues such as sensory processing. "He's like, 'You're my mum, so why should I have to accommodate you?' He doesn't really understand that I need accommodation and ... that his brothers also need accommodation. He, weirdly enough, feels like the outsider in this family." (Ivy)

The participants explained some of the consequences of disclosing their new autistic identity to their family. Fiona's parents were disappointed when she got diagnosed, even though they had accepted that she was autistic, because they believed she had acquired a label for herself. When Fiona decided to tell her daughter about her diagnosis, her parents were enraged: "My mum said,

‘You’re not going to tell her, are you?’ ‘God, of course I am.’ She’s one of those people who will hide things from you, for your own good, and it drives me nuts.” (Fiona)

Hannah had hoped that their diagnosis would bring the relationship with their autistic son closer, but, unfortunately, he “absolutely hates the idea that he’s autistic” and wanted to be like the rest of his peers. (Hannah). They tried to encourage him to take pride in his new identity, but he just said, “I’m not like these people.” When they attempted to tell them about their new identity, he replied, “Oh, I know it’s helped you, but it hasn’t helped me.” (Hannah)

Some participants attempted to educate their families about autism, aiming to increase their understanding and support, but their efforts were not always successful.

My family hasn’t changed at all. They still expect me to be able to deal with things, like they did before, and they haven’t made any adaptations whatsoever. I’ve told a few members of my extended family and I’ve got into arguments with them about it, because it’s very much, ‘But it doesn’t affect you because you’re high-functioning,’ and ‘Well, everybody does that,’ and ‘Well, I do that.’ I’ve been worked up into having a meltdown trying to explain myself, just to have, ‘Well, I disagree.’ In the end, I say, ‘Take it up with the psychologist who diagnosed me then, if you disagree.’ (Ivy)

Thankfully, in most cases, the outcomes of disclosing their new autistic identities were positive, and relationships did become closer as a result, with greater understanding and empathy between family members within each household. Anna felt her relationship with her husband had improved substantially, as well as with her two daughters.

We’ve not been in a ‘relationship’ for a long, long time, and that means we’ve not had those things either, to help you through. So, all that affects how we parent and those two children, they know that we’re getting a sex life again, and that’s new. I think it’s quite funny. (laughs) I think it’s got to be good. (Anna)

After learning more about autism, Diane’s parents became more supportive and accepting. This had been achieved by Diane’s unique method of educating her mother: “I just tagged my mum

into all sorts of Facebook pages about autistic women. There we go. (laughs)” Her parents also came to understand that autism has a strong genetic basis.

I think they understand it a lot more now. With time, they have come to really accept it, understand, and see it, especially with [child’s name] being diagnosed, as it has to have come from somewhere. Even my own mother has started saying my dad’s autistic, and my brother. (laughs) So, their initial response was sceptical, but they did begrudgingly admit that it explains a lot of things. (Diane)

Jo revealed that her husband had understood her far better after she was diagnosed. He had learnt what support she needed to cope with any issue or meltdown. “I get warning signs now and I’m able to apportion responsibility for things that I find difficult to my husband. Yeah, and he knows; I don’t have to ask him.” (Jo)

Friends, work, and education

All ten participants recalled their experiences of disclosing their diagnoses to friends, work colleagues, or in educational settings during their interviews. Some participants, such as Diane, were deliberately open about their diagnoses with as many people as possible because they felt it would improve autism awareness in their community.

Yeah, I’m completely open about my autism. I’m very open about it; I don’t see a reason not to be. Occasionally, people are like, ‘What?’ and I’m like, ‘Bottom of the spectrum. It can present very differently.’ Generally speaking, I think it helps to be open, because we need to change the perception in society that autism has a very specific look. There is no look to autism. (Diane)

Hannah had only used social media platforms such as Facebook to disclose their new identity, as they did not feel they had any close friends with whom they felt comfortable discussing this aspect of their life.

I don’t really tend to talk about it very much. Not really. I share a lot of stuff about it on social media. I guess I’ve never actually sat down and sort of said directly, ‘I’ve been diagnosed’ to many people ... I don’t have time to process much because I’m just

constantly firefighting stuff happening in everyday life. I don't really have the time to, and I need someone to bounce it off, really, but there isn't anyone. (Hannah)

On a rare occasion when they revealed that they were autistic to their friends, they had reacted with disbelief and tried to dismiss it.

The general reaction I got was, 'Oh, no, what makes you say that? No, it's just been a really hard year', which to me was just completely random. I don't know what having a hard year has got to do with it ... obviously, a lot of stereotypes come into play. They were saying, 'Oh, I know that you can't be like that because you've always cared about our friendship,' and this sort of stuff, and it's like, 'I'm autistic, not an idiot.' (Hannah)

Anna felt she had to be careful with whom she confided: "I did want to share it, but I knew that I mustn't because it could only work with those that I knew would understand, and there's very few of them in my acquaintance." (Anna) Eva recognised how beneficial it would be for autistic mothers to be able to share their experiences and provide and receive support with other autistic mothers, whether by social media, face-to-face, or in peer groups.

How amazing would it be if autistic mothers could talk to each other and could go, 'Your child does that too? Oh, then it's normal for an autistic child. It might not be normal for neurotypical people, but it's normal for us, and it's okay. There are other people who get it.' I found that there weren't any other parents who understood my experience, whoever I talked to. They just couldn't connect with what I was saying. (Eva)

The discovery of other autistic people who could be contacted on social media, and would understand and relate to shared experiences, was also a revelation for Hannah.

It's led me to online groups of other diagnosed people, and that's really helped because I've realised that there are people that I can literally just talk to, and they will just get where I'm coming from and the way I'm talking. I'm not just being awkward or obtuse, and that's been really nice to know that. (Hannah)

Eva used the disclosure of her diagnosis as a chance to describe to non-autistic people why she had particular needs or why she interacted with them in a certain way. Her clarifications prevented instances of miscommunication from remaining unexplained.

It's useful in being able to explain to other people, although I might not think, 'Oh, that's because of the autism', it can be used to explain to other people, to say, 'The reason I need this is because I'm autistic. The reason that I do this, the reason that I said that, and did that was because I'm autistic.' So, it helps other people because, if they see a behaviour that they're not expecting or if I say something that they're not expecting, they can interpret it through their neurotypical lens and think that I'm being rude or I don't like them, or that it means something that it doesn't. (Eva)

Following the disclosure of her diagnosis to her employer, Chayana was disappointed with the lack of understanding she received from them.

I used to work for the Civil Service. I told them about my diagnosis, and did they give me support? No, they were lacking in understanding. The trade union were rubbish, and the Civil Service basically just totally dismissed it. They didn't want to accept it at all. 'If she's been loyal and she's been here for so many years, there's nothing wrong with her. She's able to continue.' But every time I tried to say, 'Look at my mental health record; I'm always off sick with depression and always anxious.' I had a really bad time with them ... If you're different, even if you don't realise it, you will never fit in. You'll never be in the clicky group; you'll never get the promotion ... This is not an autism-friendly world, I'm afraid. (Chayana)

Ivy thought that, after disclosing their diagnosis to the staff at their autistic son's special school, they would appreciate that they could give them advice or provide some practical strategies and insights derived from their first-hand experience of autism. Unfortunately, that was not their reaction.

My youngest is at a special needs school, and they're a bit like, 'You can't understand what we're trying to do here because you're autistic yourself.' So, a lot of the time, I find that they dismiss me now. I would have thought they would listen to me more,

because I literally know what they don't understand, but no, it's the other way around. It's almost like, 'Well, you don't understand what we're trying to do here, because you're the same as him, and you struggle with similar issues.' So, it wasn't the breakthrough that I thought it would be. (Ivy)

Fortunately, many of the participants found that disclosing their autism diagnosis helped them get the reasonable adjustments and support from work and in education that they needed.

I think labels get a bad rap because I think they're useful when you need some sort of assistance. When I have needed assistance since my diagnosis, which hasn't been very much, the fact that I was able to say, 'Well, I need this because I'm autistic,' makes it much easier to get reasonable adjustments because you have a good reason for it and you have a piece of paper that says, 'I'm autistic.' (Jo)

Having previously dropped out of her degree programme, Bridget returned to university after her diagnosis and, with the provision of disability support, found she had more confidence to ask for support when required and was successfully completing her studies.

When I got my diagnosis, it was in the August, and I started uni in the September. It was scary for me at first, because I was like, 'Right, I can actually speak to people about getting support for this.' I had tried uni before when I was [age] ... it just did not work. I couldn't figure out what it was - if it was just because it was so different from school. I didn't know. So, to me, having a diagnosis meant that I could access help from people who would support me so that, if I was starting to feel lost or confused, or someone would put something in a really weird way that I couldn't understand, I was able to ask for help. (Bridget)

Eva also benefited from disclosing her diagnosis as she has been able to access support at work and in education, is more self-compassionate, and has grown in confidence:

If I know that I'm autistic, then I know what I can do about it; how I can help myself, and how I can support myself and be able to access support at work and in education - all the things which you can't get without a diagnosis or are more difficult to get without

a diagnosis. Do you know what? Without having the diagnoses of autism and ADHD, I don't think there is any way that I would be on this course. No, I don't think there's any way I would even have applied for this [course]. I don't think I would have felt confident enough to know how to manage it and how to cope. (Eva)

Health and social care professionals

All ten participants talked about their experiences of disclosing their diagnosis to health and social care professionals and the reactions they received. Many of the mothers were wary of disclosing to these professionals because they feared discrimination or were worried about being accused of Fabricated or Induced Illness (FII, previously known as Munchausen's syndrome by proxy).

No one has questioned my parenting, but I do actually worry, genuinely, about FII accusations. But that could also come with Ehlers-Danlos, as well. So, I've got it on two fronts. I do worry about being accused of projecting myself onto [child's name], but if you met [child's name], it's definitely not that, because his autism is a lot more obvious than mine. So, it's not a projection at all. He's a really, really happy child, and that's all that matters. But, yeah, that is my main worry: being accused of faking or Munchausen sort of stuff. (Diane)

Diane, Fiona, and Jo all stated that they were terrified of intervention from social services, and both Anna, Eva, and Georgia felt that they had been blamed for their children's behavioural and sensory issues. Georgia was directly accused of projecting their autistic traits onto their son and having attachment problems.

One of the things that I got gaslighted about was that it was always, 'Oh, he's copying you.' I hope you can appreciate what I'm talking about. 'You're just projecting yourself onto him', and I persevered, and I got the sensory assessment done. Then I got the diagnosis, but it was always, 'Oh, your mental health problems mean that you've got attachment difficulties.' Now, three different professionals in the last 12 months have told me that, actually, we have excellent attachment. (Georgia)

Anna felt that health professionals had blamed her and her husband's parenting ability for their daughter's frequent migraines: "The psychs at the hospital assessed us as parents; they filmed

us, they videoed us, each separately and together ... because of all the migraines she was having so, they videoed us and concluded that we were good parents. (laughs)” (Anna)

Ivy recalled that when they had disclosed their diagnosis to professionals in the past, they assumed they would be more accommodating of their needs during appointments and more considerate with the terminology they used. However, this did not happen. Furthermore, they seemed to disregard their opinions.

I thought I would get accommodation from them to enable me to attend meetings, and that they would understand my needs, that I may take things literally, and that they should change their language. It's more that I'm being dismissed, so that was my experience of the professionals. So, because of how I felt from those few examples, I don't disclose it anymore when I'm around professionals. (Ivy)

The participants described some of the unhelpful attitudes they had encountered from health professionals when they had tried to get referred for an autism assessment. When Anna, Chayana, Diane, Eva, and Fiona requested a referral from their GP, they realised that their doctor had difficulties identifying them as potentially autistic females, as they were more accustomed to referring children. Young boys and girls may present more ‘stereotypically’, as they would not have had the decades of experience that mature females would have had to develop expertise in masking their ‘socially undesirable’ traits.

‘Look, I think I may be autistic,’ and she was like, ‘What? How?’ because I wasn’t sitting there, doing the stereotypical sort of behaviour that society perceives autism to look like. I was a woman sat there, conversing quite nicely and everything, but I was technically stimming. She didn't see it as a stim. I tap my foot constantly and fiddle; I'm a fiddler. But, obviously, that's not hand flapping, that's not biting, that's not the stereotypical stims that a lot of people think are the only ones. (Diane)

Fiona also discovered that some health professionals found it hard to grasp that the autistic community included individuals of all genders, ages, ethnic groups, backgrounds, and so on. There is no particular ‘look’ that separates autistic from non-autistic individuals.

The doctor didn't seem to think that I could be autistic. She said, 'You don't look autistic,' and I said, 'Sorry?' I think a lot of people still think autism is like sitting in a corner, rocking back and forth, and flapping your hands. (Fiona)

When Anna received her diagnosis, she asked her GP not to include that information in her health records as she worried that some healthcare staff may make incorrect assumptions about her in the future. However, she felt quite good telling her GP that she had received her diagnosis, as her doctor had been quite reluctant to refer Anna for the assessment. She had to persuade her that she needed to know whether she was autistic to acquire greater self-understanding.

'I'm diagnosed now.' I felt good about telling her. So, there is a readiness in me to talk about it, particularly having had this therapy now. I'm more ready to talk about it. I've got a better grip on who I am and how my childhood affected me; some of which wasn't to do with autism, but some of it was. (Anna)

The mothers, particularly Jo, were surprised by the lack of post-diagnostic support offered, as they had assumed there would be counselling provided or a referral to an autism support service.

I guess there's not a hell of a lot of support once you do get your diagnosis. You think to yourself, 'Okay, so I got my diagnosis. What now?' and the answer is nothing ... There is also some stigma attached to it. I have this thing called an autism passport for the hospital, but I don't always use mine when I go into a healthcare setting, because it does mean that people treat you differently and not for good reason. (Jo)

Following Fiona's diagnosis, she reached out to the National Autistic Society using social media and has since been attending one of their local support groups. She is finding social interaction with other autistic people much easier than with neurotypicals, and they were more willing to open up to her.

I saw a Facebook post by the National Autistic Society, and they've been doing these group things, so I've been going to some of their groups. So, once a week, we do a [subject] group. It's the first time that I've been in contact with them ... I also find that people tend to be a wee bit more generous when people are talking. Some people get

wound up about the weirdest stuff. If it was somebody else's, you would just stop it and get off that subject. With this group, there's more encouragement about it, though.
(Fiona)

Discussion of Theme Three – Diagnostic disclosure

Family

The participants' motivations for disclosing to their family and close friends included seeking support and understanding, so that they would feel more comfortable dropping their masks in their company (Rum et al., 2025). Long-term masking often causes an autistic person to have an identity crisis, which may include feelings of deceit or being 'two-faced', worry that others may discover their atypical character traits, and a lack of self-understanding (Evans et al., 2023). These feelings can be incredibly distressing, with some people reporting high levels of anxiety about what exists 'underneath the mask' and whether they even have an identity (Hull et al., 2017). Autistic people who engage in prolonged masking may face burnout, fatigue, anxiety, and a lack of self-esteem and identity (Grant, Turner, et al., 2024) (see Chapter 2, Social and Historical Context, page 27). Individuals facing burnout from prolonged masking may require assistance to manage and lessen this behaviour (Pryke-Hobbes et al., 2023).

All ten participants disclosed their new autism diagnosis to their family members within their household, including their partners and those children who were old enough to learn about autism (Huang et al., 2022). Nine of the mothers were living with a partner at the time of the interviews. For eight of them, the outcome of disclosing their new autistic identity to their partner was positive. They reported that having another person who understood their specific needs was important to them (Talcer et al., 2021). Anna felt that her relationship with her husband and daughters had improved substantially. Jo and her husband took the initiative to learn about autism together to foster mutual understanding (Sedgewick et al., 2022). As a result, her husband became adept at identifying when Jo required his support. Recognising the signs when she was becoming overwhelmed and respecting the ways that she needed his assistance were highly beneficial for Jo (Lewis, 2017). Support from partners, both emotional and practical, may help autistic individuals to reduce their masking, allowing them to live an authentic and more comfortable life (Cook et al., 2023). Unfortunately for one mother, the reaction from her husband was not so positive. As Eva had been masking for a long time, her underlying autistic characteristics had not been evident to her husband during their relationship (Garcia-Molina, 2024). He had only known

the 'masked version' of his wife and was not comfortable with how she had changed since she had 'dropped her mask' (Huang et al., 2022).

All ten autistic mothers had at least one autistic child, and their diagnoses had offered them an insight into how and why they found it easier to relate to their child than others had (Sedgewick & Douglas, 2023) (see Chapter 3, Thematic Synthesis, page 50). Every participant recognised the importance of being truthful and transparent with their children regarding their diagnoses, emphasising the need to engage in conversations with them about autism by drawing on their personal experiences (Crane, Lui, et al., 2021). These discussions fostered understanding and empathy among the majority of the children (Sedgewick et al., 2022). They discussed the strengths of being autistic, rather than just describing the challenges and relying on deficit-based information from professionals and widely available reference books (Crane, Lui, et al., 2021) (see Chapter 4, Methodology, page 73). Hannah had also expected to have a closer relationship with their autistic son following their diagnosis. However, he continued to be totally against the idea that he was autistic and wanted to be like the rest of his friends (Cage, 2020). They hoped that perhaps a shift away from a pathological model of autism would help foster a positive sense of identity in their son (J. Davies et al., 2024). However, even after Hannah tried to explain neurodiversity and the benefits of "finding your tribe", he insisted that he was "not like these people". (Hannah)

Of course, it was essential to think about everyone in the household when the mothers disclosed their autism diagnoses, including any non-autistic children, as this news would have impacted the whole family (Lilley et al., 2023). Only two households had a non-autistic child; the rest of the children in all ten families either had an autism diagnosis or were awaiting a diagnostic assessment. As Fiona's neurotypical boy was only four years old at the time of her interview, there was no mention about whether her diagnosis was discussed or whether he had any significant reaction to the disclosure. Ivy, on the other hand, was distressed that their eldest son, who was 16 years old and neurotypical, was so dismissive of his other two brothers' diagnoses, as well as his mother's (Mokoena & Kern, 2022). He refused to acknowledge the challenges, such as auditory sensitivities, that were experienced by the rest of his family and for which support was required (Chang et al., 2024) (see Chapter 3, Thematic Synthesis, page 50). He seemed to resent feeling like he should accommodate and support the other members of his family and felt like "the outsider" (Ivy).

The interaction between an autistic mother and a non-autistic child may have unique dynamics that do not equal the experience of a non-autistic mother interacting with an autistic child (Libster et al., 2024). There is a plethora of research articles, support material, and general literature aimed at non-autistic parents of autistic children; in comparison, there is little information or supportive reading for autistic parents of non-autistic children, even though they also face the challenges of mixed-neurotype parenting (Pohl et al., 2020) (see Chapter 2, Social and Historical Context, pages 22-23). Research shows that autistic mothers are more likely to report feelings of isolation and depression and to have more significant difficulties with accessing social events, such as concerts or football matches, that their non-autistic children may wish to attend (Pohl et al., 2020). Research on the relationship between autistic mothers and non-autistic children is an area that is currently massively overlooked and underserved (Morgan et al., 2024).

Although studies on the quality of relationships between autistic mothers and their non-autistic children may be lacking, a 2007 review paper on the relationships between autistic and non-autistic siblings had noted an absence of closeness, along with feelings of resentment regarding the caregiving responsibilities that the non-autistic siblings carried out (Sedgewick & Douglas, 2023). They may have felt resentful after having assumed caring responsibilities during their childhood to help lessen the load for their parents (Sedgewick & Douglas, 2023). A study by Watson et al. (2021) described the mental health of non-autistic siblings of autistic children as reasonably good; although many recognised that having an autistic sibling was often a source of stress, as they frequently found themselves involved in caregiving alongside their parents (Sedgewick et al., 2022). Crompton, Ropar, et al. (2020) revealed that interactions between autistic and non-autistic people showed lower rapport and flow compared to the interactions between two autistic people, which may affect relationships between autistic and non-autistic siblings or, indeed, between autistic mothers and non-autistic children.

In addition to disclosing to their partners and children, a few participants also felt it was essential to share the news of their new autistic identity with parents with whom they maintained regular contact (Farsinejad et al., 2022). Unfortunately, not all of the participants' parents were alive at the time of their diagnosis (Anna, Chayana, and Eva). The participants were aware that their disclosure may not necessarily lead to a supportive response, which made decisions around disclosure difficult and context-dependent (Love, Edwards, et al., 2023). Some participants had chosen to have minimal contact with one or both of their parents, so they decided not to inform

them of their diagnoses (Bridget, Eva, Georgia, and Ivy). However, a few participants had close relationships with their siblings, whom they disclosed to (Huang et al., 2022). These siblings became a source of support and understanding for them, even though some were living a long distance away (Anna, Bridget, Diane, and Eva).

Once a person discloses, they cannot retract the information or control what others will say or think about it (Botha et al., 2020). It is a common experience for newly diagnosed adults to feel invalidated, disregarded, or judged after disclosing their diagnosis, even by close family members, partners, or friends (Garcia-Molina, 2024). When Jo's mother refused to believe that her diagnosis was correct, was unsupportive, and did not understand its significance, she found it extremely disturbing, and it put a strain on their relationship (Farsinejad et al., 2022). Fiona's parents had been disappointed when she got diagnosed, even though they had already accepted the fact that she was autistic, because they thought that she had acquired a label for herself (Turowetz, 2022). After Fiona had decided to tell her daughter, who was awaiting an autism assessment at the time, about her diagnosis, her mother was incensed (Huang et al., 2022). Each participant had to decide which situations or events seemed to be safe enough for them to disclose their autism diagnosis and which family members to disclose to (Farsinejad et al., 2022). Botha et al. (2020) explained how the decision whether to disclose a diagnosis or not may place an autistic person in a 'double bind', whereby their disclosure could potentially lead to undesirable responses from family members and others due to harmful perceptions of autism. However, non-disclosure could lead to ongoing misunderstandings and unfavourable judgments about them, as unusual or inappropriate behaviour is often mistaken for deliberate rudeness or disrespect (Han et al., 2022) (see Chapter 2, Social and Historical Context, pages 21-22).

The mothers' worries about the potential reactions from their families led some to decide that it would only be worth disclosing if they felt reasonably confident of a positive response or when there was a beneficial reason for doing so (Han et al., 2022). For example, Bridget and Fiona chose to inform their mothers that they were going to be assessed for autism (Farsinejad et al., 2022). It had been beneficial for them to do so, as they needed their mothers to accompany them to their autism assessments to provide the clinicians with their developmental history. Bridget was relieved that her mother had been so compassionate during her diagnostic assessment, and she had felt accepted by her (Harmens et al., 2021). She remained very close to her mother and brother and was happy to count on both of them for support when needed (Burton & Fox, 2022).

Ivy was also pleasantly surprised that their mother was so understanding, but, unfortunately, she lived quite far away and could only visit Ivy every few months (Cage, 2020). Although Diane's mother was against her getting a diagnosis at first, after learning more about autism from social media groups for autistic females, she recognised that both Diane and her son were autistic and that perhaps others within their family may have also been autistic or neurodivergent (Belek, 2020). Diane had a vast support network around her, as her mother and father, as well as her husband's parents and siblings, all lived locally (Wang et al., 2022).

Most of the participants were not so comfortable sharing their new autistic identity with their extended family (Huang et al., 2022). As they generally did not spend as much time with these relatives, they worried that they may be more judgmental of their autistic behaviours and support needs (Edwards et al., 2023). Only Eva and Ivy told all members of their family, including their extended family (Li et al., 2025). The other eight participants chose to disclose to their family more selectively. However, successful concealment of this information relied on their ability to self-monitor their interactions, modifying them when necessary, while keeping track of where and to whom disclosure had been made (Farsinejad et al., 2022). Therefore, at large family gatherings, they needed to mask more than when they were just with immediate family, in a similar way to when they met strangers or were a guest at a formal occasion (Huang et al., 2022).

Eva and Ivy had assumed that, even if some of their extended family members may not be supportive at first, their disclosure would eventually enable them to be more accepting over time (Thompson-Hodgetts et al., 2020). They hoped it would lead to more genuine social interactions and reduce awkwardness or reticence when talking about family life (Rum et al., 2025). Eva also correctly anticipated that sharing her recent autism diagnosis would prompt some relatives to question whether they were also autistic (Belek, 2020). As autism is a highly heritable condition, often the relatives of an autistic person will also have autistic traits (Thapar & Rutter, 2021). Community accounts have highlighted how being identified later in life has led people to recognise autism within their family members, including their parents (Lilley et al., 2023) (see Chapter 2, Social and Historical Context, page 19). This can mean that having family members who are autistic can be one indicator, in conjunction with other signs, that an assessment may be warranted (Xie et al., 2020).

Unfortunately, when Ivy disclosed their new autistic identity to their large Roma family, the members of their extended family were not understanding or supportive at all, even after Ivy tried to explain and educate them about autism (Edwards et al., 2023). Research suggests that relatives who share undiagnosed autistic traits may defensively dismiss an autistic person's struggles and support needs, insisting that they were 'normal' and everyone has these issues, as they experience them as well (Crane et al., 2018). Ivy identifies as autistic, Roma, and non-binary, and, due to these multiple intersecting identities, may have experienced clashing expectations and masks within their family (Lopez, 2022) (see Chapter 4, Methodology, pages 74-76). In Roma culture, the traditional gender role for mothers requires them to act "saintly in your struggle" (Ivy), to prioritise the family's needs, and not to expect support from other family members (Afanasieva et al., 2020). Ivy's relatives seemed to find their difficulties even more threatening once they were validated by a health professional, and used their diagnosis to undermine their judgment and infantilise them (Gibbs & Pellicano, 2023).

Cultural differences play a role in how autism is conceptualised and identified, and may vary in people within the same ethnic group but living in different cultural backgrounds (S. Mo et al., 2021). For example, an Asian person living in the UK may have a different racialised experience from an Asian person living in India (Tromans et al., 2021). Chayana was very reluctant to disclose her autism diagnosis to her relatives living in India (Sagar, 2024). For a traditional Indian family such as hers, having a relative who was autistic would have been unacceptable and shameful, as autism may often be perceived as a taboo subject (Hussein, 2021). If her extended family had been informed of her diagnosis, they would have worried about finding her a suitable husband, as "no one is going to want to marry me" (Chayana). In traditional Indian families, when a relative is diagnosed as autistic, they are often viewed as a failure of the family (Hussein, 2021). They often experience denial from their family members and become isolated and alienated (Garcia-Molina, 2024). Kande et al. (2020) noted the limited amount of research available on how ethnic minority populations within the UK experience autism (see Chapter 4, Methodology, pages 75-76). When there is a lack of autism education and awareness, in combination with cultural and religious differences and stigma, people may find themselves in 'intolerable, and even dangerous' situations, especially in communities where autism is perceived as a 'punishment from God' (ibid., p. 166).

Friends, work, and education

All ten of the autistic mothers in this study described their experiences of disclosing their diagnoses to their friends, as well as at work or in education (Garcia-Molina, 2024). Diane intentionally disclosed publicly, even though she could have been misunderstood or stigmatised, because she believed it would help to contribute to a greater understanding of autistic identity (Cage et al., 2020) (see Chapter 4, Methodology, page 73). When a non-autistic person meets an autistic person and interacts positively with them, it may increase their acceptance and make them more receptive to learning about autism (Thompson-Hodgetts et al., 2020). Many studies have shown that when a person proudly owns their disability, it can have a significant impact on their mental state by reducing feelings of self-consciousness and alienation, and it may also change the attitudes of non-autistic people around them (Han et al., 2022). Whilst the negative impacts of stigma may be wide-ranging, attempts to cope with it may also lead to positive outcomes such as resistance and a push for social change (Patra et al., 2025).

The participants believed that sharing their support needs with friends allowed them to be honest about the adjustments that would be necessary for maintaining their friendship, such as carefully selecting the venues where they would meet to accommodate their sensory requirements (Sedgewick & Douglas, 2023). In some cases, the disclosure increased their friends' insight and patience with some of their atypical behaviours, such as stims, that they would have previously tried to mask in their friends' company (Huang et al., 2022). The quest for acceptance from others emerged as an important factor in the experiences of many mothers following their diagnoses (Sedgewick et al., 2022).

The concept of 'being autistic' is not well understood by the general population (Rhodes & Seeley-Wait, 2025). However, this identity may become more familiar to the public if and when more autistic people feel comfortable disclosing (Edwards et al., 2023). This would rely on more widespread, accessible, and accurate concepts about autism to become available, which are not provided within traditional deficit-based constructions (Bury et al., 2022). Many autistic women and gender-diverse individuals, including Diane and Hannah, get told that they 'do not look/seem autistic' because they do not conform to prevalent cultural stereotypes associated with autism (Sedgewick & Douglas, 2023). The idea that autistic people should look or appear a particular way continues to feed stigma about autistic people, as it creates confirmation bias around what autism is, for example, a tragedy, a deficit, or 'significant impairment', and what autistic people's

lives should look like, for instance, miserable or traumatic (Trew, 2024) (see Chapter 4, Methodology, pages 72-73). Research indicates that the response to an autistic person's diagnostic disclosure varies according to the recipient's level of knowledge about the condition (A. M. Romualdez et al., 2021). When a person's understanding of autism is shallow and stereotypical, they tend to react to another individual's disclosure in a more stigmatising, dehumanising way (Turnock et al., 2022). So, openly disclosing may put a target on your back just as easily as it may liberate (Lindsay et al., 2021).

In Leedham et al. (2020), disclosing to close friends following an autism diagnosis is viewed as a crucial step in the process of building a new autism identity (Sedgewick & Douglas, 2023). When a person discloses their new diagnosis of autism, the wide variety of responses received may lead to an increased ability to discern which of their friendships and relationships are beneficial and who genuinely accepts and values them for who they are (Harmens et al., 2021). The disclosure may help individuals in their lives gain an appreciation for historical misunderstandings that may have occurred in their relationship, potentially leading to the healing of past wounds (Sedgewick et al., 2022) (see Chapter 2, Social and Historical Context, pages 21-22).

Corden et al. (2021) found that people who had known that they were autistic for longer had a more positive attitude towards their autistic identity compared to those who were newly identified (J. Davies et al., 2024). Hannah had only been diagnosed a couple of years before their interview. They felt that they had not had the space and time to process their new identity, as they had been so busy looking after their three autistic children during the COVID-19 lockdown (Spain et al., 2022). They also believed that they had no one to talk to about it, as, on the one occasion when they told their friends, they reacted with disbelief and dismissed it (McCauley et al., 2020).

In a study by Huang et al. (2022), almost all autistic adults disclosed their autism identity to at least one person, usually a friend, to seek understanding and help. However, not all were satisfied with the outcome, as they had also encountered dismissal. It is likely to be more risky for individuals with multiple minority identities to disclose, so they may be more selective in whom they share their autism identity (Sedgewick & Douglas, 2023). Therefore, masking would continue as a response to their experiences of stigma and the associated marginalisation and trauma that it perpetuates (Pearson & Rose, 2023). A study by Cage and Troxell-Whitman (2020) argued that autistic masking was driven by the potential risk of stigma related to intersecting aspects of

identity. However, the ability to ‘fly under the radar’ is cognitively demanding and often makes autistic people feel stressed, anxious, and exhausted (Rippon, 2024) (see Chapter 2, Social and Historical Context, pages 26-28). Mazurek (2014) showed that greater loneliness and lower self-esteem, depression, and anxiety were seen in autistic adults who had fewer close friends. For an autistic person, being authentic and open about their autistic identity may improve their mental health, reduce masking, and provide the confidence to disclose to others (Seers & Hogg, 2022).

Those wishing to disclose a new diagnosis may be more accustomed to trying to appear non-autistic, as they would have been more used to masking their autistic traits in the past (Farsinejad et al., 2022). Many autistic females who have been repeatedly alienated and traumatised are unsure how much of their authentic self they should reveal to others, and so adapt their behaviours to avoid further rejection (Sunagawa, 2023). Anna felt that she had to be careful about whom she disclosed her autism diagnosis to, as she believed that some of her friends and acquaintances would not be supportive (Farsinejad et al., 2022). When contacting them, she had to decide whether disclosure would be safe, needed, or wanted (Han et al., 2024). There are numerous compelling reasons to disclose your disability to someone, and many equally valid reasons to avoid doing so (Nimante et al., 2023).

One avenue for practising self-disclosure with, arguably, less risk of rejection is on social media (Edwards et al., 2023). Autistic individuals may be more inclined to use the internet for socialising than non-autistic people (Hatton & Lee, 2021). Meeting other people who are more able to relate to certain aspects of your life in ways that those without autism cannot is a fundamental way of fostering meaningful connections (Kuzminski et al., 2025). The friendships autistic people form through social media are thought to enhance their quality of life and well-being (Sedgewick & Douglas, 2023). All the participants in this study, particularly Hannah and Eva, felt that finding and receiving support and advice from groups of other autistic mothers on social media had been highly beneficial, especially since the non-autistic parents they had talked to had not always understood their experiences (Skafle et al., 2024) (see Chapter 2, Social and Historical Context, pages 22-23).

Establishing connections without having to face the sensory difficulties often present in various social settings might explain the thriving nature of the autism community online (Sedgewick et al., 2022). Howard and Sedgewick (2021) found that most autistic people hated using the phone to

connect with others and preferred face-to-face communication. However, when this option was unavailable, electronic written communication, such as email, instant messaging, or social media, was their next choice (Gilmore et al., 2023). This method allowed them additional time to absorb the conversation, craft a reply, create a record of the discussion, and use emojis to express their intentions (Kim & Bottema-Beutel, 2019). On the other hand, online communication may intensify challenges such as trusting others too readily or sharing sensitive information too early, as it may seem less personal than interacting face-to-face (Sedgewick et al., 2022).

For some participants, new contacts on social media led to the beginning of offline friendships and the formation of local peer groups (Chan et al., 2023). Autistic individuals frequently gravitate towards one another or discover each other, sometimes by chance (Crompton et al., 2020). A study examining the reasons behind the ease with which autistic individuals form friendships with each other identified two main factors: they are more likely to assume a connection can be made, and they have less need for coordination during conversations, such as turn-taking (Sedgewick & Douglas, 2023). Fiona observed these traits in other autistic people when she joined a local autism social group organised by the National Autistic Society (see Chapter 2, Social and Historical Context, pages 22-23).

In addition to forming new friendships with other autistic individuals, discovering and engaging with the autistic community was a meaningful experience for many of the participants (Botha et al., 2022) (see Chapter 4, Methodology, page 73). The opportunity to connect with other autistic people allowed them to interact with like-minded individuals, learn more about autism, and express themselves authentically (J. Davies et al., 2024). It helped them to recognise autism as inherent and 'normal', while empowering them to navigate the world on their terms (Cooper et al., 2023). The mothers acknowledged that they were different from the majority of the population, but not 'broken' or 'deficient' as many cultural descriptions depict autistic individuals to be (Sedgewick & Douglas, 2023). Studies indicate that autistic individuals who experience a stronger connection to a neurodiversity-affirming perspective through community engagement often exhibit more self-confidence and a better sense of self (Cooper et al., 2021).

Community groups can help autistic individuals view their challenges as part of a broader fight for equality (Botha & Gillespie-Lynch, 2021). The more honest the autistic community are about the challenges they face, the harder it becomes for neurotypical people to ignore autistic voices

(Horton et al., 2024). Being more radically visible is also an exercise in unlearning shame (Cleary, West, & McLean, 2023). There are positive outcomes associated with disclosure, including being part of an autistic community, increased awareness, and enhanced interpersonal understanding. However, disclosure has also been described as a balancing act between these laudable outcomes and the personal cost of the increased exposure to stigma (Huang et al., 2022).

Another good reason for the participants to disclose their autism diagnosis is that others tend to misinterpret their autistic behaviour by assuming they are being bad-mannered, rude, or insensitive (Plank et al., 2025) (see Chapter 2, Social and Historical Context, pages 22-23). These types of assumptions may often be far more demeaning than an autism label (Turnock et al., 2022). Research has shown that there are many subtle behaviours that neurotypical people pick up on as being 'atypical', though not always consciously (D. R. Jones et al., 2023). A study by Sasson et al. (2017) revealed that neurotypical people quickly and subconsciously identified that a stranger was 'different', often within milliseconds of meeting them. They did not realise that the person was autistic; they just thought they were 'weird' (Belcher, Morein-Zamir, Mandy, et al., 2022) (see Chapter 2, Social and Historical Context, page 36). They were less interested in engaging in conversation with them and liked them less than non-autistic people based on their initial impressions (Sasson et al., 2017). Interestingly, follow-up research conducted by Sasson and Morrison (2019) revealed that when participants were informed they were engaging with an autistic individual, they were more willing to interact with them, and their biases diminished. They showed a greater willingness to learn about autism (Sedgewick et al., 2022). Eva discovered that she could use her diagnosis to explain why she acted in particular ways, which she believed would prevent misunderstandings, mistrust, or accusations of rudeness from her non-autistic friends and acquaintances (Farsinejad et al., 2022).

Research suggests that autistic people who disclose their disability at work often regret having done so because they do not receive the accommodations that they had expected, and may instead be underestimated or alienated (Anna Melissa Romualdez et al., 2021). This certainly happened to Chayana, who was disappointed in the lack of support and understanding she received from the Civil Service, even though she had taken long-term sick leave with depression and anxiety in the past (Thompson-Hodgetts et al., 2020) (see Chapter 3, Thematic Synthesis, page 53). Masking consumes a significant portion of a person's mental resources, including their attention, memory, and processing capacity, making it difficult to perform a good day's work. In

some cases, such as in Chayana's, this can lead to mental health problems (Pryke-Hobbes et al., 2023) (see Chapter 2, Social and Historical Context, pages 26-28).

It is also common for autistic females to struggle with office politics involving non-autistic friendship groups within the workplace (Webster & Garvis, 2017). Behaviours such as discussing colleagues behind their backs, only inviting specific individuals to lunch, or determining who participates in various projects can all contribute to the dynamics of office politics within an organisation (Hayward et al., 2020). Chayana felt that she would never fit in with the "clicky group" and would never get the promotion she deserved (Chen & Yakubova, 2024). Victimisation and discrimination can manifest in various ways, such as isolation or ostracism, feelings of being targeted, exclusion from opportunities, or being passed over for promotion (Turner, 2023). An autistic individual may also be perceived as being the first to be fired, simply because they are not viewed as 'part of the team' in the same manner (TUC, 2019). For these and many other reasons, autistic people often choose to work from home or become self-employed, which may offer a level of flexibility and privacy (Pearson et al., 2023). Chayana chose to change her career and work with children so she would no longer have to deal with office politics (Szechy & O'Donnell, 2025).

In a study by Cage et al. (2020), autistic students who did not complete their degree course had a poorer experience of university, found the transition to academia difficult, and struggled with the social aspects of student life. While stigma surrounding autism tends to be less pronounced among university students and staff than in schools, stigmatising attitudes still occur (Sedgewick et al., 2022). Autism students may feel alienated and overlooked, which may impact their well-being as well as their academic progress (Gurbuz et al., 2019). Even if academically competent, autistic students may withdraw due to these challenges (Cage et al., 2020). In a college setting, disclosing an autism diagnosis to the disabilities or accessibility office is usually kept confidential and, therefore, reasonably safe (Davies & Bagnall, 2024). However, for an autistic university student, disclosing to professors, tutors, and fellow students may feel riskier (Lei et al., 2020). Both Bridget and Eva had access to disability support to continue their higher education (Scott & Sedgewick, 2021). They felt that disclosing their autism diagnoses to their respective universities had been beneficial in providing reasonable adjustments for their studies and increasing their self-confidence (Martin, 2020) (see Chapter 2, Social and Historical Context, page 37).

Health and social care professionals

As autism has a high heritability rate, it is not unusual for the close relatives of an autistic person to also be autistic, whether they are aware of this fact or not (Thapar & Rutter, 2021). In this study, all ten mothers had at least one autistic child; only two also had a neurotypical child. However, the mothers, particularly Diane, Fiona, and Jo, were scared of disclosing their autism diagnosis to health and social care professionals due to the risk of accusations from social services that their behaviour was potentially harmful towards their autistic children and somehow 'caused' their atypical behaviours (Pohl et al., 2020) (see Chapter 3, Thematic Synthesis, page 53). Reminiscent of the era of 'refrigerator mothers' (see Chapter 2, Social and Historical Context, pages 15-16), the participants were worried that they would be judged for their parenting ability due to their differences, assumed to be incapable, or misunderstood and dismissed by health and social care professionals, despite the limited support they had been given (Cleary, West, & McLean, 2023) (see Chapter 4, Methodology, pages 75-76).

Despite finding motherhood rewarding, the participants felt exposed to extra scrutiny from social services (Pohl et al., 2020). Autistic mothers are often afraid of asking for support due to feeling vulnerable in a system that has failed autistic families in the past (K. J. Benson, 2023). Although autistic parents may face specific challenges, related to sensory sensitivities and social interaction, they also bring particular strengths, such as having an intense connection with their children, a deep understanding of their child's needs, a logical and consistent parenting style, the ability to create a predictable and structured home environment, and to be a positive role model for their autistic children (Sutcliffe-Khan et al., 2024) (see Chapter 3, Thematic Synthesis, page 50). However, they may appear to express their emotions differently, which may lead to a lack of acknowledgement and empathy being shown towards them by non-autistic health and social care professionals (P. R. Benson, 2023). Suplee et al. (2014) found that professionals often misinterpret the body language of autistic mothers as being defensive, may find their tone of voice difficult to assess, and misjudge their direct manner as hostile despite their true intentions.

It is common for mothers of disabled children to feel scrutinised by doctors, social workers, psychologists, and teachers and to feel blamed for their child's lack of 'progress' (Mullally & Connolly, 2025) (see Chapter 4, Methodology, pages 75-76). Research by Griffiths et al. (2019) revealed that autistic parents had their caring capabilities questioned by schools, health professionals, and social services more often than non-autistic parents. Due to the necessity for

mothers to have regular contact with services regarding their autistic children's health and educational support needs, the expectation of 'intensive mothering' may be placed on them (K. J. Benson, 2023). Three of the mothers were incredibly fearful of losing their children; two had already experienced having a child protection order served against their family (Hollingworth et al., 2023). Both had been misdiagnosed with borderline personality disorder (BPD) before receiving their autism diagnoses, and, due to this, believed that health and social care professionals had assumed they could not be 'good enough' parents and would inevitably have postnatal depression and/or attachment problems (Watts, 2023). Having disclosed their diagnoses to these professionals, they felt undermined and stigmatised (Han et al., 2022). They had their capabilities questioned, which influenced their decision not to disclose in the future, particularly as the support they had requested was not provided (Pohl et al., 2020) (see Chapter 3, Thematic Synthesis, page 53). Previously, Ivy had disclosed their autism diagnosis to professionals and had expected them to put some accommodations in place to make it easier for them to attend appointments, to be more careful with the terminology they used, and to be more understanding and empathetic, but this was not the case (Mullally & Connolly, 2025). As their opinions were also totally disregarded, Ivy no longer discloses their diagnosis to professionals (Farsinejad et al., 2022).

An increasing number of families of children with neurodevelopmental conditions, such as autism, or presentations of complex or less well-known conditions, such as Ehlers-Danlos Syndrome (EDS), have found themselves being investigated for Fabricated or Induced Illness (FII) by social services and consequently labelled as potential 'perpetrators' of child abuse, based on the Royal College of Paediatrics and Child Health (RCPCH) guidelines on FII and Perplexing Presentations (PP) (RCPCH, 2021). In these guidelines, FII is presented as if it is synonymous with Munchausen Syndrome by Proxy, a rare condition now known as Factitious Disorder Imposed on Another (FDIoA) in the DSM-5 (APA, 2013). However, FII is not a diagnosis and is not listed in the DSM-5 (ibid.). The definition of FII is far broader than FDIoA, yet local authorities have child protection policies developed directly from the RCPCH guidelines (Gullon-Scott & Long, 2022). The guidance states, "Harm to the child takes several forms. Some of these are caused directly by the parent, intentionally or unintentionally, but may be supported by the doctor; others are brought about by the doctor's actions, the harm being caused inadvertently" (RCPCH, 2021, p. 16).

The broader criteria of FII outlined in the guidance go beyond intentional fabrication or induction of illness (Long et al., 2022). It includes behaviour such as when a parent, with no intention to deceive, frequently contacts professionals with concerns about their child, who are subsequently not able to identify a cause (which is not the same as saying there is no cause): “Parents who struggle with the management of their child may seek an inappropriate mental health diagnostic justification in the child such as Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD)” (RCPCH, 2021, p. 13). The guidelines also suggest that autism may help to explain the motivations for FII: “Autism Spectrum Disorder (ASD) in the parent may underpin fixed beliefs about the child’s ill-health” (RCPCH, 2021, p. 15). Another possible mechanism for the behaviour put forward by the RCPCH relates to caregivers ‘projecting’ their conditions onto their child, who in turn would receive the attention and care that they either consciously or unconsciously crave (RCPCH, 2020). Diane was anxious that she would be accused of projecting her autism onto her autistic son, although his support needs were much greater than hers (K. J. Benson, 2023). Georgia was directly accused of projecting their autistic traits onto their son and of having attachment problems due to their mental health difficulties (Gullon-Scott & Long, 2022). However, Georgia persevered and got their son assessed, and he was diagnosed as autistic with sensory processing difficulties (Gur et al., 2024). Georgia had to be assessed by three different professionals and was told that they had an excellent attachment to their son (Dugdale et al., 2021).

A systematic literature review was produced for the British Association of Social Workers (BASW) to inform new practice guidelines on FII for social workers, and it found no evidence base for the expanded concept of FII, no diagnostic criteria, no information available about the accuracy or precision of the ‘alerting signs’ for FII, and no research into the efficacy or safety of the proposed early intervention or treatment (Hollingworth et al., 2023). Families who have been investigated for FII erroneously have reported significantly high levels of trauma as a result of being viewed as possible perpetrators of child abuse (Gullon-Scott & Long, 2022). Anna and her husband’s parenting was blamed for her daughter’s frequent migraines, and clinicians in their local hospital assessed their parenting by videoing them, each separately and all together, and concluded that they had good parenting skills and attachment (Lin et al., 2023).

Mothers who initially reach out for support because they are struggling to manage an undiagnosed autistic child may find themselves being mistakenly considered at risk of FII when a

straightforward reason for their child's difficulties has not yet been identified (Sapiets et al., 2024) (see Chapter 3, Thematic Synthesis, page 53). Autistic children often present with co-occurring conditions such as epilepsy, dyslexia, ADHD, acute anxiety, pathological demand avoidance (PDA), Ehlers-Danlos Syndrome, or sensory processing differences, thus making diagnoses more challenging for clinicians (Micai et al., 2023). These children may be highly complex to support (Richdale et al., 2024). Unfortunately, not all social work practitioners are sufficiently well-informed about the complex nature of autism and young people's support needs (K. J. Benson, 2023).

Developmental psychology research has observed that autistic children, beginning from a very young age, often have insecure attachments to others, with the exception of their primary carer, to whom they may be fairly 'clingy' (Martin et al., 2020). Recent findings of a study by Narvekar et al. (2024) have indicated that early sensory hyposensitivity may increase the likelihood of showing fearfulness in infancy, particularly in individuals with a family history of autism. However, this type of atypical behaviour in undiagnosed autistic children is often misjudged as a sign of abuse or neglect on the part of the parents (K. J. Benson, 2023). A lack of understanding or knowledge by health and social care professionals about how autism may present has led to an increasing number of families being accused of having fabricated, exaggerated, or made up the level of challenge they were experiencing in an attempt to secure support for their children (Clements & Aiello, 2021).

In many cases, allegations of possible FII arose as a direct result of a parent being unhappy with the level or type of support offered, or because they had made a complaint (Clements & Aiello, 2023). The family may then be dragged through long and incredibly traumatic investigations of their lifestyle and parenting, and, in some cases, it has resulted in their child being removed (Gullon-Scott & Long, 2022). Furthermore, children are taken from their families as a predictor of 'future emotional harm' where no current or past abuse, neglect, or violence has occurred (Clements & Aiello, 2023). Autistic mothers are sometimes evaluated as being 'at risk', not because of their conduct, but due to their behavioural traits and professionals' reservations about their potential to fail at being a 'good enough mother' (Clements & Aiello, 2023) (see Chapter 3, Thematic Synthesis, page 53). When a professional lacks expertise in autism, they may fail to identify and appreciate the positive qualities and strengths that many autistic parents offer, such as the intense connection with their children due to their shared neurotype, a deep understanding

of their child's support needs, a logical and consistent parenting style, a neurodiversity-affirming home environment, the ability to create a predictable and structured routine, and to be a positive autistic role model for their children (Dugdale et al., 2021) (see Chapter 4, Methodology, pages 72-73). There is limited evidence available regarding the number of families with diagnosed or undiagnosed autistic children who have faced this situation. There is also no recognition within the RCPCH guidance of the potential harm caused by the wrongful identification of FII cases and the damage to children and families that it causes (RCPCH, 2021).

Autistic people are more likely to face disparity in healthcare, with a limited or outdated understanding of the condition affecting healthcare providers' confidence and skill in serving this section of the population (Radev et al., 2024a). Healthcare disparity has been pronounced enough to contribute to poorer health in autistic people, both physical and mental, with mortality rates double those of the non-autistic population and spanning almost all causes of death (Hirvikoski et al., 2016) (see Chapter 4, Methodology, page 73). Lum et al. (2014) found that autistic females experienced more significant anxiety and distress in accessing healthcare because of their social interaction issues. These difficulties may also lead to healthcare avoidance and adverse health outcomes (Shaw et al., 2023).

Autistic mothers may face multiple barriers by being autistic, being a woman or gender-diverse, and possibly by having other marginalised identities (Koffer Miller et al., 2022) (see Chapter 4, Methodology, pages 74-76). When Anna, Chayana, Diane, Eva, and Fiona requested a referral from their GP for an autism diagnostic assessment, they realised that their doctors were unfamiliar with autism that presented in individuals who were not 'stereotypical' young boys, as they were more used to referring children (Chown et al., 2023). As they were more mature adults, they had decades of experience developing social skills to mask their autistic behaviour (Tomaszewski et al., 2025). After Anna received her diagnosis, she asked her GP not to include the diagnostic report in her health records as she believed health professionals may make incorrect assumptions about her in the future (Radev et al., 2024a). Failure to provide appropriate support may cause a significant negative impact and an increase in the level of disability an autistic person experiences (Doherty et al., 2022).

Fiona believed that some health professionals did not appreciate that autistic people may include individuals of all genders, ages, ethnic groups and so on (Tien, Pearson, et al., 2025). With

emerging research suggesting that autistic individuals may be more likely to have gender identity differences, whether that be transgender, non-binary, or another preferred identity, there are issues around postnatal care, including chest feeding for this group (Warrier et al., 2020). For transgender and gender-diverse individuals, experiencing poorer healthcare may lead to feelings of disillusionment and distrust of the healthcare system (Green et al., 2025).

Whilst society has started to embrace neurodiversity, and there is a rising number of diagnosed autistic female and gender-diverse individuals in the population reaching adulthood, there is still evidence of a lack of support available for autistic mothers (Marriott et al., 2022) (see Chapter 4, Methodology, pages 75-76). The mothers in this study assumed that they would receive some post-diagnostic support or counselling following their autism diagnostic assessment (Norris et al., 2024). Jo was surprised that she did not receive any information or advice at the end of her diagnostic consultation (Scattoni et al., 2021). Following her diagnosis, she created a health passport for herself for when she went into hospital, which is a resource designed by the National Autistic Society (NAS) to help autistic people to communicate their needs to doctors, nurses, and other healthcare professionals (NAS, 2024). However, she did not always use it as she found that healthcare staff would infantilise her and treat her differently (Grant, Turner, et al., 2024). Some of the other mothers, such as Fiona and Hannah, had found local autism support groups in their area, which they found beneficial as they met like-minded people whom they could relate to (Crompton et al., 2022). Anna was pleased to have found and received counselling from an autistic therapist, as it was giving her more self-confidence and generally made her feel happier than she had been in years (Chapman & Botha, 2023). Her husband and daughters were also considering starting sessions with Anna's therapist, as they had witnessed the improvement in her outlook on life. Other types of support and financial assistance, such as home or workplace adaptations and accommodations, may also have been beneficial (Crowson et al., 2024).

The agency and identity of disabled parents in caring roles need to be recognised, as being a carer can also impact health and stress levels (Fine & Glendinning, 2005) (see Chapter 4, Methodology, pages 75-76). Research needs to include the reality that disabled mothers may not only need to receive care but also may provide it, and that their families are made vulnerable when they are not given the support required (Gellini & Marczak, 2023). The National Institute for Health and Care Excellence (NICE) guidelines acknowledged that autistic adults who act as caregivers need to be supported (NICE, 2012).

Findings suggest that autistic adults may be more disadvantaged than children, with professionals reporting that they have limited knowledge about the presentation of autism in adults (Hartman et al., 2023). With some healthcare providers admitting to having been unprepared to deal with autistic adults, the provision of training is vital (Hand et al., 2024). Healthcare workers should be able to recognise autistic characteristics, potential drivers of behaviours, communication, and how to make reasonable adjustments to accommodate an autistic person's differences (Brice et al., 2021). Unfortunately, autistic adults are frequently put in the position of having to educate their healthcare providers (Precious, 2024) (see Chapter 3, Thematic Synthesis, page 53). Autistic children also need strong advocates in their corner to ensure support is provided where needed, a responsibility that usually falls to the mother to apply for (Cleary, West, & McLean, 2023).

Usually, health and social care professionals do want to help but are unsure how best to do this, or they may be afraid of 'getting it wrong' (Sutcliffe-Khan et al., 2024). Enhanced knowledge and understanding often develop into enhanced empathy and an increase in the quality of care (Curnow et al., 2025). Researchers have recommended more tailored support for autistic women and gender-diverse individuals during pregnancy, childbirth, and parenting. The Autism Act 2009 in England stipulates that relevant services for autistic adults should be planned and that staff providing these services should receive training (Autism Act, 2009; DoH, 2015).

This third superordinate theme described the experiences that the mothers had when disclosing their new autistic identity to their family, friends, work colleagues, and health and social care professionals. After disclosing to their family, they revealed the impact their disclosure had on the family dynamics within their household. Sometimes, disclosing to friends and colleagues led to misunderstandings and miscommunication; on other occasions, however, they received support and understanding. The mothers had been particularly wary of disclosing their diagnoses to health and social care professionals as they feared discrimination and accusations of FII. They described some of the unhelpful comments and attitudes that they had received in the past from healthcare professionals. Some also complained about the lack of post-diagnostic support they had received. In the next superordinate theme, the mothers reflected on events in their lives when they had been undiagnosed, and how they reframed their experiences in light of their new identity and knowledge of themselves. They also reveal how they have tried to protect their children from experiencing similar problems to those they had encountered and have tried to create a positive, 'authentic', neurodiversity-affirming family environment.

CHAPTER 9 THEME FOUR – An ‘authentically autistic’ family

Findings from Theme Four – An ‘authentically autistic’ family

This fourth and final superordinate theme describes the mothers’ lived experiences of their childhood, adolescence, and those events that occurred while they were undiagnosed adults. It also reveals how, following their autism diagnosis, they reframed some of these events in light of their new knowledge and self-understanding. In their interviews, the participants expressed a wish to shield their children from facing similar negative experiences that they had gone through during their lives. They described how they had fought to get their autistic children diagnosed and battled for the educational support that they needed to thrive. Finally, this superordinate theme portrays the mother’s determination to provide a loving, stable and supportive home for their family, and the deep connection and understanding that they felt with their autistic children. The mothers explained how they had benefited from creating an ‘authentically autistic’ family home. They perceived it as being a supportive and comfortable environment that respected their family members’ individual needs and preferences related to their sensory sensitivities, executive functioning, and personal routines. In their family home, they offered understanding, affirmation, acceptance, and accommodations to promote well-being, independence, and a sense of belonging. Ideally, there would be areas to minimise sensory overload and offer opportunities for self-regulation. These findings will be followed by a discussion on this final subordinate theme in the second half of this chapter.

Undiagnosed lived experiences

All of the mothers discussed their childhood experiences and how they grew up without support for their neurodivergence. They were very anxious children, and many, particularly Anna and Chayana, felt misunderstood and unloved due to the lack of physical contact with their parents. “I don’t particularly remember being happy. I was anxious and scared a lot of the time ... I guess I felt quite lonely really.” (Hannah) After reaching adolescence and starting secondary school, they began to realise they were different and were experiencing difficulties fitting in with their peers. “I was a very well-behaved child, but I was also very quiet and not very relational ... I didn’t have a smile on my face; my ‘resting bitchface’ was there as a child.” (Anna) Many of the mothers, in particular Anna, Diane, Eva, and Fiona, explained how they were bullied at school. Fiona tried to help the bullies with their schoolwork to ingratiate herself into the peer group.

I was bullied a wee bit at school, but I tended to have one or two good friends, and they shielded me quite a lot. Also, I was quite good at maths, so I tended to help other people with their maths, and when someone is helping you, you don't tend to do anything to upset them. (Fiona)

Most of the mothers, except for Fiona and Jo, talked at length during their interviews about their experiences of bereavement, divorce, financial insecurity, alcoholism, domestic violence, mental health issues, and psychological and physical abuse within their families. "There was a lot of arguing and shouting. As soon as I hit 14 or 15, and became taller than my parents, whenever they tried to hit me, I would hit them back." (Diane) Although Bridget was not physically assaulted herself, she often witnessed her brother being beaten by her father.

I remember my brother wrestling in the front garden, and he fell and hit his head on the fence. We were terrified to tell my dad, because we knew he'd had a drink, but my brother needed to go to the hospital. My dad leathered him because he was just like, 'How dare you interrupt the football!' (Bridget)

During Georgia's teenage years, their mother had failed to monitor where they were spending time and with whom, thus exposing them to some dangerous circumstances.

As long as I did not cause my mother any embarrassment or grief, I could go off and do whatever I wanted to do. That meant that I was in some incredibly risky situations ... I had a speed addiction when I was [age] and I had a teenage pregnancy when I was [age], which ended in a natural termination. I had a coke habit when I was [age]. I was involved in an incredibly abusive relationship in my [age group]. (Georgia)

Nine of the mothers talked at length about difficult periods in their adulthood before they were diagnosed. All participants became new mothers before having their autism assessments, so they were not fully aware of their strengths and weaknesses and had no successful autistic coping strategies to fall back on. Certain circumstances made caring for their autistic children even harder. Before they died, Anna's parents both developed dementia, and, without support from her family, she felt responsible for their care. "Being a parent, particularly when I had my own parents to deal with, it was a lot to do. I didn't have any support." (Anna)

Following a traumatic event, Eva had to sell the family home during her pregnancy with her daughter. She was grieving whilst also trying to adjust to the prospect of becoming a new mother.

I fell pregnant, a few months after that, with my daughter and then, while I was pregnant, I had to navigate selling my mum's house ... It was difficult having to negotiate, clean the house, sell it, and I was pregnant. Then [child's name] was born on the day that the sale of the house completed. (Eva)

Bridget separated from her ex-husband after her son was born, when she revealed that she intended to transition into a woman.

I got engaged at [age], got married at [age] and had my son in [year]. Then shortly after, my ex-husband told me that he was trans, and wanted to change to be a lady ... It did mean that our marriage kind of fell apart completely, because I'm not interested in women. (Bridget)

As Bridget always tried to avoid confrontation, she found it difficult to ask her to leave the family home. After finally persuading her to go, Bridget was blamed for being hostile. She began to re-evaluate her life and her future, although she found it confusing without a diagnosis to confirm her suspicion that she was autistic.

Following Hannah's divorce from their ex-husband, their son became violent with family members and was diagnosed as autistic with ADHD. Hannah still feels very guilty about the marriage breakdown. "I really think about the effect of that on him at the time. It's a big regret of mine and something that I know he'll never forgive me for. He's been having counselling this last year." (Hannah) Diane went through a tough period of ill health after her son was born.

I was an undiagnosed diabetic, so with my blood sugars being so high, I was a very angry, shouty, miserable, tired woman, and I didn't engage with him very well. I left it all to my husband. The shouting for no reason at all; I feel so guilty for that. (Diane)

Although Diane was able to rely on her husband when she was ill, unfortunately, Anna was often placed in a position of responsibility for all her immediate family, including her elderly parents and

her husband, who was suicidal and had serious mental health issues. When her husband accidentally broke his back, this added to the pressure she was under.

[Partner's name] fell off a climbing wall and broke his back, so was in hospital waiting for surgery, and the younger one had stopped going to school ... So, I was the only one with anything left in them mentally, so I had to hold it together. (Anna)

Following their diagnoses, all ten participants reframed their undiagnosed life experiences in light of their new identity and knowledge of themselves. Eva had sought a diagnosis because she wanted to perceive her experiences through the appropriate lens of autism, rather than just the lens of depression and anxiety. It gave her the confidence to commence her Master's degree.

I thought that I'm not really good with people; I upset people. I'm not very good at my job ... They're the kind of things we tell ourselves about how we are wrong, or we're broken, or we don't fit. I could just reframe all of that, with those two labels: ADHD and autism. (Eva)

Chayana realised that she had been masking for most of her life, without realising it, to survive the daily social interactions that occurred, particularly at work. She believed that her mental health had deteriorated from all her masking, but she had since realised why she had always felt exhausted at the end of each day.

If I had had a diagnosis, I reckon I wouldn't have had so many mental health issues. I wouldn't have had so many crises throughout my life. I would have felt confident about who I was. Going through my life, it was always there at the back of my mind; I don't fit in. I didn't have any support. I wouldn't have thought I was so mad. (Chayana)

Following Anna's diagnosis, she realised that the anxiety she often experienced was due to the difficulties she faced in successfully maintaining her mask. She tried hard to fit in, but it left her exhausted and needing recovery time.

All through my whole life, there were certain events or activities that would absolutely knacker me out ... it's all down to what I was having to process and deal with by doing

these tasks and therefore there was a payback on the next day ... my autistic brain was trying to make sense of the world and, if I made an effort one day, then I would need to recover the next. (Anna)

Ivy went through their life believing that they were 'abnormal', but, post-diagnosis, they realised that they were "a perfectly normal autistic person". (Ivy) Their struggle to understand themselves throughout their life had affected their self-confidence and mental health. They became very emotional after receiving their diagnosis. "It's dealing with that anger of knowing that I could have had so much more support and things could have been so much easier for me, if I had known this when I was younger." (Ivy)

Eva felt that the diagnosis improved her relationship with her daughter. She understood her daughter's triggers and needs because they were similar to her own and was able to advocate on her behalf. "It changed my positionality and my understanding, and all of a sudden, I became the expert in my experience and my child's experience. I could say to other people, 'No, actually, you don't understand because you're not autistic.'" (Eva)

Hannah believed that, if they had known they were autistic at an earlier age, they would have understood why they got so anxious, had constant background chatter in their head, and had to plan for every possible eventuality in any situation. They realised that many of their children's needs clashed with their own, and they were prone to getting overwhelmed. "I think I could have been a much better mother if I had had just one child ... I probably would have done that, without getting completely overwhelmed and burnt out constantly." (Hannah)

Shielding the children

Nine participants talked in their interviews about their experiences of advocating on behalf of their children and seeking an autism diagnosis for them. The only mother who did not discuss this subject was Jo, whose 5-year-old daughter had not yet been diagnosed, and her other two children were too young to be assessed. For the rest of the mothers, the whole experience of seeking autism diagnoses for their children was upsetting and stressful. However, they recognised that it was essential for ensuring access to the support they needed. They wanted to shield their children from the bad experiences they had during their own childhood, especially at school. However, the lengthy forms they had to fill out and the questions the clinicians asked

during the assessments were disturbing and couched in very negative, deficit-based language. “The whole thing is about what you do wrong in the world, how people perceive you as wrong, bad and different and, actually, talking about my son only in those terms, for his own diagnostic process, was deeply distressing.” (Georgia)

Diane and Eva found it helpful that they had already received a confirmed parental diagnosis, both when they asked for a referral and during their child’s autism assessment. It seemed to help speed up the process, and they felt their concerns had been taken more seriously.

In our area, there's no under-five pathway for children. We were lucky that the paediatrician she saw actually sat on the board for two trusts, and she said, ‘I'm going to take her case to this other one that does have an under-five pathway, because I think it's important.’ She recognised the fact that my daughter was not stereotypically autistic. In a classroom, you wouldn't pick her out as autistic. It wouldn't be identified at school ... I'd already had a diagnosis, so I think that helped them take it more seriously. (Eva)

Fiona’s daughter was on the waiting list for a referral to the Child and Adolescent Mental Health Services (CAMHS), which had been delayed due to COVID-19 restrictions. However, Fiona was concerned that her diagnosis may obstruct the assessment, as the clinicians may conclude that she was copying her mother’s behaviours.

One thing that I do worry about is, because I’m autistic and people know I’m autistic, they may have more trouble getting a diagnosis. When I eat, I have to eat the vegetables first and then the meat and she’s started copying me, but I don't know if that’s because she’s autistic or she’s just copying me. I’m worried that they will say she’s not autistic, and that she’s just doing what I do. (Fiona)

In some of the mothers’ experiences, particularly Anna's and Bridget's, their children’s schools were unsupportive. They disagreed with the need for a diagnosis, which hampered their children’s timely referral and assessment.

She was like, 'Why do you think the school haven't seen any issues?' ... and I said, 'Well, I think the school isn't backing him up because he's quiet. He sits in the corner; he does his work. He doesn't cause a fuss.' I said, 'If he was one of those kids who presented stereotypically and threw things around and had behaviour issues, you wouldn't be questioning it. (Bridget)

Anna's daughter was nearly finished with her secondary education and was applying for university when she requested a referral. However, the school were unhelpful as her daughter would have been leaving their establishment soon.

I started talking to health professionals about my elder daughter because she was in sixth form, but school couldn't see the point in it. They thought I was one of these stupid, pushy mothers ... We managed to shove it through on the basis that she was applying to university, and they produced the diagnosis just in time for her to apply for DSA [Disability Support Allowance], which she got. (Anna)

Nine of the mothers described their experiences in their interviews of trying to secure educational support for their children. It was a highly stressful period in their lives, but they felt it was essential for them to ensure that their children did not struggle at school in the same way they had in their youth. "I was failed miserably during my education from start to finish. I'm quite tenacious in fighting for what I believe he deserves ... I know how much I struggled, and I cannot have that for my children whatsoever." (Ivy) Eva was also determined to find a school for her daughter that would appreciate her differences, encourage her strengths, and support her weaknesses.

When I went to look at local schools ... How much awareness and understanding do they have about autism and girls and women ... only one place that I visited did and they actually had a display on the wall about how autism is different in everyone and about how autism in girls is different and that it doesn't always appear stereotypically, and I was like, 'Yes, this is it'. (Eva)

For Chayana, it was a battle with the education system that she was determined to win, even though her son's school seemed to assume that he would never achieve much in his life.

I had to fight for all that: for a statement of educational needs, speech therapy, you know. It doesn't come easily because the teachers don't want to help you. They always seem to use the one-to-one help with everybody else. I think certain teachers in my son's secondary school had given up on my son's future. (Chayana)

Anna decided to place her youngest daughter in an independent special school because she was struggling to cope in a secondary mainstream school. She was refusing to attend, as she found her school day too traumatic. However, instead of devising a strategy to support her daughter, the school became increasingly hostile towards Anna.

"They were threatening us with fines ... 'So, as it happens, we've spoken about you today in a meeting, your family, and we were lenient with you last year. Any more of these absences and we're going to fine you'". (Anna)

Diane had also decided that her son might be better off in a special school rather than a mainstream school, especially since the local authority was not willing to pay for a full-time TA to support him throughout the whole school day.

He's not going to cope from year 1 onwards in mainstream. They won't give us a one-to-one ... the maximum we probably would get is 24 hours out of the 30 hours per week, which is good, but who's looking after him those hours of the day when he could be having meltdowns? They reckon that being in a specialist setting with more staff and smaller groups, because even there, he's not going to get a one-to-one. We're at that phase now, where I'm looking around specialist schools. (Diane)

Hannah was nervous about sending their son to school as he had become aggressive and difficult to manage following his parents' divorce. Instead, they home-schooled him and their two other children without any support throughout their education. This was incredibly stressful for them, and they had felt the weight of responsibility on their shoulders. "I couldn't have him in that environment while he was lashing out at people, because he would have been labelled forever, and he would never, never have got rid of that label. Once you've been labelled as violent, that's it." (Hannah)

All participants described having other concerns about their children that did not directly relate to their education. These included worries over their children's lack of confidence, socialising problems, separation anxiety, lack of a father figure, and vulnerability to being bullied and victimised. Fiona was worried about her daughter as she seemed to have the same self-esteem issues that she had had in her childhood.

The only thing is the oldest; she's so much like me when I was a kid, so I tend to worry about her more because I know what she's going to face at school. She's just started school, and she's much more self-conscious than the younger one. At playtime, she'll come home and say, 'Nobody played with me.' It's because she's just standing there, and she's not going to say, 'I've finished my lunch, can I play with you?' She just won't make the first contact. (Fiona)

When their children were younger, Hannah felt that they could not leave them with friends, relatives, or babysitters, as they would always have massive meltdowns whenever they tried. They were never able to get any respite and sometimes found the responsibility quite overwhelming. Their daughter, who was diagnosed with selective mutism, was particularly dependent on them.

I couldn't just leave my children for some respite ... none of them would actually go with anyone else. Half the time, my daughter still bloody won't. My husband tries to take her out. Sometimes she'll go and, at other times, it has to be me. (Hannah)

Following her divorce, Bridget had not had a new partner in the household, and her ex-husband had transitioned to become a woman, so she was concerned that her son had no 'male' role model in his life.

It's difficult for him because he's got me and he's got his 'mama D', as he calls her, and she's got a partner. That's the first time he's really had a male in he's life ... he's not got a 'dad' per se. So, who does he look to for male stuff? (Bridget)

As most of the mothers had experienced bullying at some point in their lives, they were particularly anxious about their children becoming targets for bullies, either at school or, later on, in the workplace. Ivy's five-year-old son had already been picked on due to his stimming behaviours.

Some of the things that he enjoys stimming with may be viewed as babyish or girly. So, he's been called a girl and gay; these labels have been put on him because he likes what is traditionally 'girly' stuff, like glitter and stuff that sparkles. He's a bit of a magpie in that way, and he likes soft textures, which comes with teddy bears, fleecy blankets, and stuff like that. (Ivy)

Perceived benefits of an 'authentically autistic' family

All ten mothers talked about trying their utmost to provide a loving, stable family home where autism is accepted and understood, and their children would be free to express themselves. They would not be required to mask their autistic behaviours or suppress their stims.

If you're an autistic girl, you may not be around other people who speak the same 'language' as you, unless your family are also 'authentically autistic' and able to communicate with you in 'authentically autistic' ways ... I don't want to parent the way my parents parented ... I don't want to do the things to my daughter that made me feel the way that I felt when they were done to me. Validating her feelings and validating her responses is really important. The whole like, 'Stop crying or I'll give you something to cry about.' I don't do any of that. That's all I had. (Eva)

Georgia was also determined to provide a supportive environment for their son. They advocated and protected him as best as they could, so that he would grow up with a positive sense of self. "It's absolutely made me choose to consciously parent differently, and at times, I have to propel myself forward and push people with me." (Georgia) The participants believed it was essential to build their children's self-confidence and encourage them with plenty of praise and affection.

I've started with [child's name]. When she comes home from school, I've got her doing a Confidence Journal. Just so that she can pick out how she's feeling during the day, because if somebody says something, for example, if she picks up an ornament and we say, 'Put it down,' she'll burst into tears because she thinks she's getting into

trouble. She's not. You're just telling her not to pick it up. She takes every little criticism so hard. (Fiona)

Those mothers with older autistic children encouraged them to pursue careers which would make the most of their ability to hyperfocus on stimulating and motivating subjects, such as their intense interests. "That's one thing I've said from day one, 'You might have weaknesses.' I just say to my sons, 'You can't be good at everything, so just focus on your strengths, and try and get the job that you love.'" (Chayana) Hannah also wanted their children to develop their potential in an 'autism-friendly' environment. They felt it was their responsibility to ensure that they would be provided for in the future.

I know that it's possible to live life healthily as an autistic person; you just need to find the right environment that suits you. I need to find that for them; I can't say that my job here is done, as a mother, until I've done that. (Hannah)

Having identified themselves as autistic, all ten mothers found that their new self-understanding bestowed an additional advantage, as it improved their maternal self-efficacy and relationship with their autistic children. With a better awareness of their strengths and weaknesses, they were able to develop effective coping strategies. They became more knowledgeable about their capabilities and more self-compassionate.

"I've made changes and I'm now really good with my 'authentic' self. So yes, I allow myself to have more downtime. I'm allowed to be kind to myself. So that I don't feel overwhelmed." (Chayana) When the mothers found themselves in a position where they could potentially become overwhelmed and experience a meltdown, they were better able to remove themselves from the situation and move to a calmer setting to regain control over their emotions and sensory sensitivities.

If I am going to get angry or I'm feeling like I need to shout, because, honestly, sometimes things happen ... it has made me realise what impact that can have, so it's changed that. Instead of being someone that would just be like, 'Oh, my God, go away,' I take a deep breath and I'm like, 'Would you just go sit on the step for a minute?' We use the step, not for him when he's been naughty, but when I need a break for two

minutes ... He comes back and I say to him, 'Listen, I'm really sorry for making you go to the step. Mummy just needed a minute.' (Bridget)

Following her autism diagnosis, Anna started therapy with an autistic therapist, which she felt was beneficial. Her whole family had noticed a transformation in her demeanour and had stopped being so concerned about her mental well-being.

My younger one is going to have this assessment with my therapist, and she's thinking about whether she could possibly see her and benefit in the same way. The therapist is up for that, and she is too. Now, I don't know whether she would have got to that point of view before I did my last three months of changing, lightening up, and generally being happier, which I am ... When parents are happy and sorting themselves out, that gives the children permission to stop worrying about them, and I think that's happening now. (Anna)

Georgia also found that some of their sensory sensitivities were similar to those of their autistic son, so they used this connection to arrange some quality, personal time together. These experiences helped them fortify their bond and relate to each other, so that any conflicts they had would fade away.

[Child's name] also sleeps on the floor because he has a high level of sensory seeking need as well, and every so often, I say to him, 'Well, do you want to come in and have a sleepover in my room?' So, we had a weekend and we got on really well and I said, 'Do you want to go to sleep in my room?' and he's like, 'Yeah,' and, actually, all of the anxiety and a lot of the conflict in our relationship has gone ... we don't bedshare, but we lay our sleeping rolls out side by side in here, and we sleep in the same space. People have been doing this for thousands of years. (Georgia)

All ten participants mentioned in their interviews that they had a special, deep connection with their children, particularly those who were autistic. Bridget felt that she could communicate well with her son and loved teaching him about the world. "When he was really young and we were seeing the health visitor, it was something that she'd always say. She'd be like, 'You know, you two have the strangest bond.' We are so close." (Bridget) Diane explained that she had

instinctively given her son what he needed emotionally, for example, by co-sleeping together, and this had helped create an incredibly deep bond between them. “We have a really, really strong bond. He's all about mummy. He's a complete mummy's boy. He's my little best friend ... we understand each other; I understand him. We're on the same level in quite a few ways.” (Diane)

Ivy also believed that they instinctively knew what their autistic children needed, even before they were diagnosed. They movingly described what they considered the best part of being a mother during their interview.

The best part of being a mum is every day watching that human being develop. I think that's the best bit, and knowing that you have had an active role in the development of that. You've seen them through bad times, good times, things that they had struggled with, most of their achievements, and celebrated that along with that person. Just literally having a first-hand account of someone's life, I think that is the best bit. (Ivy)

Eva was also amazed by the incredibly intense and powerful bond that she had with her daughter.

My daughter's joy that she experiences when she discovers things, when she experiences things, when she finds things out about the things that she's interested in, or when she does something new for the first time, and she loves it. Being able to experience that with her is amazing, and being able to see those experiences through a child's eyes again is amazing The connection that we have is a connection that I don't have with anybody else. I've never experienced before, this connection with her. It's peace and unconditional love that I haven't experienced with anybody else. It's unlike anything else. You know, it's just a totally different kind of love and bond. (Eva)

Discussion of Theme Four – An ‘authentically autistic’ family

Undiagnosed lived experiences

When they were young, the participants soon realised that their acceptance in society was conditional on whether they behaved ‘respectably’ and they were expected to be quiet, polite, and well-mannered (Keating et al., 2024) (see Chapter 2, Social and Historical Context, page 28). Because, in our society, females are generally constrained by more restrictive social standards than males, autistic females tend to, consciously or subconsciously, hide any troublesome,

aggressive, or disruptive behaviours at an early age (Piening et al., 2023). Most of the participants, in particular Anna, attempted to meet these neurotypical expectations by being “very well-behaved” and studious, therefore inadvertently giving others, such as teachers, the impression that they were not experiencing difficulties and did not require support (AGN, 2022). Many of the mothers felt misunderstood and unloved by their parents, and remembered feeling unhappy and being very anxious as children (Andrzejewski & McDonnell, 2025).

For the participants, adolescence was a time when they began to realise that they were different from the people around them and tried to change their behaviours to seem more ‘normal’ and to fit in (Morgan, 2023) (see Chapter 2, Social and Historical Context, page 28). This might be because they noticed differences between themselves and others or because other people had told them they were acting differently (Mesa & Hamilton, 2022). Research has shown that neurotypical people may quickly and subconsciously identify an autistic stranger as being different or ‘weird’, and based on their first impression, they may be less interested in conversing with them, and they generally dislike observing any ‘uncomfortable’ social performances (Rifai et al., 2021).

The changes to the participants’ friendship groups when they began secondary school may have increased their need to mask, as they would have naturally wanted to make a good impression on their new peers (Chapman et al., 2022). However, in Sedgewick et al. (2016) autistic adolescent females were found to often struggle with peer conflict and trying to fit in at school. Our participants generally had only one or two good friends when they were children, as described by Fiona; far less than their non-autistic peers and, perhaps unsurprisingly, they reported being and feeling lonely (Tsou et al., 2024). Many of the participants, particularly Hannah and Anna, seemed to withdraw from other people, and their anxiety in social situations increased (Leachman et al., 2024).

Friendships serve as a protective factor against bullying in both autistic and non-autistic children (Overland et al., 2024). The difficulty autistic children have in making and keeping friends may be one of the reasons they are at greater risk of bullying than their neurotypical peers, with 75% of autistic children without LD being bullied compared to 42% of neurotypical children (Fallon et al., 2025). Anna, Diane, Eva, and Fiona all described the extensive bullying they were subjected to during their schooldays (Junttila et al., 2024). Fiona tried to ingratiate herself with her tormenters

by helping them with their math schoolwork, as it was a subject in which she excelled (Morton, 2021). Usually, bullied children experience difficulties in engaging with their schoolwork, which may potentially have long-term consequences for their future employability (Wilson, 2024).

As well as being bullied, research has shown that autistic individuals may be more likely to experience adverse childhood events than non-autistic people (Davidsson et al., 2025) (see Chapter 2, Social and Historical Context, page 25). They are at increased risk of abuse, neglect, and loneliness and, in general, they are likely to experience a lower quality of life than their peers (Takeda et al., 2024). Many of the participants talked at length in their interviews about problematic events that they experienced in their childhood, such as family bereavement, divorce, and financial insecurity (Davidsson et al., 2025). They had also witnessed their parents' alcoholism, domestic violence, and mental health issues (Hartley et al., 2023). Some had experienced mental and physical abuse within their family home; for example, the events described by Diane, who was physically abused; Bridget, who had witnessed her brother being beaten; and Georgia, whose mother was neglectful in supervising them (Andrzejewski & McDonnell, 2025). The trauma from these types of experiences may have contributed towards the participants' development of masking, as they may have subconsciously used their masks as a 'shield' in an attempt to gain some semblance of safety (Seers & Hogg, 2022) (see Chapter 2, Social and Historical Context, pages 26-28).

By masking their social confusion, autistic people often become more vulnerable to unhealthy relationships, 'self-medication' with recreational drugs or alcohol, and stress-related illnesses (Sinclair et al., 2023). Georgia began taking drugs in their teenage years and also found themselves involved in some abusive relationships (Pearson et al., 2024). Autistic people may also use substances to seek respite from their constant state of anxiety and internalisation of their distress and discomfort, and to ease the pain, grief, trauma, and isolation that may result from feeling that they were being stigmatised (Livingston, 2021).

As the participants progressed into adulthood, their social world became even more complex with the need to navigate a variety of different social environments and balance the demands of various aspects of their lives, such as family, career, romantic relationships, and friendships, whilst trying to manage and live up to normative expectations of success and prosperity (Chapman & Carel, 2022). All the participants became new mothers before receiving their

diagnoses of autism, so they had no understanding of their autistic strengths and weaknesses (O'Nions et al., 2023). They lacked the necessary coping strategies to deal with daily challenges such as sensory overwhelm or the emotions resulting from the traumatic events that they had experienced (Smit & Hopper, 2023). They had been masking all their lives, which would have put them at a higher risk of conditions like postnatal depression and anxiety (Hull et al., 2021). Research has shown that the autistic population have higher rates of mental health difficulties in comparison to the general population (Reuben et al., 2021) (see Chapter 2, Social and Historical Context, pages 25-26). Many of the participants, including Chayana, Diane, and Eva, had received diagnoses for co-occurring mental health issues, for example, ADHD, depression, and generalised anxiety disorder (Waldren et al., 2024).

Research by Griffiths et al. (2019) revealed that autistic adults experience more adverse events in their lives compared to non-autistic individuals. They may also be more susceptible to financial exploitation, domestic violence, relational abuse, and emotional manipulation (Sedgewick & Douglas, 2023). Nine of the ten mothers described some extremely challenging periods of their lives that had occurred while they were undiagnosed adults (Parfitt, 2023). Some of these events would have made caring for their autistic children even more difficult (Radev et al., 2024b). Anna had found the responsibility of looking after her elderly parents challenging, as they both had dementia before they passed away (Heyworth et al., 2023). This extra responsibility had occurred at the same time as her husband, who was suicidal and had serious mental health issues, had broken his back in an accident (S. Hampton et al., 2022). In addition, her youngest daughter was refusing to attend mainstream school, so she had to be homeschooled while the local authority was deciding whether or not to fund her education in a special school (McMunn et al., 2024). Anna had received little support from the rest of her family, so she found this period of her life very demanding (Rabba et al., 2025). As Eva was becoming a new mother, she experienced a bereavement in her family and had to organise and sell the family home (Parfitt, 2023). Both Bridget and Hannah experienced the breakup of their marriages after they had become mothers. Hannah's autistic son had become violent within the family home following his parents' divorce, as he was deeply affected by the breakup (Heyworth et al., 2023).

As well as having experienced periods of significant difficulty, some of the mothers had co-occurring physical health conditions (Jade Davies et al., 2024). In particular, Diane became very unwell just after her son was born (White et al., 2023). She developed diabetes, although it

remained undiagnosed for some time, and she was experiencing the effects of high blood glucose levels, so she found it challenging to engage with her new baby fully (LaManna & Quelly, 2020). Autistic people often present to healthcare professionals with atypical expression of emotion, pain and other symptoms, which may lead to misdiagnosis or lack of treatment (Shaw et al., 2023). General practitioners have reported finding it more challenging to treat autistic patients, so they may face barriers to healthcare access that neurotypical people would not generally face (Radev et al., 2024a).

For all the participants, finally getting their autism diagnosis so late in their lives was described as a relief and gave them the ability to reflect on the challenges they had gone through during their lives, without the guilt and shame that they had felt for so long (Gonçalves Garcia et al., 2025) (see Chapter 2, Social and Historical Context, pages 35-37). It prompted them to reexamine their entire life and reframe their experiences in light of their new autistic identity (Kelly et al., 2024).

Like many autistic people who receive their diagnoses so late, the revelation proved to be earth-shattering for the participants, so adjusting their self-concept may take a reasonably long period of time (French & Cassidy, 2024). Corden et al. (2021) found that people who had suspected that they were autistic for a while had a more positive attitude towards their autistic identity, compared to those who had only recently identified as autistic. When interviewed, most of the mothers, including Anna, Diane, Eva, Hannah, Ivy, and Jo, had only received their diagnoses one or two years ago (Crowson et al., 2024). These mothers may have required more time to process and reframe their lived experiences entirely, which could have potentially increased their self-understanding and self-esteem (Cooper et al., 2023). Painful labels that the participants had been carrying around inside their heads for years suddenly were no longer relevant: they were not stupid, weird, or lazy; they were just autistic (Kelly et al., 2024). They realised that they had not been treated with the compassion they deserved or been given the tools that would have allowed them to flourish (Leedham et al., 2020) (see Chapter 2, Social and Historical Context, pages 35-37). Morgan (2023) found that a diagnostic label may serve to situate autistic people's struggles during childhood and young adulthood as more than just 'problem behaviour'.

Before their diagnoses, all the mothers in this study had been masking their autistic traits for decades without even realising it (Seers & Hogg, 2022). Anna had spent so much time and

concentration on perfecting her mask that she felt she had lost sight of who she truly was, and it had left her exhausted and anxious (Pearson & Rose, 2023). She realised that she required recovery time to ‘decompress’ or self-regulate after any situation or event that was socially demanding (Beck et al., 2020) (see Chapter 2, Social and Historical Context, pages 23-25). All participants had found it challenging to develop self-confidence and a healthy outlook on life before they had a clear understanding of themselves (Reid et al., 2024). The habit of ruminating and internalising events over and over in their mind, which Chayana had described, may have been a consequence of scripting and masking for so long, which would have impacted their self-esteem (Evans et al., 2023).

Recent conceptualisations from autistic scholars have suggested that masking develops as a survival mechanism to cope with a world that is hostile towards autistic people (Lawson, 2020) (see Chapter 2, Social and Historical Context, pages 26-28). Although putting on a mask of a desirable, respectable person had unsettled the participants’ identity and self-understanding, it had, to a certain extent, protected them from experiencing an even greater amount of alienation, disapproval, stigmatisation, and bullying during their childhood and younger adult years (Belek, 2023). The participants may have faced much harsher social penalties for not meeting standard neurotypical expectations (Bernardin et al., 2021).

For Chayana, successfully masking her differences at her old job working for the civil service had meant suppressing her natural behaviours and reactions as they would have marked her out as ‘different’ (Evans et al., 2023). She felt compelled to engage in office gossip and had to tolerate interruptions to her flow of concentration for ‘quick chats’ (Dupuis et al., 2022). Every social event organised by her employer may have caused her to panic for hours before arriving at the venue (Black, Greenwood, et al., 2024). Developing a mask temporarily helped her to get through each workday and helped to avoid stigmatising responses from other staff members (Cleary, West, Kornhaber, et al., 2023). However, in the long term, this dilemma led to immeasurable levels of bitterness, self-loathing, exhaustion, and mental health issues (Jones et al., 2021).

Although the participants’ diagnoses were given when they were adults, they helped explain their past difficulties and provided a framework through which to understand their current challenges (Huang et al., 2023). Receiving an autism diagnosis at any stage of life can provide autistic individuals with a profound personal insight that is invaluable (Seers & Hogg, 2022) (see Chapter

2, Social and Historical Context, pages 36-37). For Eva, it offered clarity on how and why she found it easier to relate to her daughter compared to any other adults she knew, and she was able to advocate on her behalf by becoming an ‘expert by experience’ (Murphy, 2021). Eva’s diagnosis also gave her the confidence to enrol on a full-time Master’s degree (Scott & Sedgewick, 2021). Although all participants came to see their autistic identity as a positive development in their lives, accepting their limitations was equally important, as they were able to discover autism-specific coping strategies to use when needed (J. Davies et al., 2024).

After their recent diagnoses, Ivy and Hannah struggled to come to terms with how things might have been different for them if they had been diagnosed earlier in their lives (Huang et al., 2023) (see Chapter 2, Social and Historical Context, page 36). Although a late-diagnosed autistic adult might feel immense regret about the way their life has gone so far, psychological research has shown that extending gratitude to your trauma-surviving self may be a powerful means of healing (Black, Helander, et al., 2024).

Shielding the children

All of the mothers were ‘on a mission’ to give their children a better life than the one they had experienced, so that they would not need to undergo similar challenges to those they had faced during their childhood (Dugdale et al., 2021) (see Chapter 3, Thematic Synthesis, page 50). The mothers hoped that their children would be able to reach their full potential in a career that interested them (Sandra Thom-Jones et al., 2024). Their aspirations had driven them to ensure that their autistic children’s needs were identified and met with appropriate support (Keville et al., 2024) (see Chapter 3, Thematic Synthesis, pages 52 and 55). In our society, it is often mothers who take on childcare responsibilities, and if a child has support needs, they frequently become advocates for them (Keville et al., 2024). The depiction of the ‘autism warrior mum’ stereotype is based on this necessity to advocate for their child to receive a referral for an accurate diagnosis, so that they can access appropriate support at school (Sedgewick & Douglas, 2023).

A family history of autism or another neurodivergent condition, such as ADHD, may be an indicator of a higher likelihood of autism in a child (Garcia-Molina & Cortes-Calvo, 2025) (see Chapter 2, Social and Historical Context, page 19). Diane and Eva both commented in their interviews that they believed that their confirmed parental diagnoses seemed to have helped speed up the process of waiting for their children’s appointments with the diagnosticians (Ghirardi

et al., 2021). They found that the clinicians took their concerns seriously during the assessments (Yu et al., 2022). However, Fiona, whose daughter's assessment had been put on hold due to COVID-19 restrictions, was worried that the clinicians might assume that her daughter was merely copying her behaviours and accuse Fiona of 'projecting' her anxieties and actions onto her child (Finch et al., 2022).

For many years, autism diagnostic teams in England have been overwhelmed by the high volume of referrals they have been receiving; as of September 2024, over 200,000 people were waiting for an autism assessment in England (NHS, 2024). Guidance from the National Institute for Health and Care Excellence (NICE) states that no one should wait more than 13 weeks for an assessment (NICE, 2017). However, data have shown that, of those individuals referred for an evaluation, 89% had been waiting longer than the recommended 13 weeks (NHS, 2024). The NICE guidelines also recommend that assessments should be carried out by a multidisciplinary team, which may include a combination of psychiatrists, paediatricians, clinical psychologists, speech and language therapists, and/or occupational therapists (NICE, 2017). NHS England published a framework to improve outcomes in all-age autism assessment pathways (NHSE, 2023). However, sufficient funding is needed to establish this standardised process and bring down waiting times.

The mothers in the study were responsible for arranging the assessments for their children, completing all the forms, and attending the various appointments together (O'Neill & O'Donnell, 2024). The participants, particularly Georgia, found the questions on the forms and the clinicians' enquiries about their child's development and behaviour to be very distressing, as they were expressed in such negative, deficit-based terms (Hartman et al., 2023). Information for the assessment would also need to be gathered from the child's school using standardised tools (NICE, 2017). Most diagnosticians require evidence from at least two settings, usually home and school, to provide a diagnosis (Cook et al., 2024). However, in Bridget's case, her son's school had regarded him as an 'ideal student' who listened well in class and completed all his work (Munroe & Dunleavy, 2023). The school saw a very different type of behaviour from her child than the one they saw at home, so they refused to support the referral (Whitlock et al., 2020). Children may not always present stereotypically; they may behave well all day in front of their teachers, but then experience a meltdown when they return home (Halsall et al., 2021). The meltdown may be due to the rapid and intense release of the mask they had worked hard to maintain all day at

school, and are finally able to drop at home, where they feel safer (Sedgewick & Douglas, 2023). Anna's daughter's school were also initially unsupportive because she was in the sixth form and was applying for university, so would soon be leaving secondary education (Rabba et al., 2025). However, they finally gave the evidential report to the clinician, so she received her diagnosis just in time for her to apply for disability support when she started her degree (Davies & Bagnall, 2024).

An Education, Health, and Care Plan (EHCP) is a legal document that outlines a child or young person's additional educational needs and the support they require (Keville et al., 2024). It can also help parents and young people choose the type of school or other settings that best suit their needs. The local authority is responsible for providing the additional educational provision described in the plan (NAO, 2024). For the mothers, securing an EHCP for their children would involve drafting the plan, usually with help from the school, and then gathering and documenting all the diagnostic and specialist assessment reports obtained so far, including those of a speech and language therapist, educational and/or clinical psychologist, psychiatrist, occupational therapist, and sometimes an independent social worker (Keville et al., 2024). Additionally, when an autistic child has complex issues, such as disordered eating, gender dysphoria, or other co-occurring conditions, this may increase the number of specialist assessment reports needed (Kallitsounaki & Williams, 2022).

Nine of the mothers had experienced trying to secure educational support for their children, and all nine found this process extremely stressful (Rabba et al., 2025) (see Chapter 3, Thematic Synthesis, page 54). However, they realised that it was a vitally important measure to ensure their children would be able to access the educational curriculum (Hasson et al., 2024). Ivy expressed their determination not to let their children struggle at school like they had when they were a child (Curd & Nguyễn, 2024). Chayana was also incredibly determined, despite finding that the school was not particularly helpful during the process. She felt that her son's school had given up on his future (Luymes et al., 2023). Studies have shown that autistic children from ethnic minority backgrounds, such as Ivy and Chayana's children, are more frequently given detentions, put into isolation, excluded, and sent to pupil referral units (Roman-Urrestarazu et al., 2021). Many autistic children from ethnic minorities are wrongly labelled as having social, emotional, and behavioural problems (Onabanjo, 2024). In an ideal world, it would be great if educational institutions

responded as you would like them to or acted according to disability law, but this does not always happen (Garcia-Molina, 2024).

The participants were likely to have had higher stress levels in comparison to parents of neurotypical children, due to their constant fight for better services and support for their children (Rabba et al., 2025) (see Chapter 3, Thematic Synthesis, pages 51 and 54). One of the characteristics of many autistic parents is their attention to detail and a desire to find solutions to their child's difficulties, leading them to undertake extensive internet searches and extensive exploration until understanding and resolution are achieved (Dugdale et al., 2021). This was certainly the case for Eva, who visited all the local schools in her area on behalf of her daughter to find out which of them were autism-friendly and would encourage her strengths and support her weaknesses (McKinlay et al., 2025).

Classes in secondary mainstream schools are usually larger than in primary schools, with multiple teachers, each providing lessons on specific subjects (McKinlay et al., 2025). The corridors tend to be much busier with students shouting and pushing past each other, and lunch halls are usually larger, noisier, and more intimidating (Sedgewick & Douglas, 2023). Transitioning to secondary school may impact an autistic child's learning experience and emotional well-being, increasing meltdowns and burnout (Birkett et al., 2022). Many may also experience significant challenges with their executive functioning, such as planning, organising, task-shifting, and sequencing (Kenny et al., 2024). Autistic teenagers who have avoided school have revealed that the reason for their absence was due to their sensory processing differences and executive dysfunction (Sedgewick & Douglas, 2023). Friendship issues, bullying, and the fact that the school curriculum becomes increasingly complex and abstract may exacerbate the challenges of school life for adolescents (McKinlay et al., 2022).

In England, the majority of autistic young people are educated in mainstream school settings as opposed to specialist schools, which has led to a focus on 'inclusion' (Birkett et al., 2022). However, Anna decided to place her youngest daughter in an independent special school because she refused to attend mainstream school, which she found too traumatising (Fisher et al., 2025). Due to autistic burnout and years of trauma, she had become school-phobic and was unable to leave the house (Phung et al., 2021). In the meantime, instead of supporting the family, the school repeatedly threatened them with fines due to her daughter's absence (Mullally &

Connolly, 2025). Anna had to give up work to care for her daughter whilst battling the local authority to obtain the required provision within a special school (Blackwell, 2025).

At her interview, Diane was also contemplating whether her young son might find a special school more appropriate for him, as their local authority was unwilling to fund a one-to-one teaching assistant (TA) on a full-time basis, including break times (Luymes et al., 2023). However, it is often during breaks and lunchtimes that autistic children experience the most serious difficulties with sensory overload and meltdowns, and therefore require the support of their TA (Hasson et al., 2024). Hannah had decided that their son would be better off being educated at home, as he would regularly get aggressive when distressed, and they did not want him to be labelled as a 'violent child' (Williams, 2018). Their two other autistic children were also home-schooled, which was a massive responsibility for Hannah to cope with (Pohl et al., 2020).

Multiple studies have shown that young people vary in their perception of a diagnostic label as a positive concept (Mesa & Hamilton, 2022) (see Chapter 2, Social and Historical Context, pages 35-37). Some autistic young people value a label for their difference and find that knowing they are autistic helps them to achieve self-understanding and self-advocacy, for example, by being able to share their accessibility needs in their school environment (Riccio et al., 2021). However, in a study by Mesa and Hamilton (2022), both parents and young people outlined how teachers may treat autistic young people as homogeneous, often underestimating them or expecting them to all have identical needs. Humphrey and Lewis (2008) found that autistic young people felt singled out as 'different' in comparison to their peers and treated as less capable as a result. They thought that the label of autism came with particular stereotypes that caused their peers and teachers to make negative social judgments about them (Nah & Tan, 2021).

The participants were also concerned about other issues related to their children's behaviour, apart from those directly linked to their educational needs (Lee et al., 2025). They mostly worried about their lack of confidence, socialising problems, separation anxiety and their current or potential vulnerability to being bullied (Keshavarz & Esmaeilpour, 2025). As autism is a neurodevelopmental disability, when comparing an autistic person's skills against neurotypical milestones, they may appear delayed. Many autistic children continue to grow in their social and emotional skills for longer than non-autistic children (Kniola et al., 2024). Fiona was concerned about her daughter, who struggled with low self-esteem and often played alone in the playground

(H. Schiltz et al., 2023). Autistic children tend to engage more in solitary and parallel play compared to their peers (Tsou et al., 2024). This may be attributed to their unique communication styles compared to neurotypical children or their heightened need for solitude to 'decompress' from social interactions (Sedgewick & Douglas, 2023). During this time, they may stim to regulate their emotions and process the information they have been absorbing (Neville et al., 2024). Autistic youngsters are sometimes assumed to be daydreaming because they find it easier to listen and digest instructions while looking out of a window (Pyszkowska et al., 2025).

Many of the mothers, especially Hannah, mentioned that their young children could not be left with friends, relatives, or babysitters, as they would have massive meltdowns, in particular Hannah's daughter, who also had selective mutism (Keshavarz & Esmaeilpour, 2025). Autistic children are more avoidant of strangers when they are alone than non-autistic children (Sedgewick & Douglas, 2023). Autistic children are often very anxious and lack self-confidence (Leachman et al., 2024). Some of the mothers may have experienced social exclusion because of their children's care needs, which may have meant they could not attend social or family events or even have a quiet night on their own (Easler et al., 2022). Hannah was unable to get any respite from the demands of mothering and homeschooling their three children (Williams, 2018).

The mothers tried to be conscious of their energy levels and where they could 'save' and 'spend' their strength, utilising any available support (Hwang & Heslop, 2023). In families, when there is another parent, 'tag teaming' may sometimes be the only way to manage and ensure both parents can get some time alone to rest (Heyworth et al., 2023). Anna utilised local support networks with other parents, where she 'traded' playdates so that her children could socialise and she could get some downtime (Fong et al., 2021). However, none of Hannah's children would go with anyone else; sometimes, their daughter would not even leave the home with Hannah's husband (Keshavarz & Esmaeilpour, 2025).

As so many of the mothers in this study were bullied when they were at school, they were particularly anxious about the possibility of their children becoming targets of bullies during their lives (Accardo et al., 2024). Ivy's five-year-old autistic son had been bullied by his classmates at school for his stimming behaviours (Morris et al., 2025). This type of stigma is a crucial factor in autistic masking due to the internal and external pressure for autistic people to suppress aspects of their selfhood as a survival mechanism to avoid bullying, victimisation and discrimination (Gibbs

& Pellicano, 2023) (see Chapter 2, Social and Historical Context, pages 26-28). There is a real need for safe autistic spaces within the community where both children and adults can be themselves without feeling intimidated (Doherty et al., 2023). Connecting with other autistic people, whether adults or children, particularly those who share similar interests, can significantly enhance positive self-identity (J. Davies et al., 2024). Autistic children benefit significantly from being introduced to their 'tribe' (Cooper et al., 2023). Botha (2019) highlighted the importance of belonging and connection with others in both healing from trauma and feeling able to be one's authentic autistic self.

Perceived benefits of an 'authentically autistic' family

When the participants became new mothers, they felt immense pressure to do it 'right' and provide their children with the best home life (Williamson et al., 2023). They also consciously decided to raise them differently from how they had been brought up (Murphy, 2021). As Eva described, many had experienced quite an authoritarian upbringing as their parents believed they had the authority to make all decisions and regulate their children's behaviour, enforcing this belief through punishment (Suvarna et al., 2025). Although this parenting method may sometimes result in obedient children, it is also more likely to lead to the development of conduct problems as they grow up (Cronshaw & Midouhas, 2024). The participants aimed to create a family atmosphere where every child felt appreciated for who they were, received abundant love and affection, recognised that being autistic was nothing to be ashamed of, and took pride in their strengths while receiving support for their challenges; all contributing to a safe and accepting home environment (Sandra Thom-Jones et al., 2024) (see Chapter 4, Methodology, pages 72-73).

Raising their autistic children in households that understood and accepted neurodiversity allowed them to grow up in safe and nurturing environments that were empowering and supportive, encouraging the development of a positive self-identity (Onaiwu, 2023). All participants believed that building their children's self-confidence was important (Hwang & Heslop, 2023). Fiona had encouraged her daughter to write down her feelings and describe her experiences in a 'Confidence Journal' each day she returned from school (van der Crujsen & Boyer, 2021). This gave her a means by which she could talk about her emotions with her mother (Pagnier & Moualla, 2024). Research by Cooper et al. (2023) demonstrated that autistic individuals who associated autism with more positive character attributes tended to exhibit improved collective self-esteem and a stronger affiliation with their autistic identity (J. Davies et al., 2024). Knowing that they had

a secure and understanding home to return to after school may have helped the children manage their daily challenges (Radev et al., 2024b). Although this would not have negated the need to mask in some circumstances outside the home environment, it would have, at least, reduced the pressure to mask within the home (Botha et al., 2020).

However, one has to acknowledge that many autistic people experience stigma across multiple intersecting aspects of their identities (Radulski, 2022) (see Chapter 4, Methodology, pages 74-76). By taking an intersectional approach, any discussions around masking or the potential to unmask must recognise this nuance (Cleary, West, Kornhaber, et al., 2023). For example, it may be safer for certain autistic people, such as white autistic men, to identify and change their masking behaviours than it would be for others, such as Asian autistic gender-diverse individuals (White et al., 2024). Those who live in or have heritage across different cultures, such as Chayana, might encounter during their lives specific cultural expectations that affect how and when they mask (Keating et al., 2024). Scholars and activists have highlighted that unmasking is a privilege not always afforded to members of the ethnic minority autistic community due to existing dangers around cultural perceptions of their behaviour and the risk of victimisation (Dababnah et al., 2022).

The participants hoped every autistic member of their household would be able to unmask at will and to engage with their authentic selves more regularly, which has been linked to improved mental health, quality of life, and well-being (Price, 2022). Being accepted by others and having the ability to choose when and whether to mask may significantly enhance the lives of autistic individuals (Sedgewick & Douglas, 2023). The communities need to possess knowledge, understanding, and acceptance of autistic behaviours (Dunn, 2022). Stimming, communication differences, and sensory processing divergences should be normalised to allow autistic people to be themselves without fear of victimisation (Cage, 2020)

Researchers are beginning to explore this neurodiversity-affirming parenting style, particularly regarding how discussions with their autistic child about their diagnosis may differ between autistic and non-autistic parents (Crane, Lui, et al., 2021) (see Chapter 4, Methodology, pages 72-73). A significant benefit of autistic children having autistic parents is that they can discuss autism through the lens of their own experiences, fostering understanding and empathy between them (Murphy, 2021) (see Chapter 3, Thematic Synthesis, page 50). Autistic parents may be

more inclined to emphasise the benefits of being autistic rather than focusing on the challenges that professionals often discuss (Sedgewick et al., 2022). The mothers who had teenage autistic children at the time of their interview had been encouraging them to follow their dreams and passions in an attempt to help them find their path in life (Hwang & Heslop, 2023). Including an autistic child's passions within their educational material and career aspirations may help them pursue a related career or academic discipline in which they will thrive (Bross et al., 2022).

All the participants were focused on developing a positive and constructive self-identity, which they wished to promote through their close family, as well as culturally (Nocon et al., 2022). They believed that reducing stigma and preventing the proliferation of neuronormative ideologies would allow autistic people to develop greater self-esteem and mitigate the impact of these beliefs on their autistic mental health and well-being (Evans et al., 2023). While most of the participants had been focused on notions of their personal and professional performance within society before their autism diagnosis, now they were driven to develop their embodied awareness of themselves and their needs outside of shame and stigma (Huang et al., 2023). They had begun to use their self-knowledge to shape an environment at home, work, and in their community, which would meet their needs more effectively within their sphere of power (Cleary, West, & McLean, 2023). They hoped that this would lessen the overall burden of stress for them and their family and allow them all to thrive (Kelly et al., 2024).

Along with challenges, which tend to be described more often than autistic strengths in academic research, most participants talked about parenting as a gratifying relationship that brought them genuine joy (Dugdale et al., 2021). Their hyper-focusing ability, which they acknowledged as a key strength, was helpful as they researched parenting and neurodiversity (Pagnier & Moualla, 2024). These loving and attentive mothers seem to be in stark contrast to the historical narrative about mothers of autistic children being 'refrigerator mothers' who were cold and aloof (Fletcher-Randle, 2022) (see Chapter 2, Social and Historical Context, pages 15-16). Before their autism diagnosis, however, their ability to enjoy new motherhood was harder to appreciate (Fletcher-Randle, 2022). This may have been partly due to their determination to ensure that their children felt loved and valued (Dugdale et al., 2021). As a result, they remained constantly vigilant, striving to meet every expectation and taking on all childcare responsibilities, often at the expense of their own support needs (Sedgewick et al., 2022) (see Chapter 3, Thematic Synthesis, page 51). They

were exhausted; they did not have the time or energy for straightforward enjoyment, especially as young autistic children tend to depend heavily on their carers (Williamson et al., 2023).

Although downtime is beneficial for all mothers, respite is vital for autistic people who need it to recover following long periods of masking and/or sensory overwhelm (S. Hampton et al., 2022). Unfortunately, at times, respite may have seemed impossible for the mothers, whether they were caring for a new baby, a curious toddler, or a rebellious teenager; finding time to rest may have been challenging, leading to shutdowns, meltdowns, and burnout (Sandra Thom-Jones et al., 2024) (see Chapter 3, Thematic Synthesis, page 52). However, after their diagnosis, most of the mothers, except perhaps for Hannah, became better at recognising when they were becoming tired, anxious, impatient, or overwhelmed, and were not so reticent to ask for accommodations and support from other members of their family or community when needed (Heyworth et al., 2023). The overall effect of this self-compassion was an enhanced maternal self-efficacy, reduced self-blame for their differences, increased self-confidence, and an improvement in their relationships with their children (Liang et al., 2025). They genuinely enjoyed motherhood and spending time with their children, knowing that it was acceptable to ask for some support when needed (Dugdale et al., 2021). They had more maternal self-efficacy and allowed themselves more time alone to recharge, without needing to mask their difficulties or feeling they were not being 'perfect mothers' (Hwang & Heslop, 2023) (see Chapter 3, Thematic Synthesis, page 49).

The mothers' self-understanding also provided a way to recognise the challenges and strengths that these mothers possessed throughout their lives as they grew up as undiagnosed autistic people (Pagnier & Moualla, 2024). They acknowledged their need to adapt and develop self-acceptance to enable them to manifest pride in being 'different' (Turowetz et al., 2024). As well as acquiring a better understanding of their unique differences, they also acquired an enhanced awareness of their children's emotions and behaviour (Dugdale et al., 2021).

All participants described having a special connection with their autistic children, insight into their thoughts and feelings, and an intuitive awareness of their needs (Crompton, Ropar, et al., 2020) (see Chapter 3, Thematic Synthesis, page 50). The mothers discussed their intense, unconditional love for their children and found motherhood a wonderful experience (Dugdale et al., 2021). This connection occurred immediately for some mothers, while others, like Chayana, said it developed over time (NCT, 2016). Bridget's relationship with her son was extremely close,

and when their needs occasionally clashed, they would learn from those experiences and discuss how they felt (Kulasinghe et al., 2022). Following those rare instances, they learnt valuable information about each other's triggers and the support they needed (Pagnier & Moualla, 2024).

Autistic parents may develop a better understanding of their autistic children in comparison to non-autistic parents (Murphy, 2021). Having a similar communication style is beneficial for creating a long-standing, close relationship (Chen et al., 2021) (see Chapter 3, Thematic Synthesis, page 50). The mothers believed that they could better respond to behavioural cues from their autistic children and instinctively tell when they were becoming overwhelmed or upset, as well as what type of support was required (Garcia-Molina & Cortes-Calvo, 2025). Understanding sensory processing difficulties was an advantage, as the mothers' own experiences helped them assess which sensations might upset their children and what coping strategies would soothe them (Murphy, 2021). Without any knowledge of their autism, mothers' preference for routines had proven to be a strength following the birth of their children, as it had helped their babies settle into a predictable schedule (Hampton et al., 2021). The participants' periods of introspection were used to ensure a healthy, flexible flow of thought in their family's decision-making (Williamson et al., 2023).

Many of the mothers, including Diane, Eva, Ivy, and Georgia, believed that they were instinctively able to support their children by employing more individualised autism-specific strategies and interaction techniques (Adams et al., 2021). Many also said that their atypical sensory processing had enabled them to be more perceptive of their child's needs (Talcer et al., 2021). Participants seemed to have developed extreme empathy for their autistic children and an instinctive understanding and ability to meet their children's needs, which was described as being overwhelming at times (Sarah Hampton et al., 2022). Their unique insight, bond, and ability to relate, resulting from their similar neurotype, have been seen as key to providing a level of parenting only achievable by autistic parents (Dugdale et al., 2021) (see Chapter 3, Thematic Synthesis, page 50).

A small quantitative research study suggested that levels of parenting stress and well-being of autistic families were not significantly different in those where the parents were autistic or non-autistic (Adams et al., 2021). However, these findings did not capture some qualitative reports of autistic parenting, which have highlighted the intense parent-child bonds and the benefits to

autistic children when they can grow up in autism-affirming family homes (Dugdale et al., 2021) (see Chapter 3, Thematic Synthesis, page 50). Prince (2010) described the clear advantages of being an autistic parent, such as the ability to notice their autistic child's stress responses to hostile environments. The participants felt that they were better able to empathise with their autistic children because they were also autistic (Murphy, 2021). This contrasts with historical research that suggested autistic people had weak theory of mind skills and poor empathy (Baron-Cohen et al., 1985). Indeed, other researchers have also viewed empathy as a benefit of autistic parenting (Dugdale et al., 2021).

Being autistic was beneficial for the participants, as they had first-hand knowledge of similar experiences to those of their autistic children, enabling them to empathise and support them (Sedgewick & Douglas, 2023). The mothers, in particular Eva, became advocates for their children, which included explaining or translating any problems to others or mediating conflicts (Rabba et al., 2025). They were able to do this successfully because they were also autistic and had experienced similar issues (Heyworth et al., 2023). Therefore, for our participants, a shared neurotype between themselves and their children appears to have been beneficial, as they had a special connection with their children, which transcended the norm of parenting (Onaiwu, 2023).

This final superordinate theme explored the mothers' determination to create a positive neurodivergent family environment for their children, where their autistic behaviours would be accepted and understood. The mothers described some of their own experiences of childhood and adulthood before they were diagnosed. They recalled how, after their diagnosis, they had reframed these experiences in light of their new knowledge and understanding of their neurodivergence. They also discussed their attempts to shield their children from similar experiences and their determination to provide a more loving and stable upbringing. Finally, the mothers revealed how they felt their family had benefited from creating an 'authentically' autistic family home.

CHAPTER 10 CONCLUSIONS

In this chapter, I describe my conclusions to the four research questions listed in Chapter 4, page 60. This chapter is followed by Chapter 11, which presents the limitations of this research study. Finally, Chapter 12 suggests some recommendations derived from my analysis of the participants' lived experiences of motherhood.

Research Question 1: What challenges do undiagnosed autistic mothers experience when transitioning to new motherhood?

Without the knowledge that they were autistic, the mothers in the study struggled to understand their strengths and challenges. The challenges they experienced included heightened sensory reactivity, particularly to auditory stimuli such as their newborn babies' crying, noisy toys, and children's television programmes, as well as to tactile stimuli, including breastfeeding or chestfeeding. When the mothers became overwhelmed by unpleasant sensory stimuli, they would experience meltdowns. Some of the mothers described their initial discomfort while breast/chest feeding their newborn babies, and how they felt overstimulated and overwhelmed. One participant's initial experience had been made worse when her midwife tried to help her baby latch on to her nipple without previously asking for permission to touch her. The mothers described their focused determination to breast/chest feed, as they knew it was the healthiest option for their child, and ultimately found it to be a positive experience. For two of the mothers, this determination enabled them to breastfeed for nearly three years.

During their transition to new motherhood, the participants struggled with sleep deprivation and exhaustion. Autistic individuals have different circadian rhythms and significantly different melatonin levels throughout the day and night in comparison to non-autistic people. For this reason, their sleep-wake cycles differ considerably, and many have insomnia and other sleep disorders in daily life. The additional lack of uninterrupted sleep, caused by their babies waking in the night, would inevitably have reduced the mothers' emotional control during this critical transition period. Executive functioning is significantly impaired by lack of sleep and sensory overwhelm, so it may have affected the mothers' ability to control their impulses, focus attention, and stay organised during this early stage of parenting.

All the autistic mothers in this study had given birth to at least one autistic child while they were still undiagnosed. Autistic children are, in general, significantly more challenging to care for than non-autistic children, due to their additional emotional and behavioural difficulties; issues with sleeping, feeding, and social interaction; and the battle to obtain relevant support for their education. Trying to meet all the support needs of a young autistic child would have been difficult, as they may often lack a basic sense of danger, struggle to regulate their emotions, be prone to sudden and explosive 'meltdowns', and avoid social interaction with others. The mothers mentioned that their autistic babies would cry whenever they were separated from them, so they would continually hold their babies or carry them in a sling, even while doing housework. They found it hard to settle their babies to sleep, but the guidance they received from health visitors, parenting books, and the internet suggested that the mothers should get their babies used to sleeping on their own by leaving them to 'cry it out'. Many of the mothers were instinctively aware that their children had high support needs, long before they were diagnosed, so they decided to co-sleep with them. They were aware that this strategy was controversial, but the solution had worked for their family.

For the mothers, doing everything they assumed was expected of them and overlooking their own needs, left little room for relaxation. Before becoming mothers, the participants' most effective strategy for managing overwhelming sensory stimuli or prolonged social interaction was to remove themselves from the situation. They would find a comfortable, safe space where they would have some downtime to unmask, regulate their emotions, and stim. However, the mothers believed they needed to be attentive to their children at all times, which meant they were unwilling to take regular breaks when needed. Not taking enough time to recover and recharge may have negatively affected their emotional regulation and executive functioning and increased the likelihood of mental health problems such as anxiety and depression.

Research Question 2: How does receiving a late diagnosis of autism impact a mother's maternal self-efficacy?

Following their diagnoses, all ten mothers began to recognise their strengths and challenges, discovered effective coping strategies, and became more self-compassionate. The mothers' diagnoses had made them aware of their sensory sensitivities and other difficulties. It provided an opportunity to obtain effective coping strategies from the online autistic community that did not rely on having to mask their feelings and discomfort. The mothers asked for support when they

needed some downtime from situations that could potentially overwhelm them and trigger a meltdown. They found that taking a break from their children's noise and tantrums significantly improved their well-being. As their children grew older and became more self-sufficient, some of the mothers were able to retreat into a quiet area of their house or spend time pursuing their interests. For some mothers whose autistic children required constant supervision for safety, peaceful activities like reading, drawing, or spending time in nature offered a calmer way to spend time together.

As the mothers developed insight into their sensory and social needs, they started to limit what they would say 'yes' to, whether this was taking on extra responsibilities for the family or socialising with friends and family, particularly when a situation might potentially create unbearable stress or entail too much masking and sensory issues for them. They were more willing to justify and explain their challenges, such as the anxiety they experience when socialising in large groups. This self-awareness significantly enhanced their confidence and ability to advocate for themselves, ultimately improving their well-being and quality of life.

Their newfound self-awareness also made them more confident in their parenting decisions and deepened their understanding of their autistic children, as well as themselves. Having discovered their own autistic identity, they were better able to appreciate the strengths and challenges of their children. They were able to distinguish when their autistic child was having a meltdown triggered by sensory overload from when they were just being naughty or pushing boundaries.

Following their diagnoses, most of the mothers' relationships with their autistic children got closer. They felt a deep connection with them, which they believed was a consequence of their shared neurotype. They were able to discuss autism and neurodiversity, using their own lived experiences to guide them, and shared their emotions honestly and openly. The mothers spoke about how beneficial this type of open communication was, as it encouraged them to work together as a family to support each other through their difficulties. Many of the mothers spoke about their determination to ensure their autistic children were given the best support available and their commitment to advocating for their children's needs in the future. They described how, on occasions when the mothers became overwhelmed, they were able to effectively model their coping skills to their children, who would subsequently use those same skills themselves when required.

While transitioning into new motherhood, the mothers' masking had affected not only their mental health and well-being but also, to a degree, their capacity to appreciate the joys of parenting fully. Following their diagnosis, they started to accept their limitations and stopped comparing themselves and their parenting ability with neurotypical mothers. They believed that their new identity had a positive impact on their experience of motherhood, made them more confident in their parenting ability, and increased their understanding of themselves and their children. Recognition of their needs may also have helped them to start ameliorating the impact of internalised stigma and to stop blaming themselves for their children's differences.

Research Question 3: How do family members respond to an autistic mother's disclosure of their diagnosis?

All ten participants disclosed their new autism diagnosis to their family members within their household, including their partners and children who were old enough to learn about autism. Nine of the mothers were living with partners at the time of the interviews. For most mothers, the outcome of disclosing their new autistic identity to their husband or partner was positive. They reported that having another person who understood their specific needs was important to them. Support from partners, both emotional and practical, helped them minimise their masking, allowing them to live an authentic and more comfortable life. Unfortunately for one mother, the reaction from her husband was not so positive, as he had only known the 'masked version' of his wife and was not comfortable with her 'unmasked version'. All ten autistic mothers had at least one autistic child, and the mothers' disclosure fostered understanding and empathy among the majority of the children. They discussed the strengths of being autistic, rather than just describing the challenges and relying on deficit-based information from professionals and widely available reference books. However, the autistic son of one mother was totally against the idea that he was autistic and wanted to be like the rest of his friends. Only two households had a non-autistic child; one of whom was only four years old. The other non-autistic child was a 16-year-old boy who was dismissive of both his mother's and his two younger brothers' autism diagnoses. He refused to acknowledge the challenges his family faced and needed support for, feeling like "the outsider".

In addition to disclosing to their partners and children, most participants also felt it was essential to share the news of their new autistic identity and diagnosis with parents and siblings with whom they maintained regular contact. However, the parents of three of the mothers were no longer alive, and three had chosen not to inform them of their diagnoses. Two of the participants needed

their mothers to accompany them to their autism assessments to provide their developmental history. One was relieved that her mother had been so compassionate during her diagnostic assessment and was happy to count on her for support when needed. The other participant's parents had been disappointed when she had been diagnosed, as they thought that she had acquired a label for herself, even though they had provided a developmental history and agreed with her diagnosis. For the remaining two participants in the study, one set of parents were initially against their daughter being diagnosed, but eventually came around to the idea; however, the other set refused to believe that their child's diagnosis was correct and did not understand its significance. The participant was extremely upset by their reaction, and it had put a strain on their relationship. Five of the participants had close relationships with their siblings, with whom they shared information on their new diagnosis. Although some of these siblings lived a long distance away, they still became a source of support and understanding for the participants.

Most of the mothers were far less comfortable sharing their new autistic identity with their extended family. As they generally had not spent as much time with these relatives, they worried that they may be more judgmental of their autistic behaviours and support needs. Only two of the mothers told all members of their family, including their extended family. The other eight participants chose to disclose to their relatives more selectively and therefore had to conceal this information from particular family members when they got together. They had to self-monitor their interactions, modifying them when necessary, while keeping track of where and to whom disclosure had been made. Therefore, they had to mask even more than when they were just with immediate family.

The two participants who disclosed to their extended family assumed that, even if some of their relatives may not be supportive at first, their disclosure would eventually enable them to be more accepting over time and would lead to more genuine social interactions. One of the pair had correctly anticipated that sharing her recent autism diagnosis would prompt some of her relatives to question whether they were also autistic. Unfortunately, when the other participant disclosed their new autistic identity to their large Roma family, their relatives were not understanding or supportive at all, even after they tried to explain and educate them about autism. In Roma culture, the traditional gender role for mothers requires them to act "saintly in your struggle", to prioritise the family's needs, and not to expect support from other family members. The participants'

relatives found their disability even more threatening once it was validated by a health professional and used their diagnosis to undermine their judgment and infantilise them.

Research Question 4: What are the perceived benefits of living in an ‘authentically autistic’ family home?

The autistic mothers’ own lived experiences enabled them to accept and understand their children’s unusual behaviours more readily and to value their neurodivergence. They were also more inclined to perceive many of their children’s autistic behaviours as strengths or neutral, while others may have referred to them as ‘problematic’, as their judgement would have been more likely to be based on neurotypical expectations of behaviour and etiquette. Raising their autistic children in households that understood and accepted neurodiversity allowed them to grow up in safe and nurturing environments that were empowering and supportive, encouraging the development of a positive neurodivergent self-identity.

The mothers felt that their children’s behaviours, such as their stims, were part of who they were. They did not want their children to feel ashamed or try to hide them away, especially not in the family home. The participants hoped every autistic member of their household would be able to unmask at will and to engage with their authentic selves more regularly, which they believed would improve their mental health, quality of life, and well-being. The participants aimed to create a family atmosphere where every child felt appreciated for who they were, received abundant love and affection, recognised that being autistic was nothing to be ashamed of, and took pride in their strengths while receiving support for their challenges. All these qualities would contribute to a safe and accepting home environment.

A significant benefit of autistic children having autistic parents is that they can discuss autism through the lens of their own lived experiences, fostering understanding and empathy between them. The children could talk about their emotions, which helped them manage their daily challenges. The mothers who had teenage autistic children at the time of their interview had been encouraging them to follow their dreams and passions in an attempt to help them find their path in life. By incorporating their autistic child’s passions into their educational material and career aspirations, they felt that they were helping them pursue a related career or academic discipline in which they would thrive.

Most of the participants talked about parenting as a gratifying relationship that brought them genuine joy. The mothers discussed their intense, unconditional love for their children and found motherhood a wonderful experience. They described having a special connection with their autistic children, insight into their thoughts and feelings, and an intuitive awareness of their needs. The mothers described having a similar communication style and could better respond to behavioural cues from their autistic children. They could instinctively tell when their children were becoming overwhelmed or upset, and what type of support would be required. Many of the mothers believed that they were able to support their children by employing more individualised autism-specific strategies and interaction techniques. Participants seemed to have developed extreme empathy for their autistic children and an intuitive understanding and ability to support them when they were distressed or overwhelmed. Their unique insight, bond, and ability to relate, resulting from their similar neurotype, were seen as key to providing a level of parenting only achievable by autistic parents.

Being autistic was beneficial for the participants, as they had first-hand knowledge of similar experiences to those of their autistic children, enabling them to empathise and support them. As well as acquiring a better understanding of their unique differences following their late diagnoses, they also acquired an enhanced sense of their children's emotions and behaviour. Understanding sensory processing difficulties was an advantage, as the mothers' own experiences helped them assess what sensations may upset their children or what coping strategy would soothe them. The families learnt valuable information about each other's triggers and the support that would be needed. Having experienced similar struggles, the mothers were able to pass on their skills, experience, and positive outlook to their children whenever they encountered comparable issues.

The mothers became advocates for their autistic children, which included explaining or translating any problems to others or mediating conflicts. They were able to do this successfully because they were also autistic and had experienced similar issues. Therefore, for our participants, a shared neurotype between themselves and their children seemed to have been beneficial, as they connected with their children uniquely and powerfully, transcending the norm of parenting.

CHAPTER 11 LIMITATIONS

The findings from this study do not claim to represent the views of all autistic mothers. However, they provide important insights into the experiences of autistic motherhood for seven women and three gender-diverse individuals. Two of the mothers were from an ethnic minority group: one was Asian Indian, and another was Roma. The criteria for inclusion were English-speaking mothers, living in the UK, and diagnosed with autism in adulthood (without LD or language delay, Asperger profile). Undiagnosed or self-diagnosed mothers, or those diagnosed in childhood, were not represented. The findings do not represent experiences of autistic mothers living in other parts of the world or with multiple intersecting identities, as they may differ significantly due to cultural, economic, and social issues.

Autistic mothers who lacked access to, or the skills and confidence to use, technologies such as the internet, computers, or smartphones would not have been able to participate in this study. Additionally, individuals who could not afford these devices and internet access or lacked trust in online services could not have participated due to the interviews having been conducted online via MS Teams.

Another limitation of the study is that the participants were recruited from two private Facebook groups whose members had to be autistic (either diagnosed or self-diagnosed). Therefore, the mothers were already in contact with other autistic individuals via social media. This may have impacted some of the qualitative findings, particularly those related to the second superordinate theme, Autistic Identity Development. However, as the recruitment took place in early 2022, when the country was under COVID-19 restrictions, many autistic people were reaching out to the autism community online, rather than attending local autism social or support groups.

In retrospect, another data item I should have requested from the participants and recorded was the number of years between when they realised that they may be autistic and when they received their diagnosis. Diagnostic waiting times have always varied substantially across the country; however, assessments were either suspended or restricted to online-only completion during the COVID-19 pandemic. This may have added another dimension to the study's findings.

As an autistic autism researcher with 'insider experience' of the phenomena that I was studying, my interpretations and my writing of this dissertation were limited by, and situated by, my knowledge and my experience of the world. However, I feel that my insider knowledge helped me to relate to and understand the experiences the participants described, thus providing meaningful insight and ensuring that the potential for misunderstandings, due to the double empathy problem, were reduced (Milton et al., 2022). I listened closely to my participants' narratives and interpreted how they made sense of their lives, while ensuring their interests and views were accurately represented.

Understanding the context within which autistic mothers have been framed provided the opportunity for greater appreciation and validation of the experiences of this underdiagnosed group, who were completely disregarded until recently. Notwithstanding the limitations mentioned, this research has made a novel contribution to making the narratives of autistic mothers more visible so that health and social care professionals may improve their understanding and support.

CHAPTER 12 RECOMMENDATIONS

I have listed several recommendations that have evolved from the findings of this study. Hopefully, they may assist staff working in areas such as clinical assessment, education, and support services in improving their engagement with autistic individuals of all genders throughout their life course.

- Directly after an individual's autism diagnosis, they should be provided with relevant information about autism, including a description of what autism is and how it may affect them, as well as appropriate sources of further information, such as social groups, helplines, local voluntary groups, autobiographical books on autism, useful websites, blogs, and social media groups (Kelly et al., 2024).
- Community or local support is needed for newly diagnosed adults and children to help them make sense of their experiences and adapt to their new identity (Harmens et al., 2022). Support service staff should help to develop an empowering and positive autistic identity by introducing the concept of neurodiversity. This type of community support is vital in protecting mental health and reducing self-harm and suicidality in the autistic community (Botha & Frost, 2018).
- Counselling or psychotherapy should be offered to those receiving a late adult diagnosis of autism, especially when co-occurring mental health conditions, childhood trauma, neglect or abuse are indicated, since the identification may be traumatic for some (Kelly et al., 2024).
- Health and social care professionals must be aware that many autistic women and gender-diverse individuals may be undiagnosed or misdiagnosed with mental health conditions, such as borderline personality disorder (BPD).
- Due to the highly heritable nature of autism, health and social care professionals should consider that, if a person has a close relative who is autistic, the likelihood of that person also being autistic is high, even though they may not be aware of their condition (Thapar & Rutter, 2021).
- There is an urgent need to train health and social care staff, particularly health visitors, to

accommodate the needs of autistic individuals, whether diagnosed or undiagnosed, as recommended by the National Institute for Health and Care Excellence (NICE, 2017). More up-to-date training programmes need to be co-produced to raise awareness of autism, particularly in women, gender-diverse, and ethnic minority groups (Suhrheinrich et al., 2024).

- Health and social care professionals must be aware that some autistic people, whether undiagnosed or not, may experience hypersensitivity to touch and therefore should only be touched with their verbal consent.
- Autistic people have suggested that research and investment should focus on effective public services, including the development of social care for autistic adults (Pellicano et al., 2014).
- The agency and identity of autistic parents in caring roles, for example, looking after elderly relatives, need to be recognised. Being a carer can significantly impact health and stress levels (Gellini & Marczak, 2023). The NICE guidelines acknowledged that autistic adults who act as carers need to be supported (NICE, 2012).
- More autism-friendly environments and events should be developed, thereby minimising the necessity for autistic people to mask their behaviours (Sedgewick et al., 2022).
- Professionals should acknowledge the diverse traditions, languages, and customs of marginalised groups of autistic individuals. This ideally should involve connecting with local voluntary groups in a culturally appropriate way (Maye et al., 2022).
- Further research should be carried out on autistic parenthood in all groups, including fathers and marginalised groups, such as those who identify as LGBTQIA+, from ethnic minorities and multiply marginalised individuals.
- An exploration of autistic mothers' approaches to parenting their non-autistic children compared to their approaches to parenting their autistic children would be an intriguing topic of study (Sutcliffe-Khan et al., 2024).

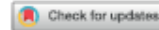
APPENDICES

Appendix A Published article

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OPEN ACCESS



Sense-making narratives of autistic women diagnosed in adulthood: a systematic review of the qualitative research

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ABSTRACT

Few qualitative studies have explored the lives of autistic women diagnosed in adulthood, despite this knowledge being essential to inform awareness of the intersection of autism and gender. This systematic review was undertaken to synthesise available qualitative evidence on the lived experience of autistic women diagnosed in adulthood. The accounts of 50 women from nine qualitative studies were synthesised using thematic analysis and four super-ordinate themes were identified: wanting to 'fit in'; making sense of past experiences; developing a new 'autistic identity'; and barriers to support. The autistic women spent many years without a diagnosis or autism-specific support, felt misunderstood, and experienced social exclusion. Following their diagnosis, they reframed these experiences into new 'sense-making narratives', used social media to contact other autistic people, and developed neurodiverse-affirming autistic identities. The studies suggested that health and social care professionals were not always able to recognise, refer, diagnose, and support autistic women effectively.

ARTICLE HISTORY

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KEYWORDS

Autism; neurodiversity; intersectionality; affirmation model; sense-making; systematic review

Points of interest

- In childhood, the autistic women who participated in the nine reviewed studies remembered feeling that they were 'weird' or 'alien' and being bullied due to their difficulties with socialising
- These participants imitated their more 'easy-going' friends in social situations to keep up appearances and look as if they were in control
- After their diagnosis, the autistic women felt more able to be themselves, rather than trying to be the 'ideal' person that others expected them to be

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- The women who participated in the studies believed that, if they had been diagnosed in childhood, they would have coped better with dangerous situations they had encountered during their lives
- Most of the women in the studies felt proud of their autistic identity and the success they had achieved, despite the number of challenges they had faced

Introduction

The researchers carried out this systematic review to explore what the findings from primary qualitative studies may reveal about the lived experience of autistic women diagnosed in adulthood, drawing on neurodiversity and intersectionality as their theoretical framework. This framework supported a critical interpretation of the experiences of the autistic women from the reviewed studies, that stemmed from an intersection of their gender and autistic identities.

Currently, there is no reliable and definitive diagnostic biomarker for autism, and so diagnosis is based on a set of behaviours which must include difficulties with social interaction and restricted, repetitive behaviours and interests which cause significant issues for an individual (WHO 2018). Without a biomarker, diagnosis is more subjective and open to interpretation by clinicians. Although people with these set of behaviours have been around since the dawn of humanity, new disciplines emerged during the last century, such as child psychiatry, that classified and managed the behaviour of the population according to normative measures (Foucault 1975). The construction of 'autism' placed a boundary within a continuum of behaviours and separated out the traits considered 'normal' and 'abnormal' (Molloy and Vasil 2002; Nadesan 2013).

When the additional autism category of Asperger syndrome (AS) was classified in 1992, the number of people diagnosed in Europe and North America increased due to the medicalisation of 'atypical' behaviours in people without a learning disability (Conrad 2007; Wheeler 2011; WHO 1992). This rising prevalence contributed to an increase in autism awareness, the availability of assessment centres and autism services, and diagnostic switching from other developmental and psychiatric conditions to autism (Russell 2021). Media interest in neurodiversity, autobiographies of autistic people, and fictional accounts increased the likelihood that a person may consider an autism diagnosis as an explanation of their differences (Hacking 2009; Russell 2021; Russell et al. 2015). This subsequently meant that even more people got diagnosed, creating a 'looping effect' (Hacking 1995). Furthermore, autism was historically regarded as a very rare condition of childhood, mainly occurring in boys, whilst now it is considered to be a lifelong neurodevelopmental divergence occurring in all genders (Brugha et al. 2011).

Autism, without a learning disability (LD) or language delay, previously known as AS, was categorised in 1992 (WHO 1992). Consequently, autistic women

without an additional learning disability or language delay, who had been at school before the early-1990s, were unlikely to have been diagnosed during their school years. Although autism is now known to be a lifelong condition, with similar prevalence rates in all age groups, it was historically understood to be a condition of childhood (Brugha et al. 2011). As autism was thought to affect predominantly young boys, many autistic women remained undiagnosed for decades without any autism-specific support (Brugha et al. 2016). It may be that women, who decide to seek a diagnosis later in life, are able to understand themselves better and make more sense of their experiences. Exploring the lived experiences of autistic women who were diagnosed in adulthood is essential for conceptualising potential avenues of support, yet their 'voices' have been largely missed, as few qualitative studies have been undertaken in this group (Milton 2014). A roundtable report identified gaps in autism research and specifically highlighted the lack of knowledge about autistic women and the small numbers of women included in research studies (Howlin et al. 2015). Feminist disability studies emphasise the importance of all women's voices being brought to the forefront, especially in research where their experiences have traditionally been dismissed and misrepresented (Garland-Thomson 2005; Piepmeyer, Cantrell, and Maggio 2014; Wendell 1989).

While writing this review, the researchers chose to use identity-first language rather than person-first language, for example the term 'autistic person' instead of 'person with autism', as this is the terminology that most of the autistic community in the UK prefers (Kenny et al. 2016; Sinclair 2013). Person-first language has been generally rejected by this community as autistic people do not wish to be disassociated from their condition, as if it is somehow shameful. The terminology used is important, as it shapes people's assumptions and beliefs. Many self-advocates have re-appropriated identity-first language, once used to evidence 'pathology', in a positive way (Bottema-Beutel et al. 2021; Gernsbacher 2017). The term 'autism' has also been used as a shorthand version for 'autism spectrum condition' without learning disability or language delay, which was the set of behaviours previously categorised as Asperger syndrome (WHO 1992).

This systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO Registration number: CRD42017084079).

The positionality of the first author

The first author's interest in autism and neurodiversity started eight years ago, when her son was diagnosed with autism and attention deficit hyperactivity disorder (ADHD). She enrolled on a Post-graduate Certificate in Autism and Asperger syndrome at Sheffield Hallam University and it was during a lecture that it suddenly struck her that her son's apparently 'atypical' behaviour was very similar to her own. She was eventually diagnosed with autism and ADHD at the age of 50 years old. The diagnosis explained many of the difficulties, as well as

strengths, she had experienced throughout her life, but particularly in her teenage years when she dropped out, had mental health and substance abuse issues, and attempted suicide. However, she managed to gain her academic qualifications as a mature student on a part-time, distance-learning basis whilst working full-time. In 2017, she started a part-time Professional Doctorate in Health Research at the University of Hertfordshire, and this review was undertaken during this programme. She still works full-time at the UK Health Security Agency (formally known as Public Health England) as a senior scientist coordinating a quantitative survey of people living with HIV in the UK called Positive Voices. Since February 2020, she has also been assisting in the production of the daily COVID-19 surveillance figures as part of the public health response to the pandemic.

Positionality, along with reflexivity, are critical examinations conducted by feminist researchers which are used to reveal their position in the complex hierarchies of power within society. Having conducted this review as part of her doctoral studies with insider experience of the phenomena explored, her interpretations of the data and writing have been limited by, and situated by, the knowledge she has learnt and her experiences of the world (Haraway 1988; Willig 2013). However, this knowledge has helped her relate to and understand the experiences and emotions that the participants in the articles described (Chown et al. 2017; Fletcher-Watson et al. 2019; Milton 2014; Woods et al. 2018). Feminist research encourages this type of insider research and criticises the way positivist approaches emphasise objectivity and neutrality (Franks 2002; Frost and Holt 2014). She believes, as many feminist scholars do, that maintaining a completely objective stance to a research matter is not possible, or even appropriate (Willig 2013). As qualitative research necessitates a researcher's involvement and so, to yield any worthwhile insight into participants' lived experiences, it cannot be done in a neutral or disengaged manner (Madill, Jordan, and Shirley 2000). She has attempted to use her own experience of acquiring an autism diagnosis in adulthood to enrich her interpretations, rather than thinking of it as a bias needing to be eliminated or 'bracketed out' (Bertilsson Rosqvist et al. 2019; Frost 2016).

As subjectivity is an inevitable part of research, the first author maintained an ongoing process of reflexivity throughout this systematic review. Reflexivity is a critical examination of how one sees the social world and understands the relations between content, context and consequences of knowledge that arise from the research process (May and Perry 2017). 'Reflexivity is not just about the ability to think about our actions—that is called reflection—but an examination of the foundations of frameworks of thought themselves' (3). She considered her motivation and reasons for conducting this review and how these may have affected her interpretation of the findings. She kept a reflexive journal from the beginning of her doctoral programme in which she recorded her thoughts and questions about the research, decisions made, challenges addressed and critical themes that she identified (Finley 2002). Whilst writing, she became more aware of her own assumptions and beliefs, as well as the

context that surrounded the studies, and how they related to her research interpretations (Frost 2016). She confesses to having developed a positive autistic identity following her own autism diagnosis and is pleased that there are other autistic women who have experienced similar diagnostic journeys to her own. However, she made sure that the interests and views of the study participants were expressed, thus mitigating the risk of bias associated with the subjectivity in the review (Bertilsdotter Rosqvist et al. 2019).

Theoretical framework: neurodiversity and intersectionality

The researchers' understanding of autism was shaped by the theories of neurodiversity and intersectionality. These perspectives underpinned and informed the process and interpretation of the data in this review.

Neurodiversity

'Neurodiversity' was first described in the literature by Singer (1999) who proposed the concept for intersectional analysis. It was based on biodiversity that describes how ecosystems benefit from having a wide variety of life, for example by making them more resilient and sustainable. The behaviours of neurodivergent individuals, including autistic people and those with other neurodevelopmental conditions such as ADHD and dyslexia, may be more extreme when one considers the distribution of sensory, affectual and cognitive processing within the general population (Murray 2020). Although the minority of the population may diverge strongly from the 'norm', they should still be recognised and respected as a natural expression of human diversity that fills an 'ecological niche' in society (Blume 1997; Singer 1999). Autistic people can bring many complementary and beneficial skills to a community, particularly if it values and promotes diversity by moving beyond essentialist binaries of 'us' and 'them' (Chapman 2020; Runswick-Cole 2014).

The neurodiversity paradigm, in line with the social model of disability, challenges the medical model which links autism to a specific stigmatising 'deficit', laden with negative beliefs about restricted abilities and limited potential (Gillman, Heyman, and Swain 2000; Goffman 1963; Ho 2004). These negative attitudes are a form of psycho-emotional disablement that can significantly impact on the emotional well-being and self-esteem of autistic people (Milton and Moon 2012; Reeve 2004; Watermeyer and Swartz 2008). Humanity is neurologically diverse but propositions about normality still assume an ideal, male, white, neurotypical person - defined as a 'normate' by psychologists within the eugenics movement (Garland-Thomson 2017). Autistic people are stigmatised because they exhibit behaviours that currently deviate from the 'norm', so are treated as 'other' and in need of 'treatment' (Scuro 2017; Wolbring 2008). However, to say that there exists a 'normal' human with a 'normal' brain is no more valid than there being a 'normal' ethnic group, gender, or class (Crow 2017; Walker 2014).

Proponents of the neurodiversity movement, particularly autistic activists, have reclaimed autism for their own and promote diagnosis in a less pathologised form (Kapp 2020; Thibault 2014). Autistic activism emerged in resistance to the medical model discourse depicting autism as a deficit and argued for autism as an identity that should not be cured or regarded as a tragedy. However, autistic people may require support in order to lead a fulfilling life in a world in which they experience specific and nuanced forms of social oppression (Baker 2006; Castells 2009; Shakespeare 2010). The neurodiversity movement challenges autism research funding that primarily focuses on aetiology, screening, treatment, prevention, and cure. They have shifted attention to research aimed at critically understanding and improving autistic experiences, quality of life and decreasing health care inequalities (Kapp et al. 2013; Raymaker and Nicolaidis 2013; Robertson 2009).

Autism advocates also reject functioning labels associated with autism, as they feel that those given the 'low-functioning' label may be devalued and those given the 'high-functioning' label may not be considered for the support they need (Milton and Moon 2012). Clinicians usually distinguish levels of functioning using standard intelligence tests, however these tests have been shown to underestimate autistic intelligence, so their usage may lower expectations and deny autistic people access to appropriate educational support (Dawson et al. 2007). Furthermore, distinguishing between levels of functioning is misleading as the functioning of a person fluctuates depending on the context, for example their perception of control over and inclusion within their environment, their emotional state, other people's expectations, and what support has been provided (Beardon 2017; den Houting 2019; Murray 2009).

This process of resistance and redefinition has started to reshape the autism landscape into a more progressive and less stigmatising one (Gobbo and Shmulsky 2016). Ultimately, the goal is to reduce discrimination and stigmatisation and create a more compassionate and inclusive world that does not pathologise and dehumanise diverse people (Chapman 2020). The neurodiversity theory has enabled many autistic individuals to regard autism as a cognitive style; not a 'disorder' which must be removed or cured like a disease (Bumiller 2008, 4; Cameron 2014b; Swain and French 2000).

Intersectionality

Within an increasingly complex world, intersectionality theory has developed into a valuable interdisciplinary concept for understanding the shared and the unique complexity of multiple social and cultural identities. Originally conceived as a tool for analysing black women's oppression in America, intersectionality is now widely used in social sciences (Crenshaw 1989; King 1988). In intersectionality theory, when a person is a member of more than one marginalised group, they intersect to create a group with a qualitatively unique experience of oppression that is different to the combination of the original

groups. Such a group has its own specific needs and problems, as well as ways of meeting those needs and making their mark, which may differ or conflict with those of the original groups and therefore, their 'distinct voice' needs to be recognised (Begum 1992; Garland-Thomson 2005). Biological and cultural categories such as ethnic group, class, gender identity, sexual orientation, marital status, nationality, disability, age, and religion are considered 'multiple and interlocking' (Bowleg 2012, 1267), allowing people to recognise 'the outcomes of these interactions in terms of power' (Davis 2008, 68).

Historically, disability was often unrecognised in contemporary feminist research; however, this intersection is vital for feminist and general philosophy (Hall 2015). Fine and Asch (1988) suggested that feminists excluded women that were disabled from studies in the past because of fear that they may bolster stereotypical notions of females as dependent. Deep-seated beliefs of female emancipation, independence, and self-sufficiency were the foundation of feminism, but conflicted with the stereotypical view of disabled women (Mohamed and Shefer 2015; Simpson and University of Oxford 2019). In addition, the disabled people's movement historically favoured the representation of disabled males within society (Bê 2014). The barriers associated with female gendered role responsibilities, such as assistance with childcare or looking after elderly relatives in order to enable paid employment, were mostly ignored (Morris 1996; Thomas 1999). When individuals with multiple identities are not even recognised within their identity groups, this is known as 'intersectional invisibility' (Purdie-Vaughns and Eibach 2008). Intersectionality theory seeks to make the less visible or under-recognised, visible and explore the inequalities that result in some individuals being marginalised (Smooth 2013). The union of the theoretical fields of gender and disability has deepened our understanding of gender roles, interdependence, experience of care, lived experience and social justice (Garland-Thomson 2002; Wendell 1989).

Saxe (2017) asserts that an intersectional framework should be used to study the lived experiences of autistic women, who are often disregarded due to the male-biased understanding of the condition that dominates autism discourse. Feminist scholars have described how 'stereotypical autistic traits, and their discursive representations have been culturally coded as masculine rather than feminine' (Davidson 2008b, 660). As men often play the role of autistic characters in literature and in the media, the public seem to find it more difficult to envisage an autistic woman (Murray 2012). Unfortunately, when characteristics of a condition are stereotypical of one gender, there is a risk that clinicians will be biased diagnostically (Hughes 2015).

Neurodiversity and intersectionality provided a valuable framework to explore the experiences, social oppression and psycho-emotional disablement faced by autistic women through the male-biased and ableist discourse around autism (Strand 2017; Thomas 2007).

Methods

Search strategy

Throughout the process of identifying the included studies, the researchers followed the guidelines stated in the *PRISMA Statement of Preferred Reporting Items for Systematic Reviews and Meta-analyses* (Moher et al. 2015). Eleven electronic databases were searched for peer-reviewed primary research: Global Health, Scopus, Embase, OVID Medline, PsycINFO, SocINDEX, Cumulative Index to Nursing and Allied Health Literature (CINAHL), the National Autistic Society database, Social Policy and Practice, Allied and Complementary Medicine (AMED) and PubMed (Figure 1). We used the

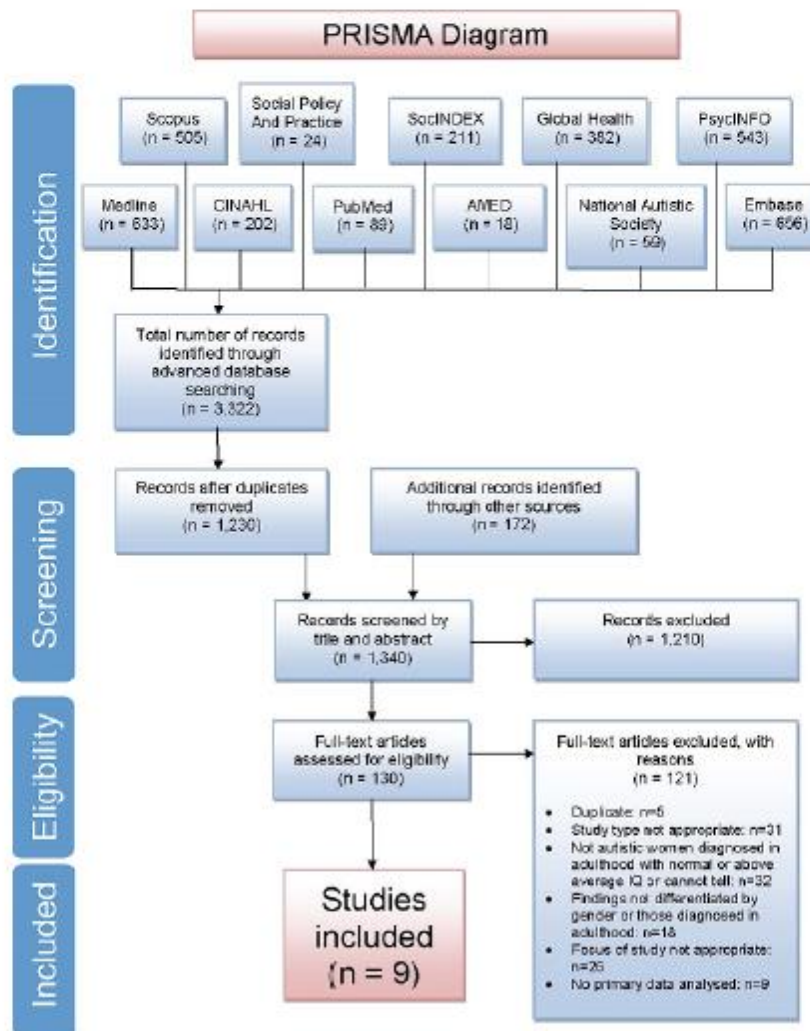


Figure 1. PRISMA diagram for systematic review

search term: (autis* OR asperger* OR AS*) AND (wom* OR female* OR gender). The publications were limited to English language articles dated between 1st January 1943 and 21st August 2020. References were managed in EndNote X9.3.3 software and 3,322 publications were identified from the searches. This broad approach was chosen to allow for the identification of papers that might not otherwise have been found (Boland, Cherry, and Dickson 2017). Staying abreast of newly published articles throughout the course of this review provided a further 172 articles. Duplicates were removed, leaving 1,340 articles available for screening.

The titles and abstracts of 1,340 articles were screened by consulting the inclusion and exclusion criteria (Table 1). The third author (A-TJ) independently screened a random selection of 15% of the articles in order to check for consistency. If any disparities were found and were not resolved, arbitration would have been sought from the first author's two doctoral supervisors: SS and SR. During the title and abstract screening process, 1,210 articles were excluded, leaving 130 articles to be assessed for eligibility by reading the full text of each publication. After SS and SR verified their eligibility, nine articles were classified as 'accepted'.

Table 1. Inclusion and exclusion criteria.

	Inclusion	Exclusion
Period of publication	Between 1st January 1943 and 21 st August 2020	
Study design/type	- Qualitative studies - Mixed method studies	- Publication types without original data, e.g. expert opinions, clinical reports, letters, editorials, comments, reviews, books, book chapters, book reviews, blogs and social media posts, news items, or articles not describing studies on the lived experience of adult women diagnosed with ASD without ID or AS aged >18 years. - Quantitative studies (e.g. randomised controlled trials, comparative, case-control, observational, and cross-sectional studies) - Conference abstracts and dissertations
Study population	Women with a diagnosis of ASD without ID or AS aged >18 years	- Girls or adolescents aged ≤18 years - Women not formally diagnosed in adulthood
Subject matter/focus	Lived experience of women aged >18 years before being diagnosis with ASD without ID or AS, of the diagnostic process itself and/or life post-diagnosis	- Proposed cause(s), medications, interventions, therapies or 'cures' - Evaluation of methods or diagnostic/ screening tools - Lab-based, animal, genetic, biochemical, neurological or molecular studies - Accounts given by parents or carers - Studies not using primary data - Comparison studies with non-autistic controls or between genders - Studies where one cannot differentiate findings by gender and age group of participants

Study characteristics

Whilst the subject matter of the nine included articles were broadly about the lived experiences of autistic adults, their original research topics varied: Bargiela, Steward, and Mandy (2016) investigated the female autism phenotype, Griffith et al. (2012) support needs, Hurlbutt and Chalmers (2004) challenges of employment, Kanfischer, Davies, and Collins (2017) gender and social relationships, Krieger et al. (2012) perceptions of the workplace, Leedham et al. (2020) diagnosis in middle to late adulthood, Smith and Sharp (2013) unusual sensory experiences, Stagg and Belcher (2019) diagnosis in later life and Webster and Garvis (2017) success and critical life moments (Table 2). The countries of origin were mainly from the United Kingdom, with the rest from the United States, Switzerland and Australia. In two of the articles, the ages and age at diagnosis of participants were provided as a range, however the articles confirmed that they had been diagnosed after the age of 18 years of age (Stagg and Belcher 2019; Webster and Garvis 2017).

Three studies used narrative analysis as their methodology, two used interpretative phenomenological analysis (IPA), and the others used framework analysis, thematic analysis, content analysis and grounded theory. While some researchers argue that primary qualitative studies should have similar methodologies to be included within a meta-synthesis, others maintain that combining evidence from different analytical approaches is acceptable (Dixon-Woods et al., 2005). Out of these different methodologies, IPA seems to be the approach that is most suitable for primary autism research as it is committed to viewing people as experts on their own personal world, establishing an 'equality of voice' and promoting the process of reflexivity (Dowley 2016; Howard, Katsos, and Gibson 2019; MacLeod 2019). It focuses on the specific, unique perspectives of each participant, the meanings behind their interpretations, and how they relate to their historical, cultural and societal context (Creswell and Poth 2016).

Data analysis

Thematic analysis was chosen as the methodology for analysing the findings from the nine primary research articles in this systematic review. Thematic analysis is a well-tested technique that encourages reviewers to have an evidential link between their findings and the results of primary studies, using quotes as examples to describe the themes developed, therefore preserving principles that are fundamental to systematic reviewing (Thomas and Harden 2008). The articles were read and reread until the first author (CK) was very familiar with the studies and notes were made about possible themes and concepts that related to the review question, as recommended by Braun and Clarke (2013). To thematically analyse the qualitative findings, digitised pdf copies of the articles were downloaded into the qualitative data analysis software, NVivo Mac Release 1.3, for coding and categorisation.

Table 2. Characteristics of the primary research articles included (n=9).

Author(s)	Title of article	Country	Methodology	Research design/conceptual framework	No. participants in article	Women diagnosed in adulthood			Themes
						No. participants in article	Number of themes	Number of subthemes	
Bargiela, Steward, and Mandy (2016)	The experiences of late-diagnosed women with autism spectrum conditions: an investigation of the female autism phenotype	UK	Framework analysis	This study investigated the female autism phenotype and its impact upon the under-recognition of autism in girls and women in clinical practice. Framework analysis was used to yield hypotheses about this phenotype, to generate new ideas and deepen understanding of key concepts such as camouflaging, and to promote the development of measures to capture both female and male manifestations of autism.	14 (all women but two diagnosed in childhood and two did not contribute in findings)	10	4	19	You're not autistic: labelled with non-autistic diagnosis; Unhelpful professional stereotypes of autism; Quiet at school; so went unnoticed - 'I should have burnt more cars'; Misunderstood, unsupported or blamed by teachers; The costs of a late diagnosis. Pretending to be 'normal': 'Wearing a mask'; learning social behaviours from TV, books and magazines; Social mimicry; The costs of masking. Passive to assertive: Please, appease, avoid conflict; Entrapment in abusive relationships or risky situations; Victim of sexual abuse; Learning to be assertive. Forging an identity as a woman with ASD: Social pressures - what is expected of young women; Friendships - uncertainty and intensity; Hard to be friend with neurotypical girls; Easier to be friend with boys; Friendships and support online; Interests define identity and self-confidence. Some days I do struggle' - living with AS; They don't expect you to have problems with things' - employment issues; I just fall through the gaps between' - experiences with mainstream support.
Griffith et al. (2012)	I just don't fit anywhere: support experiences and future support needs of individuals with Asperger syndrome in middle adulthood	UK	IPA	The research explored what autistic people aged 35 years and over thought of their previous and current support. The researchers used IPA to get an 'insider's perspective' and to explore how the participants made sense of their world.	11 (seven men of whom only six diagnosed, one woman undiagnosed)	3	3	0	Adults wit AS experience frequent unemployment and underemployment situations: Several factors affect employability, including social skills, communication and sensory issues; Recommendations for aiding success in the workplace.
Hulbutt and Chalmers (2004)	Employment and adults with Asperger syndrome	US	Content analysis	This paper was the earliest publication of the nine papers used in the review. Its purpose was to provide information about the participants' employment issues and recommendations for preparing autistic people for successful job experiences. Unfortunately, the paper did not discuss the research design or methodology used in the study	6 (three men and one did not contribute to findings)	2	3	0	

(Continued)

Author(s)	Title of article	Country	Methodology	Research design/conceptual framework	No. participants in article	Women diagnosed in adulthood			Themes
						No. participants in article	Number of themes	Number of subthemes	
Karlischer, Davies, and Collins (2017)	I was just so different: The experiences of women diagnosed with autism spectrum disorder in adulthood in relation to gender and social relationships	UK	Multi-stage narrative analysis	This study used narrative analysis to reveal the life stories of autistic women and to extend existing conceptualisations of autistic experience to include socially and culturally located factors. Its purpose was to enable the marginalised voices of autistic women to be heard and to understand the various multifaceted aspects of their experiences.	7 (although three had ID)	4	2	5	Gender identity: 'I was just so different'; 'I think there's some sort of gender identity thing'; 'I never had any mothering instincts'. Social relationships: 'When I try, the conversation just goes dead'; 'People don't want to know me'.
Krieger et al. (2012)	Becoming a member of the work force: perceptions of adults with Asperger Syndrome	Switzerland	Narrative analysis	The purpose of this study was to gain in-depth knowledge about how autistic individuals assign meaning to contextual and influential factors that occurred throughout their childhood and adolescence and how these factors may have enabled or hindered their participation as adults in competitive employment. The temporal-biographical aspects of the study meant that a hermeneutic, narrative approach was used in the research design, based on Paul Ricoeur's theory of interpretation.	6 (four men)	2	4	9	Social context - To feel socially secure and be familiar with social environments: Mom left me alone without accusations; Through her I met other children in the neighbourhood. Cultural context - To achieve cultural competence: Teachers are for learning and not for relationships; I am open for new ideas but in the end I must experience them as my own. This is not my world but I know the rules of the game; I like my job but I need enough to do to not feel bored. Physical context - To be protected or offended: Working behind a window in the post office protected me. Temporal context - Receiving and disclosing a diagnosis: It became clear - my strange needs are legitimate; There is a subtle black and white thinking in Swiss society. A hidden condition: Pretending to be 'normal' and fitting in; Mental health and mislabelling. The process of acceptance: Initial reactions and search for understanding; Reliving life through a new lens; Grief and reflections on the past. Post diagnostic impact of others: Initial reaction of others; Stereotyped assumptions. A new identity on the autism spectrum: Negotiating relationships, connectors and community; Changing wellbeing and views of the self; The meaning of diagnosis.
Leedham et al. (2020)	I was exhausted trying to figure it out: The experiences of females receiving an autism diagnosis in middle to late adulthood	UK	IPA	This study used IPA in order to focus on the subjective accounts of specific lived experiences of autistic women, including their response to and interpretation of these experiences. The data was analysed via an in-depth iterative process where the researchers engaged in a 'double hermeneutic' process, making sense of how individuals make sense of their world.	11	11	4	10	

(Continued)

Author(s)	Title of article	Country	Methodology	Research design/conceptual framework	No. participants in article	Women diagnosed in adulthood	Number of themes	Number of subthemes	Themes
Smith and Sharp (2013)	Fascination and isolation: a grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome	UK	Grounded theory	Using a modified grounded theory methodology, the study aimed to generate a model describing the nature of the relationship between unusual sensory perception and their effects on the person's internal experience, social life and daily functioning. Semi-structured interviews were conducted with Instant Messaging software. A model was generated revealing how unusual sensory experiences affect the lives of autistic people and describing the coping strategies utilised.	9 (six men)	3	9	18	Heightened senses. Sensory stress: Fear/anger; Attack/escape; Avoidance. Moderating factors: Single versus many inputs; Low intensity versus high intensity; Order versus chaos; Calm versus stressed. The stress avalanche. Coping strategies: Blocking out other inputs; Dampeners; Creating order; Calming strategies. Other people: Source of sensory stress; Negative interactions with others; Positive interactions with others. Isolation. Self-acceptance. Fascination: Pleasurable/calming; Skills/abilities; Long-term pursuits; Distracting.
Stagg and Beldar (2019)	Living with autism without knowing: receiving a diagnosis in later life	UK	Thematic analysis	Interviews were conducted using the free-associative narrative interview technique, where the interviewee was able to guide the direction of the interview, thus allowing the focus and agenda of the interview to change depending on their own experience. Therefore the autistic participants had the freedom to take the interview in the direction they wished. The resulting transcripts were analysed using thematic analysis.	9 (four men and one did not contribute to findings)	4	5	0	Early signs of ASD: Behavioural manifestations of ASD; Education; Experiences in youth. Awareness of being different: Disability; Positive aspects of having ASD; Being different; Ways of seeing the world; Fitting in; Recognising or failure to recognise ASD; Family concerns; Relationship problems; Receiving a diagnosis: Revelation; Negatives of diagnosis; Relief; Stress. The usefulness of a diagnosis: Emotion; The future; Advantages of a late diagnosis; Happiness; Creativity; Confidence; Self awareness; Working life; Work colleagues. Support and coping: Getting older; Modern technology; Social media; Specific ASD help from the authorities; Health care; Support; Government departments. Agents of change. Belief of others in their capability. Changed identity after diagnosis. Mentor to others.
Webster and Garvis (2017)	The importance of critical life moments: An explorative study of successful women with autism spectrum disorder	Australia	Narrative-themed analysis	This study explored the women's experience from a social constructionist perspective, emphasising the social processes by which they developed their social reality, and knowledge about that reality in an ongoing way during interaction with others. The findings captured the emotional nature of the lived experiences of the autistic women involved as they reflected on being successful.	11	11	4	0	

Table 3. Participants from the nine included articles (n=50).

Article	Country	Participant's pseudonym	Age Range (From)	Age Range (To)	Age at Diagnosis (From)	Age at Diagnosis (To)
Bargiela, Steward, and Mandy 2016	UK	P01	23	26	19	22
		P03	27	30	27	30
		P05	22	26	22	25
		P06	27	30	23	26
		P07	19	22	19	22
		P08	22	26	19	22
		P09	27	30	19	22
		P10	27	30	23	26
		P11	27	30	27	30
		P14	27	30	23	26
		Brooke	45	45	35	35
Griffith et al. 2012	UK	Rebecca	54	54	45	45
		Sheila	57	57	49	49
		Daina	56	56	52	52
Hurlbutt and Chalmers 2004	US	Rosalind	43	43	38	38
Kanfisz, Davies, and Collins 2017	UK	Danielle	20	59	20	59
		Emma	20	59	20	59
		Fay	20	59	20	59
		Gemma	20	59	20	59
Krieger et al. 2012	Switzerland	Celestine	30	30	28	28
		Hannah	34	34	32	32
Leedham et al. 2020	UK	Alice	43	64	40	62
		Celia	43	64	40	62
		Elizabeth	43	64	40	62
		Hannah	43	64	40	62
		Kate	43	64	40	62
		Lily	43	64	40	62
		Marie	43	64	40	62
		Merrell	43	64	40	62
		Mia	43	64	40	62
		Olivia	43	64	40	62
		Ruby	43	64	40	62
Smith and Sharp 2013	UK	Lucy	49	49	47	47
		Rebecca	25	25	23	23
		Ruth	30	30	29	29
Stagg and Belcher 2019	UK	Brenda	52	54	unknown	unknown
		Debra	52	54	unknown	unknown
		Linda	52	54	unknown	unknown
		Mary	52	54	unknown	unknown
Webster and Garvis 2017	Australia	Janelle	28	55	unknown	unknown
		Judy	28	55	unknown	unknown
		Julie	28	55	unknown	unknown
		Mary	28	55	unknown	unknown
		Michelle	28	55	unknown	unknown
		Morgan	28	55	unknown	unknown
		Patty	28	55	unknown	unknown
		Peggy	28	55	unknown	unknown
		Robin	28	55	unknown	unknown
		Susan	28	55	unknown	unknown
		Terry	28	55	unknown	unknown

Only quotes and analysed results and interpretations that were specifically associated with 50 of the participants, who were women who had been diagnosed in adulthood, were analysed (Table 3). Data associated with other participants from the studies, such as men and women diagnosed in childhood, were not extracted. When a strand of data related to multiple concepts, it was coded multiple times. When similarities and associations across the

studies were identified, the coded data were grouped into clusters of related concepts. These clusters were identified inductively, and constantly compared and regrouped into sub-themes. Some of the concepts were refined by moving to and from each of the studies to determine how they might relate together. Super-ordinate themes were then developed, enabling the creation of a higher-order interpretation of the translations. The creation of the super-ordinate and sub-ordinate themes were considered by SS and SR and were subsequently approved.

Throughout the data analysis process, the codes, categories, and themes were evaluated for accuracy and clarity. Whenever the researchers felt uncertain about their decisions or findings, they were double-checked to make sure interpretations were firmly grounded in the data.

Thematic analysis

Four super-ordinate themes were identified in the analysis, which are described below.

Wanting to 'fit in'

When the women in the studies described their childhood experiences, they remembered thinking that they were 'weird', 'alien' or 'a different type of human' due to the difficulties they had interacting with their friends (Kanfischer, Davies, and Collins 2017; Leedham et al. 2020; Stagg and Belcher 2019). At school they were bullied and persecuted for being 'odd' and felt lonely and distanced from their peers (Bargiela, Steward, and Mandy 2016; Huws and Jones 2010). Culture determines how one interprets and responds to other people's verbal and non-verbal communication and, in Western European and North American nations (WENA), one can be judged harshly for not giving enough eye contact, not smiling, raising your voice, being too direct and so on. Goffman (1963) argued that individuals are continuously trying to manage the impressions they make during social interactions. Those with the ability to perform well are considered 'normal', while those who exhibit unusual behaviour are considered 'abnormal' and stigmatised as a result (Milton 2013). A woman in Kanfischer, Davies, and Collins (2017) felt that she had been perceived as deviating from the expectations placed upon her:

'... they just ostracised me ... what they called 'sent to Coventry' where no one in the dormitory would speak to me (laughs) because I so alienated them ...It's my reactions, and the way I interacted with people wasn't appropriate ...' (664).

Difficulties with social interaction and misunderstandings frequently occur between autistic and non-autistic individuals, described as the 'double empathy problem' (Chown 2014; Milton 2012). This theory challenges the idea that autistic individuals lack empathy for others and proposes that both

autistic and non-autistic people can misunderstand the feelings and behaviours of the other; after all, social communication is a two-sided affair (Milton 2017). Growing evidence demonstrates that non-autistic people often find understanding autistic people really difficult, are unable to infer their emotional state, and tend to judge them negatively based on first impression (Heasman and Gillespie 2018; Sasson et al. 2017; Sasson and Morrison 2019). 'Acts of invalidation' may occur in the form of disapproving looks or comments, and this psycho-emotional disablism, as described earlier, can have a cumulative negative impact on a person's self-esteem (Reeve 2004).

The women who participated in the studies were unaware that they were autistic during their childhood and adolescence, so they felt compelled to keep up appearances and look as if they were in control. They observed their more 'easy-going' friends and imitated them in social situations, learning their mannerisms and speech, mimicking small talk, and repressed behaviours that others might think were 'weird'. (Krieger et al. 2012; Willey 2015). They described how they had changed their 'persona' or wore a 'mask' as a survival strategy to cover up their difficulties interacting: '[when I] appear sort of normal, that is because of the years of actual effort that I've put into it' (Leedham et al. 2020, 141). 'Masking', also known as 'camouflaging' or 'passing', is a strategy where a person disguises their underlying authentic self and 'passes' as socially competent by using learnt behaviours to act in a 'socially acceptable' manner (Ginsburg and Pease 1996; Kalei Kanuha 1999). However, autistic women often find this lack of authenticity particularly disturbing and damaging to their self-esteem (Foucault 1975; Murray 2020). Masking may also involve suppressing their repetitive movements, known as stims (short for self-stimulation), such as hand flapping or twiddling hair, despite the fact that they can be used as coping mechanisms during stressful situations (Kapp et al. 2019; Lingsom 2008).

Butler (2006) argued that being gendered as a woman is, in itself, a kind of improvised performance. In this patriarchal culture, women are often expected to be socially accommodating by being hospitable, communicative, nurturing and biddable, which may motivate some autistic women to emulate this behaviour (Gould and Ashton-Smith 2011). However, a few women in the review found it hard to envisage themselves in traditional gendered roles that others expected them to fulfil, such as a mother or carer (Bargiela, Steward, and Mandy 2016; Kanfischer, Davies, and Collins 2017). They disregarded these expectations, along with the social construct of gender in general, and adopted more 'personal' gender identities (Butler 2006; Davidson and Tamas 2016). In Kanfischer, Davies, and Collins (2017), a few women described themselves as 'tomboys' and preferred playing with boys when they were younger:

'Girls are sort of bothered about what they're wearing and what their hair looks like and their nails and who's cute in what band ... it's not actually possible for me

to be less interested ... whereas the guys would be mucking about ... something I felt more inclined to be involved with.' (665)

In some locations, such as in the workplace, women often felt a huge pressure to blend in and consequently there was an even greater need to 'mask' in these situations (Russell 2021). In Bargiela, Steward, and Mandy (2016), participants explained that, although masking helped them to interact, it meant that their struggles went unrecognised and so no adjustments were made for them. 'Switching' between masking in different contexts, such as at home, at work and while socialising, was exhausting and detrimental to their sense of self. Social events were stressful, and some women in the studies spent a long time ruminating over conversations afterwards. Many avoided socialising altogether for fear of negative evaluation by others: 'I thought maybe I'm a bad person, I've got a horrible personality, there's something about me people don't like, and I didn't understand why' (Stagg and Belcher 2019, 353). Clinicians may find it difficult to differentiate between autistic masking and the social role ordinarily adopted by non-autistic individuals, but can distinguish the former by the overwhelming intellectual effort required, emotional cost and recovery time needed for an autistic individual to perform their persona (Beck et al. 2020; Russell 2021).

Making sense of past experiences

Most women felt their diagnosis had been a positive experience as they finally understood their uniqueness and were able to make sense of their lives (Haney and Cullen 2017; Leedham et al. 2020; Tan 2018). Following their diagnosis, autistic women initially felt a range of emotions, such as anger, disbelief, shock, and joy: 'A relief, because for years and years everything has been put down to anxiety and depression. Everything from the last 30 years made sense, it just all fitted in and it made sense' (Stagg and Belcher 2019, 353). Many felt proud of who they had become and the success they had achieved, despite all the challenges they had faced (Krieger et al. 2012; Webster and Garvis 2017). The diagnosis conceptualised their lifelong challenges as real, not just a quirk of their personality that should be cured; removing some guilt and blame from themselves (Punshon, Skirrow, and Murphy 2009; Stagg and Belcher 2019).

One woman described crying and feeling overwhelmed when she was finally diagnosed, as it explained why she had struggled so much when she was younger (Webster and Garvis 2017). The women seemed to have revised their understanding of their challenges and negative experiences; reattributing struggles and misunderstandings to autism within their 'sense-making narrative' (Leedham et al. 2020). A sense-making narrative may be revised when a person, who previously had an inadequate way of understanding themselves,

gains new insight into their past and feels they understand themselves better (Bury 1982; Kim 2013). Before having acquired this knowledge, the women were forced to concoct incomplete explanations for their developmental history and life experiences (Limburg 2016). Other people had attributed their autistic traits to issues of motivation, poor character, or a flawed upbringing (Bargiela, Steward, and Mandy 2016). Following their diagnosis, the women went through a period of intense research and growing self-awareness (Leedham et al. 2020). Some began to read autobiographies written by autistic women, giving them a greater understanding of themselves (Hacking 2006; Linton 2014; Webster and Garvis 2017). They described their diagnostic journeys in autistic women's groups on social media platforms, which allowed them to compare their experiences with those of others (Davidson 2008a).

Many of the women felt that a diagnosis in childhood would have increased the quality of their lives, helped them to progress in life, and giving them the knowledge to better understand themselves (Webster and Garvis 2017). They believed that, if they had been diagnosed earlier, they would have been better able to sense danger, 'read' other people's intentions, and cope with dangerous situations: 'I think women tend to be diagnosed later in life when they actually push for it themselves... if people had helped me from earlier on, then life would have been a whole lot easier' (Bargiela, Steward, and Mandy 2016, 3286). Reflecting on their past, during and after their diagnosis, was upsetting for some who had experienced abuse, bullying, rape, and harassment (Kanfischer, Davies, and Collins 2017; Leedham et al. 2020; Webster and Garvis 2017).

Compensatory strategies such as masking, although used to avoid rejection from their peers, may have resulted in their social interaction difficulties going unnoticed and their support needs being underestimated (Beck et al. 2020). Some women felt they had been misdiagnosed with other mental health conditions when they were younger (Bargiela, Steward, and Mandy 2016). However, these previous diagnoses may have accurately reflected clinicians' understandings of their difficulties at that time, as autistic girls and women went largely under the radar until relatively recently. Moreover, autistic women often experience concurrent mental health difficulties related to the stress of living in a neurotypical world that expects social competency, especially those diagnosed later in life (Atherton et al. 2021).

For most women, the late diagnosis proved valuable, as did having long-term relationships with close friends and family members, both autistic and non-autistic, who accepted and encouraged them to achieve their goals, without criticising their 'quirky' traits (Kock et al. 2019; Leedham et al. 2020; Webster and Garvis 2017). However, a small number worried that the 'label' may be seen by others as shameful and may limit their future potential (Ho 2004; Leedham et al. 2020). A diagnosis not only allows a person to reflect on themselves differently, but it can also change the way others perceive them and consequently treat them (Becker 2008; Goffman 1963). Unfortunately,

when someone constantly hears negative messages about their value and ability, it can become a self-fulfilling prophecy as they internalise these judgements and start to believe them (Jussim et al. 2000; Merton 1948; Reeve 2004). The reaction of a person to being diagnosed with autism may depend on when the diagnosis is given and under what circumstances. Perhaps most women in this review found it a positive experience because they voluntarily sought a diagnosis for themselves in adulthood, rather than 'receiving' the label in childhood, without being well informed (Molloy and Vasil 2002).

Developing a new 'autistic identity'

The growing popularity of social media and the neurodiversity paradigm during the last decade has increased the number of autistic women seeking out like-minded others and connecting and sharing their experiences; empowering them, increasing their well-being and reducing feelings of alienation (Milton and Sims 2016; Straus 2013; Webster and Garvis 2017). In Bargiela, Steward, and Mandy (2016), several women described the importance of finding new autistic friends online who accepted and understood them, highlighting the importance of informal peer support: 'Something that I really appreciate about having the diagnosis is actually being in this club now where people talk about their experiences and having so many echoes of my own' (3289). Socialising with other autistic women online may have helped them construct a positive 'autistic identity', which otherwise may have proved difficult due to the competing discourse around autism, particularly the powerful medical or 'deficit' model (Bagatell 2007; Davidson 2008a). However, neurodiversity represents autism as a cognitive style, rather than as a 'discreditable' deficit that should be overcome, and this concept seemed to have encouraged the women to redefine autism as a distinct cultural identity, positively influencing their self-image and encouraging them to disclose to others (Haney and Cullen 2017; Tan 2018; Wright, Spikins, and Pearson 2020).

Many of the women felt more able and free to be themselves, rather than an idealised version of what others expected them to be, and so they were absolved from having to wear a mask, particularly around their autistic friends (Leedham et al. 2020). Developing a positive 'autistic identity' appears to have increased personal and collective self-esteem, offering a protective mechanism for psychological wellbeing (Milton and Sims 2016; Tan 2018). In a society where autistic people have traditionally been devalued, this identity construction involves resisting normalising ideology and feeds back into our understanding of autism via the looping effect, as discussed earlier (Hacking 2006; O'Dell et al. 2016). Hopefully a greater societal appreciation of autism and autistic behavioural traits may reduce the compulsion for autistic females to mask their authentic selves (Hodge, Rice, and Reidy 2019).

For some women, receiving a diagnosis seems to have encouraged them to set goals based on their unique strengths, assert their opinions, ask for support when needed, and realise their potential (Bargiela, Steward, and Mandy 2016; Leedham et al. 2020; Webster and Garvis 2017). One key strength that was frequently mentioned was the ability to 'hyperfocus' on interests; a result of their enhanced processing using a cognitive strategy called monotropism (Murray 2018; Murray, Lesser, and Lawson 2005). Some autistic individuals tend to intensely focus on a task that they are particularly interested in, to the point where the rest of the world seems to disappear and any other, less interesting, tasks get ignored (Grant and Kara 2021). Working on, or building a career from, activities of specific interest to the women provided a sense of stimulation and fulfilment, despite the challenges the women had faced in the past (Bargiela, Steward, and Mandy 2016; Krieger et al. 2012; O'Neil 2008; Stagg and Belcher 2019).

Although the mental health of a few women continued to fluctuate after they were diagnosed, many seemed to have developed more self-compassion and an increased sense of agency. For example, some women managed to gain the confidence to end unsupportive and abusive relationships and friendships (Webster and Garvis 2017). One woman felt less anxious after her diagnosis: 'I don't get as much anxiety as I used to ... because I've got better understanding of—and because I understand it better I'm actually able to deal with it better ... so I build strategies around that really' (Leedham et al. 2020, 142). An increase in the women's autonomy was indicated by their decision-making and efforts to improve their quality of life. This illustrated the importance of measures that may increase their sense of agency and awareness that they can succeed.

Developing a positive social identity and contacting others in the autism community has the potential for autistic women to increase their self-esteem and to reduce feelings of isolation and alienation (Cameron 2014a; Cooper, Smith, and Russell 2017). Swain and French (2000) proposed a new model called the affirmation model that embraces positive social identities and respects the diverse ways of being in society; challenging presumptions about the 'tragedy' of disability (Cameron 2014b; Swain and French 2008). By contacting the autism community and sharing their narratives about their lives and diagnostic journey, the women in these studies were reframing their sense-making narrative in a neurodiversity-affirming way (Kapp 2020; Swain and Cameron 1999).

Barriers to support

While seeking a diagnosis in adulthood, the women in the study by Bargiela, Steward, and Mandy (2016) felt that healthcare professionals lacked an understanding of the way autistic traits present in women. Some women had found that General Practitioners (GPs) and psychiatrists had dismissed

their concerns: 'When I mentioned the possibility to my psychiatric nurse, she actually laughed at me...I asked my mum, who was a GP at the time... if she thought I was autistic. She said, 'Of course not' (ibid, 3286). As GPs are more used to identifying autistic features in boys, they may not initially think of autism when they meet a woman with social difficulties in their clinic, but instead think of social anxiety or depression, for which medication can be prescribed (Fletcher-Watson and Happé 2019). Studies have revealed a large gender disparity in autism referral and diagnosis (Dworzynski et al. 2012; Russell, Steer, and Golding 2011). This could either reflect a significant gender bias by clinicians or the fact that females are more motivated and successful at emulating non-autistic behaviour (Hurley 2014).

Another possibility for the gender disparity could be that clinicians have been under the impression that women could not be autistic due to misinterpreting a theory about extreme male brains. The theory was informally suggested by Hans Asperger in 1944, who stated that 'the autistic personality is an extreme variant of male intelligence. In the autistic individual, the male pattern is exaggerated to the extreme.' (Frith 1991, 84). More recently, the Extreme Male Brain (EMB) theory hypothesised that autistic brains were extreme forms of the male brain, as they were better at analysing and systemising which are male traits, but less good at empathising which is a female trait (Baron-Cohen 2002). Further research suggested a relationship between pre-natal exposure to the sex-linked hormone testosterone in amniotic fluid and autistic traits (Baron-Cohen et al. 2015). However, this theory was heavily criticised for failing to distinguish between sex and gender; rather it subsumed one into the other (Butler 2006). The theory relies on a binary model of brains which suggests that differences in social skills between males and females are biologically determined, but fails to account for cultural expectations and learnt behaviour (Jack 2011).

An autism diagnosis may function as a key to unlocking legal and financial support that would otherwise not be accessible, including welfare benefits, reasonable adjustments in the workplace, protections, rights, services, social groups, information and educational support (Booth 2016). There was an expectation amongst the women in the review that some post-diagnostic social care support would be available, but unfortunately, their attempts to access it were unsuccessful (Griffith et al. 2012). Women felt that this was due to a lack of specific adult autism services: '... I don't fit mental health. I don't fit learning disability. I just fall through the gaps between departments, whether it's in the health service or social services. I just don't fit anywhere' (ibid, 540).

In workplace environments, assessments should be carried out and recommendations made for reasonable adjustments, for example to lessen specific sensory stimuli that may be a hindrance to an autistic individual's work performance and wellbeing (Booth 2016). However, the women had

come across a general lack of autism awareness by their employers who did not understand or appreciate the kind of difficulties autistic people may experience in the workplace or what accommodations may be required (Griffith et al. 2012; Hurlbutt and Chalmers 2004). In fact, many felt that their difficulties in socially interacting with co-workers had led to their dismissal from a post in the past. A few of the women were so disheartened that they stopped looking for work altogether:

'It's interacting ... they come up to you and start asking you questions about your problems, see, I may make a comment, I may do something inappropriate and it builds up and then the employer ... usually it leads to a reason for dismissal' (Griffith et al. 2012, 539).

One woman revealed that, due to some previous bad experiences, she had become reluctant to disclose her diagnosis to potential employers. She felt that many employers were reluctant to employ autistic members of staff (Hurlbutt and Chalmers 2004). Autistic individuals must choose carefully whether or not to disclose their diagnosis in particular contexts, as disclosure can have potential ramifications such as social exclusion (Lingsom 2008). Fear of invalidation by others also negatively affected the confidence of some women to disclose their diagnosis to family and friends (Baines 2012; Leedham et al. 2020; MacLeod, Lewis, and Robertson 2013). However, even while trying hard to appear socially competent and pass as 'normal', the women may sometimes fail to maintain their performance and, because of their unusual behaviour, others may assume that they were being deliberately offensive (Goffman 1963; Portway and Johnson 2005). Stigmatisation can therefore result from the application of a diagnostic label or from the autistic behaviour itself. Perhaps if the concept of neurodiversity was more widely accepted within our culture, autistic people may feel more comfortable disclosing to others, and social support may be offered more readily (Sasson and Morrison 2019).

Limitations

Only the main issues described by participating autistic women were highlighted, so unfortunately other potentially important nuances contained within their personal stories may have been missed (Finfgeld-Connett 2010). The criteria for inclusion in the review were women who had been diagnosed in adulthood, so undiagnosed and self-diagnosed autistic women, autistic individuals with other gender identities and individuals diagnosed in childhood were not represented (Brugha et al. 2011). The countries of origin of all nine articles were from the minority world, traditionally known as 'developed countries'. Data on the women's ethnicity group were only included in one study, in which all the participating women were White British (Smith and Sharp 2013). It is possible that minority ethnic groups may have been

under-represented in this review. Demographic information about the participants from the nine studies were limited and not consistent in all of the studies, which meant that we could not apply the full framework of intersectionality to any other aspects of the women's identity, such as ethnicity or class, that may have empowered or disadvantaged them (Kim 2012). A recommendation for future research would be to study the impact of an autism diagnosis on autistic women's intimate relationships, such as with their partners, children or parents (Kock et al. 2019).

Conclusions

Receiving the diagnostic label of autism proved to be a positive 'turning-point' for many of the women who participated in the nine studies reviewed. The identity of 'autism' provided the women with an explanatory framework which allowed them to rewrite their biography and make sense of their experiences. The women's sense-making narratives were affirming and recognised autism as an intrinsic part of them. These narratives may be viewed as an act of resistance to the metanarrative of autism that have been historically rooted in medicalised approaches to autism (Loftis 2021). In its place, the autistic women in the studies used the paradigm of neurodiversity to interpret and construct a new autistic identity which accepted and valued all types of human diversity and challenged the dominant ideology of the deficit-based medical model. The women expressed the importance of communicating with other autistic individuals following a diagnosis, especially other autistic women. It provided opportunities for mutual recognition and demonstrated how diversity is something to be celebrated and embraced. The women developed a positive identity by virtue of being autistic and proudly described their autistic strengths that made them unique.

However, the studies did suggest that health and social care professionals were not always able to recognise, refer, and support autistic women and were unaware of autistic women's specific challenges. By focusing on the intersection of autism and gender, the review revealed practices of stigma and marginalisation that had affected the women's psycho-emotional disablement. The autistic women were routinely disabled by societal, attitudinal, and structural barriers and experienced frequent discrimination, disadvantage, and social exclusion in employment and within the broader society. Following their diagnosis, the women used their new positive autistic identity to overcome some of these barriers, to facilitate social interaction with other autistic people, and to access and obtain better outcomes for themselves. Further exploration of the lived experiences of autistic women is essential for conceptualising potential approaches to support, particularly as their 'voices' have been largely missing in qualitative studies (Howlin et al. 2015; Milton 2014). Approaches could include the following:

- At the point of diagnosis, information should be given on autistic female social groups, helplines, local voluntary groups, autobiographical books on autism, useful websites, blogs and social media groups
- Counselling support should be made available for women following a late autism diagnosis, since the identification may be traumatic for some
- Support service staff should help to develop an empowering and positive autistic identity for women, for example by providing first-hand accounts from autistic individuals and introducing the concept of neurodiversity

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References

- Atherton, G., E. Edisbury, A. Piovesan, and L. Cross. 2021. "Autism through the Ages: A Mixed Methods Approach to Understanding How Age and Age of Diagnosis Affect Quality of Life." *Journal of Autism and Developmental Disorders* doi:10.1007/s10803-021-05235-x.
- Bagatell, Nancy. 2007. "Orchestrating Voices: Autism, Identity and the Power of Discourse." *Disability & Society* 22 (4): 413–426. doi:10.1080/09687590701337967.
- Baines, AnnMarie D. 2012. "Positioning, Strategizing, and Charming: How Students with Autism Construct Identities in Relation to Disability." *Disability & Society* 27 (4): 547–561. doi:10.1080/09687599.2012.662825.
- Baker, Dana Lee. 2006. "Neurodiversity, Neurological Disability and the Public Sector: Notes on the Autism Spectrum." *Disability & Society* 21 (1): 15–29. doi:10.1080/09687590500373734.
- Bargiela, S., R. Steward, and W. Mandy. 2016. "The Experiences of Late-Diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype." *Journal of Autism and Developmental Disorders* 46 (10): 3281–3294. doi:10.1007/s10803-016-2872-8.
- Baron-Cohen, Simon. 2002. "The Extreme Male Brain Theory of Autism." *Trends in Cognitive Sciences* 6 (6): 248–254. doi:10.1016/S1364-6613(02)01904-6.

- Baron-Cohen, Simon., Bonnie. Au-Yeung, Bent. Nørgaard-Pedersen, David M. Hougaard, Morsi W. Abdallah, Lars. Melgaard, Arieh. S. Cohen, Bhisma. Chakrabarti, Liliana. Ruta, Michael, and V. Lombardo. 2015. "Elevated Fetal Steroidogenic Activity in Autism." *Molecular Psychiatry* 20 (3): 369–376. doi:10.1038/mp.2014.48.
- Bê, Ana. 2014. "Feminist Disability Studies." In *Disability Studies: A Student's Guide*, edited by Colin Cameron, 59–62. London: Sage.
- Beardon, Luke. 2017. *Autism and Asperger Syndrome in Adults*. UK: Hachette.
- Beck, J. S., R. A. Lundwall, T. Gabrielsen, J. C. Cox, and M. South. 2020. "Looking Good but Feeling Bad: "Camouflaging" Behaviors and Mental Health in Women with Autistic Traits." *Autism : The International Journal of Research and Practice* 24 (4): 809–821. doi:10.1177/1362361320912147.
- Becker, Howard S. 2008. *Outsiders; Studies in the Sociology of Deviance*. New York: Simon and Schuster.
- Begum, Nasa. 1992. "Disabled Women and the Feminist Agenda." *Feminist Review* 40 (1): 70–84. doi:10.2307/1395278.
- Bertilsdotter Rosqvist, Hanna., Marianthi. Kourti, David. Jackson-Perry, Charlotte. Brownlow, Kirsty. Fletcher, Daniel. Bendelman, and Lindsay. O'Dell. 2019. "Doing It Differently: Emancipatory Autism Studies within a Neurodiverse Academic Space." *Disability & Society* 34 (7-8): 1082–1101. doi:10.1080/09687599.2019.1603102.
- Blume, Harvey. 1997. *Autism & the Internet or It's the Wiring, Stupid*. Massachusetts: Media In Transition.
- Boland, Angela. Gemma. Cherry, and Rumona. Dickson. 2017. *Doing a Systematic Review: A Student's Guide*. London: Sage.
- Booth, Janine. 2016. *Autism Equality in the Workplace: Removing Barriers and Challenging Discrimination*. London: Jessica Kingsley Publishers.
- Bottema-Beutel, Kristen., Steven K. Kapp, Jessica Nina. Lester, Noah J. Sasson, and Brittany N. Hand. 2021. "Avoiding Ableist Language: Suggestions for Autism Researchers." *Autism in Adulthood* 3 (1): 18–29. doi:10.1089/aut.2020.0014.
- Bowleg, L. 2012. "The Problem with the Phrase Women and Minorities: Intersectionality-an Important Theoretical Framework for Public Health." *American Journal of Public Health* 102 (7): 1267–1273. doi:10.2105/AJPH.2012.300750.
- Braun, Virginia, and Victoria. Clarke. 2013. *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage.
- Brugha, T. S., N. Spiers, J. Bankart, S. A. Cooper, S. McManus, F. J. Scott, J. Smith, and F. Tyrer. 2016. "Epidemiology of Autism in Adults across Age Groups and Ability Levels." *The British Journal of Psychiatry : The Journal of Mental Science* 209 (6): 498–503. doi:10.1192/bjp.bp.115.174649.
- Brugha, T. S., S. McManus, J. Bankart, F. Scott, S. Purdon, J. Smith, P. Bebbington, R. Jenkins, and H. Meltzer. 2011. "Epidemiology of Autism Spectrum Disorders in Adults in the Community in England." *Archives of General Psychiatry* 68 (5): 459–465. doi:10.1001/archgenpsychiatry.2011.38.
- Bumiller, K. 2008. "Quirky Citizens: Autism, Gender, and Reimagining Disability." *Signs: Journal of Women in Culture and Society* 33 (4): 967–991. doi:10.1086/528848.
- Bury, Michael. 1982. "Chronic Illness as Biographical Disruption." *Sociology of Health & Illness* 4 (2): 167–182. doi:10.1111/1467-9566.ep11339939.
- Butler, Judith. 2006. *Gender Trouble: Feminism and the Subversion of Identity*. London: Routledge.
- Cameron, Colin. 2014a. "Alienation." In *Disability Studies: A Student's Guide*, edited by Colin Cameron, 11–14. London: Sage.

- Cameron, Colin. 2014b. "Developing an Affirmative Model of Disability and Impairment." In *Disabling Barriers—Enabling Environments*, edited by John Swain, Colin Barnes and Carol Thomas, 22–28. London: Sage.
- Castells, M. 2009. *The Power of Identity. Vol. 2, the Information Age: Society, Economy, and Culture*. Oxford: Wiley-Blackwell.
- Chapman, Robert. 2020. "Defining Neurodiversity for Research and Practice." In *Neurodiversity Studies: A New Critical Paradigm*, edited by H. B. Rosqvist, N. Chown and A. Stenning, 218–220. Abingdon, Oxon: Routledge.
- Chown, Nicholas. 2014. "More on the Ontological Status of Autism and Double Empathy." *Disability & Society* 29 (10): 1672–1676. doi:10.1080/09687599.2014.949625.
- Chown, Nick., Jackie. Robinson, Luke. Beardon, Jillian. Downing, Liz. Hughes, Julia. Leatherland, Katrina. Fox, Laura. Hickman, and Duncan. MacGregor. 2017. "Improving Research about Us, with Us: A Draft Framework for Inclusive Autism Research." *Disability & Society* 32 (5): 720–734. doi:10.1080/09687599.2017.1320273.
- Conrad, Peter. 2007. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore: John Hopkins University Press.
- Cooper, Kate., Laura G. E. Smith, and Ailsa. Russell. 2017. "Social Identity, Self-Esteem, and Mental Health in Autism." *European Journal of Social Psychology* 47 (7): 844–854. doi:10.1002/ejsp.2297.
- Crenshaw, Kimberlé. 1989. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics." *University of Chicago Legal Forum* 1 (8): 139–167.
- Creswell, John W, and Cheryl N. Poth. 2016. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. London: Sage.
- Crow, Maxx. 2017. "Anarchism: In the Conversations of Neurodiversity." <https://theanarchistlibrary.org/library/maxx-crow-anarchism-in-the-conversations-of-neurodiversity>.
- Davidson, J., and S. Tamas. 2016. "Autism and the Ghost of Gender." *Emotion, Space and Society* 19: 59–65. doi:10.1016/j.emospa.2015.09.009.
- Davidson, Joyce. 2008a. "Autistic Culture Online: Virtual Communication and Cultural Expression on the Spectrum." *Social & Cultural Geography* 9 (7): 791–806. doi:10.1080/14649360802382586.
- Davidson, Joyce. 2008b. "In a World of Her Own...: Re-Presenting Alienation and Emotion in the Lives and Writings of Women with Autism." *Gender, Place & Culture* 14 (6): 659–677. doi:10.1080/09663690701659135.
- Davis, Kathy. 2008. "Intersectionality as Buzzword." *Feminist Theory* 9 (1): 67–85. doi:10.1177/1464700108086364.
- Dawson, Michelle., Isabelle. Soulières, Morton Ann. Gernsbacher, and Laurent. Mottron. 2007. "The Level and Nature of Autistic Intelligence." *Psychological Science* 18 (8): 657–662. doi:10.1111/j.1467-9280.2007.01954.x.
- den Houting, J. 2019. "Neurodiversity: An Insider's Perspective." *Autism : The International Journal of Research and Practice* 23 (2): 271–273. doi:10.1177/1362361318820762.
- Dixon-Woods, Mary, Shona Agarwal, David Jones, Bridget Young, and Alex Sutton. 2005. "Synthesising Qualitative and Quantitative Evidence: A Review of Possible Methods." *Journal of Health Services Research & Policy* 10 (1): 45–53. doi:10.1177/135581960501000110. 15667704
- Dowley, Becky. 2016. "The Development and Importance of the Autistic Voice in Understanding Autism and Enhancing Services." *Good Autism Practice* 17 (1): 48–53.
- Dworzynski, K., A. Ronald, P. Bolton, and F. Happe. 2012. "How Different Are Girls and Boys above and below the Diagnostic Threshold for Autism Spectrum Disorders?" *Journal of the American Academy of Child and Adolescent Psychiatry* 51 (8): 788–797. doi:10.1016/j.jaac.2012.05.018.

- Fine, Michelle, and Adrienne. Asch. 1988. *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Philadelphia: Temple University Press.
- Finfeld-Connett, D. 2010. "Generalizability and Transferability of Meta-Synthesis Research Findings." *Journal of Advanced Nursing* 66 (2): 246–254. doi:10.1111/j.1365-2648.2009.05250.x.
- Finley, L. 2002. "Outing' the Researcher: The Provenance, Process, and Practice of Reflexivity." *Qualitative Health Research* 12 (4) doi:10.1177/104973202129120052.
- Fletcher-Watson, S., J. Adams, K. Brook, T. Charman, L. Crane, J. Cusack, S. Leekam, D. Milton, J. R. Parr, and E. Pellicano. 2019. "Making the Future Together: Shaping Autism Research through Meaningful Participation." *Autism: The International Journal of Research and Practice* 23 (4): 943–953. doi:10.1177/1362361318786721.
- Fletcher-Watson, Sue, and Francesca. Happé. 2019. *Autism: A New Introduction to Psychological Theory and Current Debate*. Abingdon, Oxon: Routledge.
- Foucault, Michel. 1975. *Discipline and Punish: The Birth of the Prison*. London, UK: Penguin.
- Franks, M. 2002. "Feminisms and Cross-Ideological Feminist Social Research: Standpoint, Situatedness and Positionality—Developing Cross-Ideological Feminist Research." *Journal of International Women's Studies* 3: 38–50.
- Frith, Uta. 1991. *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press.
- Frost, Nollaig. 2016. *Practising Research: Why You're Always Part of the Research Process Even When You Think You're Not*. London: Palgrave.
- Frost, Nollaig, and Amanda. Holt. 2014. "Mother, Researcher, Feminist, Woman: Reflections on 'Maternal Status' as a Researcher Identity." *Qualitative Research Journal* 14 (2): 90–102. doi:10.1108/QRJ-06-2013-0038.
- Garland-Thomson, Rosemarie. 2002. "Integrating Disability, Transforming Feminist Theory." *NWSA Journal* 14 (3): 1–32. doi:10.1353/nwsa.2003.0005.
- Garland-Thomson, Rosemarie. 2005. "Feminist Disability Studies." *Signs* 30 (2): 1567–1587. doi:10.1086/423352.
- Garland-Thomson, Rosemarie. 2017. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. USA: Columbia University Press.
- Gernsbacher, M. A. 2017. "Editorial Perspective: The Use of Person-First Language in Scholarly Writing May Accentuate Stigma." *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 58 (7): 859–861. doi:10.1111/jcpp.12706.
- Gillman, Maureen, Bob. Heyman, and John. Swain. 2000. "What's in a Name? The Implications of Diagnosis for People with Learning Difficulties and Their Family Carers." *Disability & Society* 15 (3): 389–409. doi:10.1080/713661959.
- Ginsburg, E. K., and Donald E. Pease. 1996. *Passing and the Fictions of Identity*. USA: Duke University Press.
- Gobbo, Ken, and Solvegi. Shmulsky. 2016. "Autistic Identity Development and Postsecondary Education." *Disability Studies Quarterly* 36 (3) doi:10.18061/dsq.v36i3.5053.
- Goffman, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Books.
- Gould, J., and J. Ashton-Smith. 2011. "Missed Diagnosis or Misdiagnosis?: Girls and Women on the Autism Spectrum." *Good Autism Practice* 12 (1): 34.
- Grant, Aimee, and Helen. Kara. 2021. "Considering the Autistic Advantage in Qualitative Research: The Strengths of Autistic Researchers." *Contemporary Social Science* 16 (5): 589–603. doi:10.1080/21582041.2021.1998589.
- Griffith, G. M., V. Totsika, S. Nash, and R. P. Hastings. 2012. " 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood." *Autism: The International Journal of Research and Practice* 16 (5): 532–546. doi:10.1177/1362361311405223.

- Hacking, I. 2009. "Autistic Autobiography." *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences* 364 (1522): 1467–1473. doi:10.1098/rstb.2008.0329.
- Hacking, Ian. 1995. "The Looping Effects of Human Kinds." In *Causal Cognition: A Multidisciplinary Approach*, edited by Dan Sperber, David Premack and Ann James Premack. USA: Oxford University Press.
- Hacking, Ian. 2006. "Making up People." *London Review of Books* 28 (16): 23–26.
- Hall, Kim Q. 2015. "New Conversations in Feminist Disability Studies: Feminism, Philosophy, and Borders." *Hypatia* 30 (1): 1–12. doi:10.1111/hypa.12136.
- Haney, J. L., and J. A. Cullen. 2017. "Learning about the Lived Experiences of Women with Autism from an Online Community." *Journal of Social Work in Disability & Rehabilitation* 16 (1): 54–73. doi:10.1080/1536710X.2017.1260518.
- Haraway, Donna. 1988. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies* 14 (3): 575–599. doi:10.2307/3178066.
- Heasman, B., and A. Gillespie. 2018. "Perspective-Taking is Two-Sided: Misunderstandings between People with Asperger's Syndrome and Their Family Members." *Autism: The International Journal of Research and Practice* 22 (6): 740–750. doi:10.1177/1362361317708287.
- Ho, Anita. 2004. "To Be Labelled, or Not to Be Labelled: That is the Question." *British Journal of Learning Disabilities* 32 (2): 86–92. doi:10.1111/j.1468-3156.2004.00284.x.
- Hodge, Nick., Emma J. Rice, and Lisa. Reidy. 2019. "They're Told All the Time They're Different': How Educators Understand Development of Sense of Self for Autistic Pupils." *Disability & Society* 34 (9-10): 1353–1378. doi:10.1080/09687599.2019.1594700.
- Howard, K., N. Katsos, and J. Gibson. 2019. "Using Interpretative Phenomenological Analysis in Autism Research." *Autism: The International Journal of Research and Practice* 23 (7): 1871–1876. doi:10.1177/1362361318823902.
- Howlin, Patricia., Joanne. Arciuli, Sander. Begeer, Jon. Brock, Kristina. Clarke, Debra. Costley, Peter. di Rita, et al. 2015. "Research on Adults with Autism Spectrum Disorder: Roundtable Report." *Journal of Intellectual and Developmental Disability* 40 (4): 388–393. doi:10.3109/13668250.2015.1064343.
- Hughes, Elizabeth. 2015. "Does the Different Presentation of Asperger Syndrome in Girls Affect Their Problem Areas and Chances of Diagnosis and Support?" *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* 1 (4).
- Hurlbutt, Karen., and Lynne. Chalmers. 2004. "Employment and Adults with Asperger Syndrome." *Focus on Autism and Other Developmental Disabilities* 19 (4): 215–222. doi:10.1177/10883576040190040301.
- Hurley, Elisabeth. 2014. *Ultraviolet Voices: Stories of Women on the Autism Spectrum*. UK: Autism West Midlands.
- Huws, J. C., and R. S. P. Jones. 2010. "They Just Seem to Live Their Lives in Their Own Little World': Lay Perceptions of Autism." *Disability & Society* 25 (3): 331–344. doi:10.1080/09687591003701231.
- Jack, Jordynn. 2011. "The Extreme Male Brain? Incrementum and the Rhetorical Gendering of Autism." *Disability Studies Quarterly* 31 (3) doi:10.18061/dsq.v31i3.1672.
- Jussim, Lee. Polly. Palumbo, Alison. Smith, and Stephanie. Madon. 2000. "Stigma and Self-Fulfilling Prophecies." In *The Social Psychology of Stigma*, edited by T. Heatherton, R. Kleck, M. R. Hebl and J. G. Hull, 374–418. New York: Guilford Press.
- Kalei Kanuha, Valli. 1999. "The Social Process of 'Passing' to Manage Stigma: Acts of Internalized Oppression or Acts of Resistance?" *Journal of Sociology & Social Welfare* 26 (4): 27.
- Kanfiszer, L., F. Davies, and S. Collins. 2017. "'I was just so different': The Experiences of Women Diagnosed with an Autism Spectrum Disorder in Adulthood in Relation to

- Gender and Social relationships." *Autism: The International Journal of Research and Practice* 21 (6): 661–669. doi:10.1177/1362361316687987.
- Kapp, S. K., K. Gillespie-Lynch, L. E. Sherman, and T. Hutman. 2013. "Deficit, Difference, or Both? Autism and Neurodiversity." *Developmental Psychology* 49 (1): 59–71. doi:10.1037/a0028353.
- Kapp, S. K., R. Steward, L. Crane, D. Elliott, C. Elphick, E. Pellicano, and G. Russell. 2019. "People should be allowed to do what they like: Autistic adults' views and experiences of stimming." *Autism: The International Journal of Research and Practice* 23 (7): 1782–1792. doi:10.1177/1362361319829628.
- Kapp, Steven K. 2020. *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. UK: Palgrave Macmillan.
- Kenny, L., C. Hattersley, B. Molins, C. Buckley, C. Povey, and E. Pellicano. 2016. "Which Terms Should Be Used to Describe Autism? Perspectives from the UK Autism Community." *Autism: The International Journal of Research and Practice* 20 (4): 442–462. doi:10.1177/1362361315588200.
- Kim, Cynthia. 2013. *I Think I Might Be Autistic: A Guide to Autism Spectrum Disorder Diagnosis and Self-Discovery for Adults*. New York: Narrow Gauge.
- Kim, Hyun Uk. 2012. "Autism across Cultures: Rethinking Autism." *Disability & Society* 27 (4): 535–545. doi:10.1080/09687599.2012.659463.
- King, Deborah K. 1988. "Multiple Jeopardy, Multiple Consciousness: The Context of a Black Feminist Ideology." *Signs: Journal of Women in Culture and Society* 14 (1): 42–72. doi:10.1086/494491.
- Kock, Elizabeth., Andre. Strydom, Deirdre. O'Brady, and Digby. Tantam. 2019. "Autistic Women's Experience of Intimate Relationships: The Impact of an Adult Diagnosis." *Advances in Autism* 5 (1): 38–49. doi:10.1108/AIA-09-2018-0035.
- Krieger, B., A. Kinebanian, B. Proding, and F. Heigl. 2012. "Becoming a Member of the Work Force: Perceptions of Adults with Asperger Syndrome." *Work (Reading, Mass.)* 43 (2): 141–157. doi:10.3233/WOR-2012-1392.
- Leedham, A., A. R. Thompson, R. Smith, and M. Freeth. 2020. "I Was Exhausted Trying to Figure It Out: The Experiences of Females Receiving an Autism Diagnosis in Middle to Late Adulthood." *Autism: The International Journal of Research and Practice* 24 (1): 135–146. doi:10.1177/1362361319853442.
- Limburg, Joanne. 2016. "But That's Just What You Can't Do: Personal Reflections on the Construction and Management of Identity following a Late Diagnosis of Asperger Syndrome." *Life Writing* 13 (1): 141–150. doi:10.1080/14484528.2016.1120639.
- Lingsom, Susan. 2008. "Invisible Impairments: Dilemmas of Concealment and Disclosure." *Scandinavian Journal of Disability Research* 10 (1): 2–16. doi:10.1080/15017410701391567.
- Linton, Kristen F. 2014. "Clinical Diagnoses Exacerbate Stigma and Improve Self-Discovery according to People with Autism." *Social Work in Mental Health* 12 (4): 330–342. doi:10.1080/15332985.2013.861383.
- Loftis, Sonya Freeman. 2021. "The Metanarrative of Autism: Eternal Childhood and the Failure of Cure." In *Metanarratives of Disability*, 94–105. London: Routledge.
- MacLeod, Andrea. 2019. "Interpretative Phenomenological Analysis (Ipa) as a Tool for Participatory Research within Critical Autism Studies: A Systematic Review." *Research in Autism Spectrum Disorders* 64: 49–62. doi:10.1016/j.rasd.2019.04.005.
- MacLeod, Andrea., Ann. Lewis, and Christopher. Robertson. 2013. "Why Should I Be like Bloody Rain Man?!" Navigating the Autistic Identity." *British Journal of Special Education* 40 (1): 41–49. doi:10.1111/1467-8578.12015.
- Madill, Anna., Abbie. Jordan, and Caroline. Shirley. 2000. "Objectivity and Reliability in Qualitative Analysis: Realist, Contextualist and Radical Constructionist Epistemologies." *British Journal of Psychology* 91 (1): 1–20. doi:10.1348/000712600161646.

- May, Tim, and Beth. Perry. 2017. *Reflexivity: The Essential Guide*. London: Sage.
- Merton, Robert K. 1948. "The Self-Fulfilling Prophecy." *The Antioch Review* 8 (2): 193–210. doi:10.2307/4609267.
- Milton, D. E. 2014. "Autistic Expertise: A Critical Reflection on the Production of Knowledge in Autism Studies." *Autism : The International Journal of Research and Practice* 18 (7): 794–802. doi:10.1177/1362361314525281.
- Milton, Damian E. M. 2012. "On the Ontological Status of Autism: The 'Double Empathy Problem.'" *Disability & Society* 27 (6): 883–887. doi:10.1080/09687599.2012.710008.
- Milton, Damian. 2013. "Filling in the Gaps: A Micro-Sociological Analysis of Autism." *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* 1 (2).
- Milton, Damian. 2017. *A Mismatch of Salience: Explorations of the Nature of Autism from Theory to Practice*. UK: Pavilion Press.
- Milton, Damian., and Lyte. Moon. 2012. "The Normalisation Agenda and the Psycho-Emotional Disablement of Autistic People." *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* 1 (1).
- Milton, Damian., and Tara. Sims. 2016. "How is a Sense of Well-Being and Belonging Constructed in the Accounts of Autistic Adults?" *Disability & Society* 31 (4): 520–534. doi:10.1080/09687599.2016.1186529.
- Mohamed, Kharnita., and Tamara. Shefer. 2015. "Gendering Disability and Disabling Gender: Critical Reflections on Intersections of Gender and Disability." *Agenda* 29 (2): 2–13. doi:10.1080/10130950.2015.1055878.
- Moher, David, Larissa. Shamseer, Mike. Clarke, Davina. Ghera, Alessandro. Liberati, Mark. Petticrew, Paul. Shekelle, and Lesley A. Stewart, PRISMA-P Group 2015. "Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (Prisma-P) 2015 Statement." *Systematic Reviews* 4 (1): 1–9. doi:10.1186/2046-4053-4-1.
- Molloy, Harvey., and Latika. Vasil. 2002. "The Social Construction of Asperger Syndrome: The Pathologising of Difference?" *Disability & Society* 17 (6): 659–669. doi:10.1080/0968759022000010434.
- Morris, Jenny. 1996. *Encounters with Strangers: Feminism and Disability*. London: The Women's Press.
- Murray, D., M. Lesser, and W. Lawson. 2005. "Attention, Monotropism and the Diagnostic Criteria for Autism." *Autism : The International Journal of Research and Practice* 9 (2): 139–156. doi:10.1177/1362361305051398.
- Murray, Dinah. 2018. "Monotropism – an Interest Based account of Autism." In *Encyclopedia of Autism Spectrum Disorders* 1–3.
- Murray, Dinah. 2020. "Dimensions of Difference." In *The Neurodiversity Reader: Exploring Concepts, Lived Experience and Implications for Practice*, edited by Damian Milton, 7–17. Shoreham by Sea, UK: Pavilion.
- Murray, Stuart. 2009. "Autism Functions/the Function of Autism." *Disability Studies Quarterly* 30 (1) doi:10.18061/dsq.v30i1.1048.
- Murray, Stuart. 2012. *Autism*. New York: Routledge.
- Nadesan, Majia Holmer. 2013. *Constructing Autism: Unravelling The truth and Understanding the Social*. Abingdon, Oxon: Routledge.
- O'Dell, Lindsay., Hanna Bertilsdotter. Rosqvist, Francisco. Ortega, Charlotte. Brownlow, and Michael. Orsini. 2016. "Critical Autism Studies: Exploring Epistemic Dialogues and Intersections, Challenging Dominant Understandings of Autism." *Disability & Society* 31 (2): 166–179. doi:10.1080/09687599.2016.1164026.
- O'Neil, Sara. 2008. "The Meaning of Autism: Beyond Disorder." *Disability & Society* 23 (7): 787–799. doi:10.1080/09687590802469289.

- Piepmeyer, Alison., Amber. Cantrell, and Ashley. Maggio. 2014. "Disability is a Feminist Issue: Bringing Together Women's and Gender Studies and Disability Studies." *Disability Studies Quarterly* 34 (2) doi:10.18061/dsq.v34i2.4252.
- Portway, Suzannah M., and Barbara. Johnson. 2005. "Do You Know I Have Asperger's Syndrome? Risks of a Non-Obvious Disability." *Health, Risk & Society* 7 (1): 73–83. doi:10.1080/09500830500042086.
- Punshon, C., P. Skirrow, and G. Murphy. 2009. "The Not Guilty Verdict: Psychological Reactions to a Diagnosis of Asperger Syndrome in Adulthood." *Autism : The International Journal of Research and Practice* 13 (3): 265–283. doi:10.1177/1362361309103795.
- Purdie-Vaughns, Valerie., and Richard P. Eibach. 2008. "Intersectional Invisibility: The Distinctive Advantages and Disadvantages of Multiple Subordinate-Group Identities." *Sex Roles* 59 (5-6): 377–391. doi:10.1007/s11199-008-9424-4.
- Raymaker, Dora, and Christina. Nicolaidis. 2013. "Participatory Research with Autistic Communities: Shifting the System." In *Worlds of Autism: Across the Spectrum of Neurological Difference*, edited by Joyce Davidson and Michael Orsini, 169–188. UK: University of Minnesota Press.
- Reeve, D. 2004. "Psycho-Emotional Dimensions of Disability and the Social Model." In *Implementing the Social Model of Disability: Theory and Research*, edited by C. Barnes and G. Mercer. Leeds: The Disability Press.
- Robertson, Scott Michael. 2009. "Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges." *Disability Studies Quarterly* 30 (1) doi:10.18061/dsq.v30i1.1069.
- Runswick-Cole, Katherine. 2014. "Us' and 'Them': The Limits and Possibilities of a 'Politics of Neurodiversity' in Neoliberal Times." *Disability & Society* 29 (7): 1117–1129. doi:10.1080/09687599.2014.910107.
- Russell, G., C. Steer, and J. Golding. 2011. "Social and Demographic Factors That Influence the Diagnosis of Autistic Spectrum Disorders." *Social Psychiatry and Psychiatric Epidemiology* 46 (12): 1283–1293. doi:10.1007/s00127-010-0294-z.
- Russell, G., S. Collishaw, J. Golding, S. E. Kelly, and T. Ford. 2015. "Changes in Diagnosis Rates and Behavioural Traits of Autism Spectrum Disorder over Time." *BJPsych Open* 1 (2): 110–115. doi:10.1192/bjpo.bp.115.000976.
- Russell, Ginny. 2021. *The Rise of Autism: Risk and Resistance in the Age of Diagnosis*. Abingdon, Oxon: Routledge.
- Sasson, N. J., and K. E. Morrison. 2019. "First Impressions of Adults with Autism Improve with Diagnostic Disclosure and Increased Autism Knowledge of Peers." *Autism : The International Journal of Research and Practice* 23 (1): 50–59. doi:10.1177/1362361317729526.
- Sasson, N. J., D. J. Faso, J. Nugent, S. Lovell, D. P. Kennedy, and R. B. Grossman. 2017. "Neurotypical Peers Are Less Willing to Interact with Those with Autism Based on Thin Slice Judgments." *Scientific Reports* 7: 40700. doi:10.1038/srep40700.
- Saxe, Amanda. 2017. "The Theory of Intersectionality: A New Lens for Understanding the Barriers Faced by Autistic Women." *Canadian Journal of Disability Studies* 6 (4): 153–178. doi:10.15353/cjds.v6i4.386.
- Scuro, Jennifer. 2017. *Addressing Ableism: Philosophical Questions via Disability Studies*. USA: Lexington Books.
- Shakespeare, Tom. 2010. "The Social Model of Disability." In *The Disability Studies Reader*, edited by Lennard J. Davis, 266–273. New York: Routledge.
- Simpson, H, University of Oxford. 2019. "Disability, Neurodiversity, and Feminism." *Journal of Feminist Scholarship* 16 (16): 81–83. (Fall): doi:10.23860/jfs.2019.16.10.
- Sinclair, Jim. 2013. "Why I Dislike 'Person First' Language." *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* 1 (2): 1–2.

- Singer, Judy. 1999. "Why Can't You Be Normal for Once in Your Life? From a Problem with No Name to the Emergence of a New Category of Difference." In *Disability Discourse*, edited by Mairian Corker and Sally French, 59–67. Buckingham, UK: Open University Press.
- Smith, R. S., and J. Sharp. 2013. "Fascination and Isolation: A Grounded Theory Exploration of Unusual Sensory Experiences in Adults with Asperger Syndrome." *Journal of Autism and Developmental Disorders* 43 (4): 891–910. doi:10.1007/s10803-012-1633-6.
- Smooth, Wendy G. 2013. "Intersectionality from Theoretical Framework to Policy Intervention." In *Situating Intersectionality*, edited by Angelia R. Wilson, 11–41. New York: Palgrave Macmillan.
- Stagg, S. D., and H. Belcher. 2019. "Living with Autism without Knowing: Receiving a Diagnosis in Later Life." *Health Psychology and Behavioral Medicine* 7 (1): 348–361. doi:10.1080/21642850.2019.1684920.
- Strand, Lauren Rose. 2017. "Charting Relations between Intersectionality Theory and the Neurodiversity Paradigm." *Disability Studies Quarterly* 37 (2) doi:10.18061/dsq.v37i2.5374.
- Straus, Joseph N. 2013. "Autism as Culture." In *The Disability Studies Reader*, edited by Lennard J. Davis, 460–484. Abingdon, Oxon: Routledge.
- Swain, John, and Colin. Cameron. 1999. "Unless Otherwise Stated: Discourses of Labelling and Identity in Coming Out." In *Disability Discourse*, edited by Mairian Corker and Sally French, 68–78. Buckingham: Open University Press.
- Swain, John, and Sally. French. 2008. *Disability on Equal Terms*. London: Sage.
- Swain, John., and Sally. French. 2000. "Towards an Affirmation Model of Disability." *Disability & Society* 15 (4): 569–582. doi:10.1080/09687590050058189.
- Tan, C. D. 2018. "I'm a normal autistic person, not an abnormal neurotypical': Autism Spectrum Disorder diagnosis as biographical illumination." *Social Science & Medicine* (1982) 197: 161–167. doi:10.1016/j.socscimed.2017.12.008.
- Thibault, Ronnie. 2014. "Can Autistics Redefine Autism? The Cultural Politics of Autistic Activism." *Trans-Scripts* 4: 57–88.
- Thomas, Carol. 1999. *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.
- Thomas, Carol. 2007. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. Basingstoke: Palgrave Macmillan.
- Thomas, J., and A. Harden. 2008. "Methods for the thematic synthesis of qualitative research in systematic reviews." *BMC Medical Research Methodology* 8: 45. doi:10.1186/1471-2288-8-45.
- Walker, Nick. 2014. "Neurodiversity: Some Basic Terms and Definitions." <https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions>.
- Watermeyer, Brian., and Leslie. Swartz. 2008. "Conceptualising the Psycho-Emotional Aspects of Disability and Impairment: The Distortion of Personal and Psychic Boundaries." *Disability & Society* 23 (6): 599–610. doi:10.1080/09687590802328477.
- Webster, A. A., and S. Garvis. 2017. "The Importance of Critical Life Moments: An Explorative Study of Successful Women with Autism Spectrum Disorder." *Autism : The International Journal of Research and Practice* 21 (6): 670–677. doi:10.1177/1362361316677719.
- Wendell, Susan. 1989. "Toward a Feminist Theory of Disability." *Hypatia* 4 (2): 104–124. doi:10.1111/j.1527-2001.1989.tb00576.x.
- Wheeler, Marc. 2011. "Syndrome or Difference: A Critical Review of Medical Conceptualisations of Asperger's Syndrome." *Disability & Society* 26 (7): 839–851. doi:10.1080/09687599.2011.618739.
- WHO, (World Health Organization). 1992. *The Icd-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva, Switzerland: World Health Organization.

- WHO, (World Health Organization). 2018. *The Icd-11 Statistical Classification of Diseases and Related Health Problems*: World Health Organization.
- Wiley, Liane Holliday 2015. *Pretending to Be Normal: Living with Asperger's Syndrome (Autism Spectrum Disorder)*. London: Jessica Kingsley Publishers.
- Willig, Carla. 2013. *Introducing Qualitative Research in Psychology*. UK: McGraw-Hill Education.
- Wolbring, Gregor. 2008. "The Politics of Ableism." *Development* 51 (2): 252–258. doi:10.1057/dev.2008.17.
- Woods, Richard., Damian. Milton, Larry. Arnold, and Steve. Graby. 2018. "Redefining Critical Autism Studies: A More Inclusive Interpretation." *Disability & Society* 33 (6): 974–979. doi:10.1080/09687599.2018.1454380.
- Wright, B., P. Spikins, and H. Pearson. 2020. "Should Autism Spectrum Conditions Be Characterised in a More Positive Way in Our Modern World?" *Medicina (Kaunas)* 56 (5): 233. doi:10.3390/medicina56050233.

Appendix B CASP Qualitative Checklist



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
<i>CONSIDER:</i> • <i>what was the goal of the research?</i> • <i>why was it thought important?</i> • <i>its relevance</i>	
2. Is a qualitative methodology appropriate?	☐ Yes ☐ No ☐ Can't Tell
<i>CONSIDER:</i> • <i>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</i> • <i>Is qualitative research the right methodology for addressing the research goal?</i>	
3. Was the research design appropriate to address the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
<i>CONSIDER:</i> • <i>if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)</i>	
4. Was the recruitment strategy appropriate to the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
<i>CONSIDER:</i> • <i>If the researcher has explained how the participants were selected</i> • <i>If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</i> • <i>If there are any discussions around recruitment (e.g. why some people chose not to take part)</i>	

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: • <i>If there is an in-depth description of the analysis process</i> • <i>If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data</i> • <i>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</i> • <i>If sufficient data are presented to support the findings</i> • <i>To what extent contradictory data are taken into account</i> • <i>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</i>	
9. Is there a clear statement of findings?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • <i>If the findings are explicit</i> • <i>If there is adequate discussion of the evidence both for and against the researcher's arguments</i> • <i>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</i> • <i>If the findings are discussed in relation to the original research question</i>	
Section C: Will the results help locally?	
10. How valuable is the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • <i>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)</i> • <i>If they identify new areas where research is necessary</i> • <i>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</i>	

APPRAISAL SUMMARY: <i>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.</i>		
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.

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I am looking for mothers who have been diagnosed with autism in adulthood to take part in an exciting new study!

This study is being led by an autistic researcher, and aims to explore how an autism diagnosis in adulthood impacts a woman's experience of motherhood.

- Are you a mother who is 18 years or over?
- Were you diagnosed with Asperger syndrome or Autism Spectrum Disorder, without intellectual difficulties or language delay, in adulthood?



The experience of autistic motherhood has received hardly any attention in research, despite autism being a lifelong condition. Many feel that autistic mothers have been underserved by policies and support services. There is certainly very little awareness of motherhood as an identity and social role for autistic women. This study hopes to bring the voices of autistic mothers to the forefront, as their experiences have historically been unheard and misunderstood.

The findings of this research will contribute to a greater understanding and appreciation of autistic motherhood, therefore enabling professionals to better support and accommodate autistic mothers and their families. If you decide to participate, you would take part in an online interview that would last around one hour.

To learn more about this study, please email Carole Kelly at ck17abg@herts.ac.uk. I would be grateful to hear from you. Thank you.

University of Hertfordshire UH

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Appendix D Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Please note: Unfortunately, due to the current COVID-19 pandemic, the researcher will not be able to interview you face-to-face until this public health crisis is over. However, ethical approval has been granted for interviews to take place by telephone, video, or email, so we hope you will take part in this study remotely. You will have received this information sheet and consent form by email, and not by post, to avoid any contamination. Of course, if you would prefer to take part in a face-to-face interview with the researcher, I would be happy to contact you after restrictions have been lifted, and we can arrange a convenient time and place to meet up. In the meantime, please be aware that any references to face-to-face interviews in the following information does not apply at the present time.

1 Title of study

The impact of an autism diagnosis on women's experience of motherhood: an interpretative phenomenological analysis*

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement could include. Please take the time to read the following information carefully and discuss it with others, if you wish. Do not hesitate to ask me anything that is not clear or for any further information that may help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulations governing the conduct of studies involving human participants can be accessed via this link: <http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this information sheet.

3 What is the purpose of this study?

The aim of this user-led study is to explore the impact of an autism diagnosis on women's experience of motherhood and how it may affect their confidence in their maternal abilities. It plans to reveal what aspects of women's own childhood experiences may be perceived differently after receiving an autism diagnosis and how their new identity may affect women's relationships with their children. It is hoped that a greater understanding of the experience of motherhood for autistic women will enable professionals to better support autistic mothers and their families.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage, without needing to give a reason. A decision to withdraw at any time, or a decision not to take part at all, will not disadvantage you in any way.

*Please note: Identity-first language has been used in this information sheet instead of person-first language, for example the term 'autistic person' instead of 'person with autism', as this term has been shown to be preferred by most autistic people. Research conducted by The National Autistic Society (NAS), the Royal College of GPs and the University College London's Institute of Education asked 502 autistic people their language preferences. The term 'autistic' was preferred by 61% of autistic people. In contrast, only 18% of autistic people preferred the term 'person with autism'. Person-first language is often rejected by those who do not wish to be disassociated from their condition, as if it is somehow shameful. Although it was once negatively used to evidence 'pathology', it is now used by many self-advocates in a positive way. However, we respect and understand that you may have your own opinion about this topic, and you will be asked if you have a language preference at the beginning of the interview. If you do have a preference, your choice will be applied from that point on.

5 Are there any age or other restrictions that may prevent me from participating?

We are looking for adult mothers (18 years or over) who were diagnosed with Asperger syndrome (or Autism Spectrum Disorder without an additional intellectual disability) in adulthood.

6 How long will my part in the study take?

The interviews should take approximately one hour, although the duration may vary. It could take a shorter or longer length of time, depending on how much you want to talk.

7 What will happen to me if I take part?

- You will be asked to sign a consent form to participate in the study.
- The researcher will arrange a suitable time and place for the interview. The setting will be at a comfortable and convenient place and time of your choosing. If you prefer, the interviews can be conducted by telephone, video or email.
- The interview questions can be forwarded to you before the interview, if requested.
- The researcher will ask you whether there may be accommodations/adaptions that could make the experience of participating in the research easier for you. For example, taking regular breaks or low lighting. We will try to arrange these for you.
- There will be some time before and after the interview to settle in and relax. Where possible, a separate quiet space will be provided for you to collect your thoughts.
- During the interview, the researcher will ask questions about different times in your life and ask for your reflections on your experience of being an autistic mother. The interview will be audio-recorded.
- There will be an opportunity to ask questions during and after the interview.
- You are free to withdraw at any stage, without needing to give a reason.
- As the interviews may entail emotional reflection of the past, the researcher can recommend support services that are available via the National Autistic Society helpline.

8 What are the possible disadvantages, risks or side effects of taking part?

You will be asked to take part in a relatively long interview and asked about life experiences personal to you. It is possible you may reflect on some past difficult experiences during your interview, which you may find distressing. The researcher will be happy to speak to you about seeking support for any distress that you may experience during the interview. Although it is helpful for the researcher to hear about your life experiences, we do not want to cause you any distress. Be aware that you do not have to talk about any issue you find difficult to discuss.

9 What are the possible benefits of taking part?

By reflecting on your experiences, you may find that you develop a better self-awareness and perhaps a greater understanding of the reactions of other towards your diagnosis. The benefits to others will hopefully come from the contribution that the research findings will make to the very limited published information about the lived experiences of autistic mothers currently available. We anticipate publishing the findings in scientific journals and the study will also form part of a PhD dissertation. The goal is that these published findings will provide health care professionals with a greater understanding of the experience of motherhood for autistic women, enabling them to better support autistic mothers and their families.

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

The audio-recordings will be password protected, and deleted immediately after transcription. The researcher will be the only person to have access to the audio files; the supervisors will only be able to see the anonymised transcripts. All the remaining data, including the consent form and transcription files, will be stored securely and password-protected. Any personally identifiable information will be anonymized, for example your name will be replaced with a pseudonym.

11 What will happen to the data, including the audio material, collected within this study?

The anonymised transcripts will be stored electronically, in a password-protected word processing file, for five years, after which time it will be destroyed under secure conditions. During this time, they will be analysed into themes across all the interviews, and the interpretations presented as part of a doctoral dissertation. The findings will also be published in one or more academic journals. The dissertation and articles will include some direct, anonymised quotes from participants, however at no point will the identities of any of the participants be revealed.

12 Will the data be required for use in further studies?

The data will not be used in any further studies.

13 Who has reviewed this study?

This study has been reviewed by: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is

14 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances become apparent, such as potential harm to self or others, the University may refer the matter to the appropriate authorities.

15 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with Carole Kelly by email: ck17abg@herts.ac.uk. This research is supervised by Professor Shulamit Ramon, School of Health and Social Work, University of Hertfordshire.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield AL10 9AB

Thank you very much for reading this information and considering taking part in this study.

Appendix E Consent form



INFORMED CONSENT FORM FOR PARTICIPANTS

OF PROJECT:

**The impact of an autism diagnosis on women's experience of motherhood:
an interpretative phenomenological analysis**

Please read the Information Sheet before completing this Consent Form

Title of Study:

The impact of an autism diagnosis on women's experience of motherhood: an interpretative phenomenological analysis

Department:

School of Health and Social Work, Centre for Research in Public Health and Community Care,
University of Hertfordshire

Name and Contact Details of Principal Researcher:

Caroline Marion Kelly

ck17abq@herts.ac.uk

Details of Researchers involved:

Professor Shulamit Ramon, Department of Nursing, Midwifery and Social Work, University of Hertfordshire

Dr Shivani Sharma, Department of Psychology and Sports Sciences, University of Hertfordshire

Approval for research:

This study has been approved by UH Research Ethics Committee

Ethics Approval Number:

		Tick Box
1.	I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim or design of the study I will be informed, and asked to renew my consent to participate in it.	
2.	I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.	
3.	In giving my consent to participate in this study, I understand that voice recording may take place and I have been informed of how/whether this recording will be transmitted.	
4.	I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself. In signing this consent form I accept that support might be sought for me, should circumstances require this.	
5.	I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.	
6.	I understand that my participation in this study may reveal findings that could indicate that I might require medical or mental health advice. In that event, I will be informed and advised to consult relevant third parties such as my GP..	
7.	I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.	
8.	I have been told that I may at some time in the future be contacted again in connection with this study.	

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

of [please give contact details here, e.g. a mobile number or email address]

hereby freely agree to take part in the study entitled: **The impact of an autism diagnosis on women's experience of motherhood: an interpretative phenomenological analysis**

UH Protocol number:

Signature of participant.....Date.....

Signature of (principal) investigator.....Date.....

Name of (principal) investigator *[in BLOCK CAPITALS please]*

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA
ETHICS APPROVAL NOTIFICATION

TO Caroline Marion Kelly
CC Professor Shulamit Ramon
FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA
Chair
DATE 29/09/2020

Protocol number: HSK/PGR/UH/04137

Title of study: The impact of an autism diagnosis on women's experience of
motherhood: an interpretative phenomenological analysis

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 01/09/2020

To: 30/09/2021

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.

Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix G Short biographies of each of the ten participants

Anna

Anna was 54 years old, a reflexologist, and lived with her husband and two autistic daughters aged 16 and 21 years old at the time of her interview. She had been diagnosed only a couple of years before at the age of 52 years old, long after her children's diagnoses, so she was undiagnosed throughout most of their school years. Anna grew up in a small family and was the eldest of two sisters. Her parents' lack of physical affection had a profound impact on Anna throughout her childhood and beyond. As she had no family members living nearby, she was unable to get familial support or childcare when her children were growing up, apart from her mother-in-law, who occasionally looked after them. However, Anna had found her "hard work", and she often upset her youngest daughter. Anna had hyperemesis gravidarum during her pregnancy with her second daughter, which caused excessive nausea and vomiting, so she found it a struggle to look after her eldest daughter during that time. After her second daughter was born, she had to start caring for her elderly parents, who had developed vascular dementia. They both attended a residential care home near Anna before they died. During this time, her youngest daughter, who had substantial support needs, was having difficulties attending mainstream primary school. Anna had to leave her job to homeschool her until the local authority finally agreed to fund her attendance at an independent special school. Her husband's sister also died, and following this bereavement, Anna's husband developed depression and suicidal ideation. Due to his mental health issues, their marital relationship went through a difficult period. Thankfully, it was improving at the time of the interview. Following her autism diagnosis, Anna had been attending therapy sessions with an autistic counsellor, which she felt had helped her to understand herself better, particularly her feelings about not having been shown affection by her parents as a child.

Bridget

At the time of her interview, Bridget was 34 years old and had been diagnosed four years previously. She was completing a full-time undergraduate degree and worked part-time at a restaurant. She was divorced and had one autistic son aged eight years old, who had also been diagnosed. Bridget had spent the first four years of motherhood undiagnosed. She grew up in a small family with her elder brother and her mother. Her

parents got divorced when she was young, and her father remarried. Following her parents' divorce, her dad had become very depressed and tried to kill himself several times. Since her mum worked seven days a week, she spent a lot of weekends with her dad. He was very moody most of the time and was physically abusive to her brother. Both Bridget's mum and dad drank a lot of alcohol during her childhood, and her elder brother had become addicted to drugs for a while. She was still very close to her mum and brother and was happy to count on her mum for support. More recently, her dad had expressed a wish to become a responsible grandfather and wanted to be a part of her son's life. Bridget felt angry and resentful about this because he had never tried to be a dependable dad when she was a child. Shortly after she was married and her son was born, her ex-husband informed her that she was transgender and was going to transition to become a woman. After this revelation, their marriage fell apart, and Bridget found the whole experience quite traumatic. She felt that her ex-husband blamed her for the way they separated, and she felt uncomfortable asking her for support or advice about their son. They shared custody, but Bridget felt that, when her son went to stay at his other mum's home, he was treated in a more laid-back and carefree way, without any rules or routine. She worried that he enjoyed his time at his other mum's house more than with her.

Chayana

Chayana described herself as an autistic British Indian mum. She was 48 years old at the time of the interview and had received her autism diagnosis 15 years previously, when she was 33 years old. She was married, worked part-time as a nanny, and had two sons, one of whom was 25 years old and the other 20 years old. Both sons had been diagnosed when they were children, before Chayana was, so she had spent the first ten years of motherhood undiagnosed. She was born in India and moved to England with her parents and sister as a toddler. Her mother and father were unemotional and very traditional. When Chayana was young, her mother died, which was very traumatic for her, and the whole family returned to India. Her father remarried, and they returned to England. Her stepmother followed them to England two years later, with her half-sister and three stepchildren. When Chayana was a child, she was told that she was dumb and stupid and was constantly compared to her more intelligent sister. However, her family never sought any educational support for her. She believed

that they were aware of her differences but were embarrassed and did not want to admit this fact openly. Having a child with a neurodevelopmental condition was a taboo subject for them within their culture. They did not want their community to know about it, as they were worried that no one would want to marry her. Her father died when Chayana was in her early twenties. Although she had a large extended family, they all lived in India. She had fallen out with her stepfamily, who thought she had become too 'westernised'. She admitted that she had turned her back on her culture and had issues with her cultural identity. She felt isolated and depressed because she lacked a network of support and family.

Diane

Diane was 28 years old and had been diagnosed a couple of years before her interview. She was married and a full-time mother to a four-year-old son, who had been diagnosed shortly after her. Although Diane's immediate family was small, she came from a large Irish extended one. Diane described her family as being very neurodiverse, although they would never have admitted it. She also believed her husband was autistic and had many autistic relatives in his family. Diane had quite a wealthy upbringing and enjoyed foreign holidays all over the world. However, she felt that her parents were emotionally distant and believed that she was not the daughter they had expected. There was always a lot of arguing and shouting in their household. Her parents would hit her when she was young, but in her teenage years, she became taller than them and began to hit back, so the abuse finally stopped. Diane was also bullied at school and was told she was 'weird', but she never understood why. She was told that she acted strangely, which she thought implied that she had deserved the abuse. Her mum would accuse her of being mentally ill when she had meltdowns. Diane realised very early on that her son was autistic, as his support needs were very evident. They had been looking for a special school at the time of her interview, as he was not coping in mainstream primary school. She had reconciled with her parents, and they had an excellent relationship. Her mum, dad, her husband's parents, and their siblings all lived locally, so she had a huge support network around her.

Eva

Please note: Eva had experienced a couple of traumatic events in her life and, although she talked freely about them in her interview, she preferred that they were not mentioned in this dissertation or in any subsequent publications resulting from this research. This was mainly due to concerns that others within the autistic community may recognise her from her distinctive life history. Due to these concerns, I provided Eva with her interview transcript to review, and she was able to see how I had anonymised the text and blanked out the conversations we had shared about those traumatic events. She was satisfied that there were no privacy concerns in the text and was happy to continue participating in this study.

At her interview, Eva was 36 years old and had been diagnosed two years before. She was married and had a five-year-old daughter, who was diagnosed soon after she had been. Eva had spent her first few years of motherhood undiagnosed. She was a full-time student enrolled in a postgraduate Master's degree programme. When she was a child, she lived with her mum, dad, and younger sister. She also had a lot of support from her maternal grandparents, who lived close by and were like "a second set of parents" to her. There was a history of mental health problems within Eva's family, and she suspected many of her relatives may have been autistic as well. Eva thought that this may have been the reason no one in her family had ever noticed that she was autistic, as they had similar behavioural traits to her own. Her parents had divorced when she was a teenager, and her mum had met her stepdad, who, shortly after, moved into the family home. Eva found this change hard to cope with, and her behaviour and attitude deteriorated during that time. She was pleasantly surprised to discover that her stepdad turned out to be a relatively stable and consistent figure for a short while. After [first traumatic event], Eva and her sister went to live with their grandparents. Eva met her husband, got married, and a few months after [second traumatic event], she fell pregnant. She had the responsibility of selling the family home, which she found stressful, especially since her daughter was born on the day the house sale completed. Although her mum's brother and sister were still alive, there had been tension between them since her rebellious teenage years. Eva saw little of her biological father because he was unreliable and mentally unstable, and she deliberately limited the influence he could have on Eva's daughter. Fortunately, Eva was still close to her sister, who she found very supportive.

Fiona

Fiona was 40 years old when I interviewed her for this study and had been diagnosed four years previously at the age of 36. She worked as a part-time missionary and lived with her husband and two children: a six-year-old girl who was awaiting an assessment for autism, and a four-year-old boy who was neurotypical. When Fiona was a schoolgirl, she asked a teacher whether she might be dyslexic and was told that she was not. However, years later, when she went to university to study for a post-graduate certificate in education (PGCE), she was diagnosed with dyslexia. As an adult, she developed epilepsy and took regular medication to prevent any seizures from occurring. Fiona was keen to get her daughter diagnosed, although she believed she probably would not require the level of support that Fiona would have needed as a child. However, she realised that her daughter would need support in socially interacting with others. Fiona knew, from her own experience, how problematic it could be for autistic people to understand non-autistic people, who rarely made sense and were so unpredictable. Fiona's mum had disagreed with her decision to approach her daughter's school about getting her diagnosed and had said, "She's too young to get a label that will ruin her whole life." However, Fiona was determined to go through with her decision, as she thought her daughter had a right to know whether or not she was autistic. Fiona's mum and dad lived in the same town as her, only a short walk away, so she had their support with childcare.

Georgia

Georgia was 38 years old, gender-fluid, and lived with their partner and eight-year-old son, and all three of them were autistic. They were currently enrolled on a PhD programme. Georgia had been diagnosed three years earlier, so they spent the first five years of motherhood undiagnosed, and their son was diagnosed a year before our interview. Georgia described their upbringing as chaotic, as both their parents were narcissistic. They divorced when Georgia was young, and the family frequently moved house and, consequently, schools. Both their parents had married multiple times, so they had many stepsiblings; however, Georgia had not kept in touch with most of their relatives. As a teenager, they developed an amphetamine and cocaine habit, got involved in an abusive relationship and got pregnant, although their pregnancy ended in a miscarriage. Recently, Georgia had applied for a subject access request from their

local Children's Service Department regarding their son. In the notes, it was written that the educational service disagreed with their son's diagnosis and had expressed doubts about the necessity of the interventions recommended by his clinicians. Furthermore, the report described Georgia as manipulative, controlling, and inflexible. As a result, Georgia lodged a formal complaint. During the previous year, Georgia's partner had two meltdowns, one where he kicked a hole in a door and the other where he grabbed his son's collar and spanked his bottom. Georgia had put in a referral through their social worker, and social services had held a strategy meeting to decide whether to commence child protection investigations. However, they concluded that their partner had usually been a protective factor in the family and that his behaviour had been rare. Georgia felt that the past couple of years had been the most stable period they had experienced, as the family had put down roots in the area where they were currently living. Georgia's mum also lived relatively close by; however, they hardly ever spoke to each other.

Hannah

Hannah was 47 years old and identified as a woman, although they had been exploring being non-binary at the time of our interview. They had three children: an 18-year-old child who identified as non-binary, a 16-year-old boy, and a nine-year-old girl. Hannah's middle child had been diagnosed, and the oldest and youngest were both awaiting assessments. Hannah was married, although their husband was not the father of their first two children. He also had two non-autistic children from a previous marriage, who lived with their mother. Their husband believed he was not autistic, although Hannah was not so sure. He had found it challenging to deal with their daughter's autistic behaviour. Hannah's middle child had found it very hard after his parents divorced, and his behaviour became quite violent at times. When he received his autism and ADHD diagnoses, Hannah had known very little about autism. They got "caught up with the deficit model" and tried to alter his behaviour. At their interview, they still felt guilty about how they had reacted to the news of his diagnoses. They had no family nearby, although Hannah had briefly moved closer to their parents when their children were very young. Although their parents had tried to help with childminding, they had found their son hard to deal with. Their mum and dad had always been very predictable, structured, and routine-driven, even when Hannah was

young. Hannah was diagnosed two years before our interview, having realised they were autistic while researching autism on behalf of their son. However, they had spent their first 16 years of motherhood undiagnosed and had educated all three children at home throughout their school years. At the time of the interview, their eldest was at college doing a very prestigious apprenticeship. However, they had been struggling with the pressure of the programme, so Hannah was trying to support them through it. Their son had secured a place at college for the following September, and they were concerned that he might not cope very well there.

Ivy

At our interview, Ivy was 33 years old, identified as non-binary, and had been diagnosed for only a year. They had their first child at 17 years old, so they had spent their first 16 years of motherhood undiagnosed. They were married and had three children: a 16-year-old neurotypical son, a diagnosed 11-year-old autistic son, and a five-year-old son, also diagnosed. Ivy's ethnicity was Roma, and they explained that their culture had a strict set of rules, particularly around gender roles, and motherhood was very important for a person generally perceived to be a woman. In their culture, there was the view that family life was supposed to be hard, and a mother should always be "saintly in their struggle". Life for a mother was all about juggling tasks, putting yourself last, and going to bed exhausted. If a person was not able to live up to this ideal, the community would look down on them, rather than support them. Their parents' relationship had been very turbulent, and they grew up within a very unsettled household with financial problems and domestic violence. Their dad had left when they were young, and their mum was a single parent for a long time until she married her present English husband and had another child. Ivy's dad also remarried and had another child, but then got divorced again. He was in and out of relationships, had drug abuse issues, and was occasionally homeless, so Ivy felt that he was not a good influence in their lives. They perceived their present family, the one that they had created, as entirely separate from the family they had grown up in. Ivy had a good marriage, played an equal role within their marital relationship, and they supported each other. They felt settled and secure, which was extremely important to them, given their upbringing. They had no support from their extended family, although their mum visited every few months.

Jo

Jo was a 35-year-old woman, a self-employed part-time writer, and was living with her husband and three young children at the time of our interview. They had a five-year-old girl, who was awaiting an assessment, a three-year-old boy, and a baby boy who was less than one year old; neither boy had a diagnosis due to their young age. Jo had been diagnosed a couple of years earlier but had been undiagnosed for her first three years of motherhood. She had a relatively "normal upbringing", as her mum stayed at home and her dad initially worked as a labourer but later transitioned to an office job. Jo had been an intelligent child who loved reading and writing and had an imaginary friend when her brother was born. Her brother was less academic than she was, but far more practical. Jo did very well at school until she hit puberty, when she began to find socialising with her peers a lot harder. She only had one friend at any time and would latch onto them. After she left school, she had trouble finding a job, but eventually secured a position at a finance company. When she met her husband, she described her life as becoming a lot better. Unfortunately, during her pregnancy with her second child, she developed a blood clot in her lung, was in intensive care for two weeks, and nearly died. The baby was also breech, so she needed to have a Caesarean section, but to undergo the procedure, she had to have a filter fitted in her inferior vena cava to prevent any additional blood clots from travelling into her lungs. Following this medical trauma, she became mentally unwell, started to tic, and became non-verbal for a while.

REFERENCES

- Accardo, A. L., Neely, L. C., Pontes, N. M. H., & Pontes, M. C. F. (2024). Bullying victimization is associated with heightened rates of anxiety and depression among autistic and ADHD youth: National Survey of Children's Health 2016-2020. *J Autism Dev Disord*.
<https://doi.org/10.1007/s10803-024-06479-z>
- Adams, D., Stainsby, M., & Paynter, J. (2021). Autistic mothers of autistic children: A preliminary study in an under-researched area. *Autism in Adulthood*, 3(4), 339-346.
<https://doi.org/10.1089/aut.2020.0078>
- Adams, N., & Liang, B. (2020). *Trans and autistic: Stories from life at the intersection*. Jessica Kingsley Publishers.
- Afanasieva, L., Bukrieieva, I., Glyns' ka, L., Hlebova, N. I., & Semikin, M. (2020). Family roles of Roma and ways to overcome its socio-cultural isolation. *Journal of History Culture and Art Research*, 9(3), 288-296. <https://doi.org/http://dx.doi.org/10.7596/taksad.v9i3.2716>
- AGN. (2022). *Autism, girls, and keeping it all inside*. <https://autisticgirlsnetwork.org/wp-content/uploads/2022/11/Keeping-it-all-inside.pdf>
- Alaghband-Rad, J., Hajikarim-Hamedani, A., & Motamed, M. (2023). Camouflage and masking behavior in adult autism. *Front Psychiatry*, 14, 1108110. <https://doi.org/10.3389/fpsy.2023.1108110>
- Alle, M. C., Schneider, P., Rigoulot, L., Gandolphe, M. C., Danion, J. M., Coutelle, R., & Berna, F. (2025). Narrative identity differences in autism. *Sci Rep*, 15(1), 16990.
<https://doi.org/10.1038/s41598-025-00178-0>
- Alper, M. (2023). *Kids across the spectrums: Growing up autistic in the digital age*. MIT Press.
- Amir-Behghadami, M. (2024). SPIDER as a framework to formulate eligibility criteria in qualitative systematic reviews. *BMJ Supportive & Palliative Care*, 14(e1), e312-e313.
<https://doi.org/10.1136/bmjspcare-2021-003161>
- Amstein, S. (1969). A ladder of citizen participation. *Journal of the American Planning Association*, 35(4), 216-224. <https://lanwt.i8.dgicloud.com/flysystem/repo-bin/2024-10/TD%20202-20%281%29%20A%20Ladder%20of%20Citizen%20Participation%2C%20Arnstein%2C%201969.pdf>
- Anderson-Chavarria, M. (2021). The autism predicament: Models of autism and their impact on autistic identity. *Disability & Society*, 37(8), 1321-1341. <https://doi.org/10.1080/09687599.2021.1877117>
- Anderson, L. K. (2023). Autistic experiences of applied behavior analysis. *Autism*, 27(3), 737-750.
<https://doi.org/10.1177/13623613221118216>
- Andrew, A., Bandiera, O., Costa Dias, M., & Landais, C. (2024). Women and men at work. *Oxford Open Economics*, 3(Supplement_1), i294-i322. <https://doi.org/10.1093/ooec/odad034>
- Andrzejewski, T., & McDonnell, C. G. (2025). Examining adverse and benevolent childhood experiences and associated psychosocial outcomes among autistic adults. *Autism in Adulthood*.
<https://doi.org/10.1089/aut.2024.0230>
- APA. (1994). *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV*. American Psychiatric Association.
- APA. (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. American Psychiatric Association.
- APA. (2022). *APA style and grammar guidelines*. Retrieved 08/06/2023 from
<https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/disability>
- Archer, M. (2003). *Structure, agency, and the internal conversation*. Cambridge University Press.
- Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023). Confirming the nature of autistic burnout. *Autism*, 13623613221147410.
https://researchers.mq.edu.au/files/293087552/224114452_AV.pdf
- Arnold, S. R. C., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023). Towards the measurement of autistic burnout. *Autism*, 27(7), 1933-1948.
<https://doi.org/10.1177/13623613221147401>

- Asaridou, M., Wodka, E. L., Edden, R. A. E., Mostofsky, S. H., Puts, N. A. J., & He, J. L. (2024). Could sensory differences be a sex-indifferent biomarker of autism? Early investigation comparing tactile sensitivity between autistic males and females. *J Autism Dev Disord*, 54(1), 239-255. <https://doi.org/10.1007/s10803-022-05787-6>
- Ash, G., Hilton, C., Freudenthal, R., Stephenson, T., & Ikkos, G. (2020). History of psychiatry in the curriculum? History is part of life and life is part of history: Why psychiatrists need to understand it better. *Br J Psychiatry*, 217(4), 535-536. <https://doi.org/10.1192/bjp.2020.64>
- Asperger, H. (1944/1991). 'Autistic psychopathy' in childhood. In U. Frith (Ed.), *Autism and Asperger syndrome*. University Press.
- Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2021). Autism through the ages: A mixed methods approach to understanding how age and age of diagnosis affect quality of life. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-021-05235-x>
- Autism Act 2009 §Chapter 15 (2009). <https://www.legislation.gov.uk/ukpga/2009/15/introduction>
- Autistica. (2018). *We promise to involve you*. <https://www.autistica.org.uk/downloads/files/Autistica-Involvement-Promise.pdf>
- Bachmann, C. J., Hofer, J., Kamp-Becker, I., Kupper, C., Poustka, L., Roepke, S., Roessner, V., Stroth, S., Wolff, N., & Hoffmann, F. (2019). Internalised stigma in adults with autism: A German multi-center survey. *Psychiatry Res*, 276, 94-99. <https://doi.org/10.1016/j.psychres.2019.04.023>
- Bai, D., Marrus, N., Yip, B. H. K., Reichenberg, A., Constantino, J. N., & Sandin, S. (2020). Inherited risk for autism through maternal and paternal lineage. *Biol Psychiatry*, 88(6), 480-487. <https://doi.org/10.1016/j.biopsych.2020.03.013>
- Bai, D., Yip, B. H. K., Windham, G. C., Sourander, A., Francis, R., Yoffe, R., Glasson, E., Mahjani, B., Suominen, A., Leonard, H., Gissler, M., Buxbaum, J. D., Wong, K., Schendel, D., Kodesh, A., Breshnahan, M., Levine, S. Z., Parner, E. T., Hansen, S. N.,...Sandin, S. (2019). Association of genetic and environmental factors with autism in a 5-country cohort. *JAMA Psychiatry*, 76(10), 1035-1043. <https://doi.org/10.1001/jamapsychiatry.2019.1411>
- Bannister-Tyrrell, M., & Meiqari, L. (2020). Qualitative research in epidemiology: Theoretical and methodological perspectives. *Ann Epidemiol*, 49, 27-35. <https://doi.org/10.1016/j.annepidem.2020.07.008>
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of autism and developmental disorders*, 46(10), 3281-3294. <https://doi.org/https://dx.doi.org/10.1007/s10803-016-2872-8>
- Barker, C., Plstrang, N., & Mandy, W. (2016). *Research methods in clinical psychology: An introduction for students and practitioners*. Wiley Blackwell Publishing.
- Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Sciences*, 6(6), 248-254. [https://doi.org/10.1016/S1364-6613\(02\)01904-6](https://doi.org/10.1016/S1364-6613(02)01904-6)
- Baron-Cohen, S. (2010). Empathizing, systemizing, and the extreme male brain theory of autism. *Prog Brain Res*, 186, 167-175. <https://doi.org/10.1016/B978-0-444-53630-3.00011-7>
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind"? *Cognition*, 21(1), 37-46. http://autismtruths.org/pdf/3.%20Does%20the%20autistic%20child%20have%20a%20theory%20of%20mind_SBC.pdf
- Bastan, E., Beck, S. R., & Surtees, A. D. (2025). Autistic people differ from non-autistic people subjectively, but not objectively in their reasoning. *Autism*, 29(2), 355-366. <https://doi.org/10.1177/13623613241277055>
- Bazen, A., Barg, F. K., & Takeshita, J. (2021). Research techniques made simple: An introduction to qualitative research. *J Invest Dermatol*, 141(2), 241-247 e241. <https://doi.org/10.1016/j.jid.2020.11.029>
- Bê, A. (2014). Feminist disability studies. In C. Cameron (Ed.), *Disability studies: A student's guide* (pp. 59-62). Sage.

- Beardon, L. (2008). Is autism really a disorder part 2: Theory of mind? Rethink how we think. . *The Journal of Inclusive Practice in Further and Higher Education*, 1(1), 19–21.
- Beardon, L. (2017). *Autism and Asperger syndrome in adults*. Hachette.
- Beardon, L. (2018, 7 November 2018). Three golden rules for supporting autistic pupils. *TES Magazine*. <https://www.tes.com/magazine/archive/three-golden-rules-supporting-autistic-pupils>
- Beck, J. S., Lundwall, R. A., Gabrielsen, T., Cox, J. C., & South, M. (2020). Looking good but feeling bad: "Camouflaging" behaviors and mental health in women with autistic traits. *Autism*, 24(4), 809-821. <https://doi.org/10.1177/1362361320912147>
- Beck, K. B., MacKenzie, K. T., Kumar, T., Breitenfeldt, K. E., Chang, J. C., Conner, C. M., Mandell, D. L., White, S. W., & Mazefsky, C. A. (2024). "The world's really not set up for the neurodivergent person": Understanding emotion dysregulation from the perspective of autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0214>
- Belcher, H. L., Morein-Zamir, S., Mandy, W., & Ford, R. M. (2022). Camouflaging intent, first impressions, and age of ASC diagnosis in autistic men and women. *J Autism Dev Disord*, 52(8), 3413-3426. <https://doi.org/10.1007/s10803-021-05221-3>
- Belcher, H. L., Morein-Zamir, S., Stagg, S. D., & Ford, R. M. (2022). Shining a light on a hidden population: Social functioning and mental health in women reporting autistic traits but lacking diagnosis. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-022-05583-2>
- Belcher, H. L., Uglik-Marucha, N., Vitoratou, S., Ford, R. M., & Morein-Zamir, S. (2023). Gender bias in autism screening: Measurement invariance of different model frameworks of the autism spectrum quotient. *BJPsych Open*, 9(5), e173. <https://doi.org/10.1192/bjo.2023.562>
- Belek, B. (2019). Articulating sensory sensitivity: From bodies with autism to autistic bodies. *Med Anthropol*, 38(1), 30-43. <https://doi.org/10.1080/01459740.2018.1460750>
- Belek, B. (2020). Autism as heredity, autism as heritage. *Medicine Anthropology Theory*, 7(1). <https://doi.org/10.17157/mat.7.1.758>
- Belek, B. (2023). 'A smaller mask': Freedom and authenticity in autistic space. *Cult Med Psychiatry*, 47(3), 626-646. <https://doi.org/10.1007/s11013-022-09794-1>
- Benedetto, M. S. (2024). The "dual masking phenomenon": A critical autoethnography of an autistic multiracial Latina amid the presence of white autistic researchers and self-advocates. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0105>
- Benevides, T. W., Shore, S. M., Andresen, M. L., Caplan, R., Cook, B., Gassner, D. L., Erves, J. M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism*, 24(6), 1345-1359. <https://doi.org/10.1177/1362361320913664>
- Benson, K. J. (2023). Perplexing presentations: Compulsory neuronormativity and cognitive marginalisation in social work practice with autistic mothers of autistic children. *British Journal of Social Work*, 53(3), 1445-1464. <https://doi.org/https://dx.doi.org/10.1093/bjsw/bcac229>
- Benson, P. R. (2020). Examining the links between received network support and marital quality among mothers of children with ASD: A longitudinal mediation analysis. *Journal of Autism and Developmental Disorders*, 50(3), 960-975. <https://doi.org/http://dx.doi.org/10.1007/s10803-019-04330-4>
- Benson, P. R. (2023). Maternal mental health and the behavior of children with autism spectrum disorder: Unidirectional and bidirectional effects. *Research in Autism Spectrum Disorders*, 103. <https://doi.org/10.1016/j.rasd.2023.102133>
- Berenguer, C., Baixauli, I., Rosa, E., & De Stasio, S. (2024). Sleep problems in children with autism spectrum disorder and attention-deficit/hyperactivity disorder: A comparative study and effects on communication skills. *Autism Res*, 17(2), 355-365. <https://doi.org/10.1002/aur.3077>
- Bernard, S., Doherty, M., Porte, H., Al-Bustani, L., Murphy, L. E., Russell, M. C., & Shaw, S. C. K. (2023). Upholding autistic people's human rights: A neurodiversity toolbox for autism research. *Autism Res*, 16(4), 683-684. <https://doi.org/10.1002/aur.2907>

- Bernardin, C. J., Mason, E., Lewis, T., & Kanne, S. (2021). "You must become a chameleon to survive": Adolescent experiences of camouflaging. *J Autism Dev Disord*, 51(12), 4422-4435. <https://doi.org/10.1007/s10803-021-04912-1>
- Bernat, A., Turnpenny, A., & Petri, G. (2025). Do public attitudes support intellectual disability and autism rights and inclusion? – lessons from a representative survey. *Tizard Learning Disability Review*, 30(2), 105-116. <https://doi.org/10.1108/tldr-05-2024-0023>
- Bettleheim, B. (1967). *The empty fortress: Infantile autism and the birth of self*. The Free Press.
- Bhargava, A., & Ashwin, C. (2025). Barriers and facilitators towards an autism diagnosis for females within healthcare: A thematic analysis of interviews with UK healthcare professionals. *Research in Autism*, 121-122. <https://doi.org/10.1016/j.reia.2025.202547>
- Bhaskar, R. (1978). *A realist philosophy of science*. Harvester Wheatsheaf.
- Bhaskar, R. (1998). Philosophy and scientific realism. In M. Archer, R. Bhaskar, A. Collier, A. Norrie, & T. Lawson (Eds.), *Critical realism: Essential readings* (Vol. 6). Routledge.
- Bhaskar, R., & Danermark, B. (2006). Metatheory, interdisciplinarity and disability research: A critical realist perspective. *Scandinavian Journal of Disability Research*, 8(4), 278-297. <https://doi.org/10.1080/15017410600914329>
- Billstedt, E., Gillberg, I. C., & Gillberg, C. (2007). Autism in adults: Symptom patterns and early childhood predictors. Use of the disco in a community sample followed from childhood. *J Child Psychol Psychiatry*, 48(11), 1102-1110. <https://doi.org/10.1111/j.1469-7610.2007.01774.x>
- Bird, S., Moid, L. A. E., Jones, C. A., & Surtees, A. D. R. (2024). The relationships between restrictive/repetitive behaviours, intolerance of uncertainty, and anxiety in autism: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*, 117. <https://doi.org/10.1016/j.rasd.2024.102428>
- Birkett, L., McGrath, L., & Tucker, I. (2022). Muting, filtering and transforming space: Autistic children's sensory 'tactics' for navigating mainstream school space following transition to secondary school. *Emotion, Space and Society*, 42, 100872. <https://www.sciencedirect.com/science/article/pii/S1755458622000044>
- Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability. *Res Autism Spectr Disord*, 63, 34-41. <https://doi.org/10.1016/j.rasd.2019.01.001>
- Black, M. H., Clarke, P. J. F., Deane, E., Smith, D., Wiltshire, G., Yates, E., Lawson, W. B., & Chen, N. T. M. (2023). "That impending dread sort of feeling": Experiences of social interaction from the perspectives of autistic adults. *Research in Autism Spectrum Disorders*, 101. <https://doi.org/10.1016/j.rasd.2022.102090>
- Black, M. H., Greenwood, D. L., Hwa, J. C. C., Pivac, J., Tang, J., & Clarke, P. J. F. (2024). What are you worried about? Content and extent of worry in autistic adults. *J Autism Dev Disord*, 54(5), 2040-2054. <https://doi.org/10.1007/s10803-023-05963-2>
- Black, M. H., Helander, J., Segers, J., Ingard, C., Bervoets, J., de Puget, V. G., & Bolte, S. (2024). Resilience in the face of neurodivergence: A scoping review of resilience and factors promoting positive outcomes. *Clin Psychol Rev*, 113, 102487. <https://doi.org/10.1016/j.cpr.2024.102487>
- Blackwell, C. (2025). The impact of school challenges on parental employment among families with children on the autism spectrum. *Disability & Society*, 40(4), 881-899. <https://doi.org/10.1080/09687599.2024.2313096>
- Blakemore, M. (2015). *Human rights violations against parents that are autistic, have an autism spectrum condition*.
- Bleiker, J., Morgan-Trimmer, S., Knapp, K., & Hopkins, S. (2019). Navigating the maze: Qualitative research methodologies and their philosophical foundations. *Radiography (Lond)*, 25 Suppl 1, S4-S8. <https://doi.org/10.1016/j.radi.2019.06.008>
- Bleuler, E. (1911/1950). *Dementia praecox or the group of schizophrenias*. International Universities.
- Blume, H. (1997). *Autism and the internet or it's the wiring, stupid*. Media In Transition.

- Bohadana, G., Morrissey, S., & Paynter, J. (2021). Self-compassion in mothers of children with autism spectrum disorder: A qualitative analysis. *Journal of Autism and Developmental Disorders*, 51(4), 1290-1303. <https://doi.org/http://dx.doi.org/10.1007/s10803-020-04612-2>
- Bolis, D., Lahnakoski, J. M., Seidel, D., Tamm, J., & Schilbach, L. (2021). Interpersonal similarity of autistic traits predicts friendship quality. *Soc Cogn Affect Neurosci*, 16(1-2), 222-231. <https://doi.org/10.1093/scan/nsaa147>
- Bölte, S., Neufeld, J., Marschik, P. B., Williams, Z. J., Gallagher, L., & Lai, M.-C. (2023). Sex and gender in neurodevelopmental conditions. *Nature Reviews Neurology*, 19(3), 136-159. <https://pmc.ncbi.nlm.nih.gov/articles/PMC10154737/pdf/nihms-1894875.pdf>
- Bonazzi, G., Peyroux, E., Jurek, L., Souiller, L., Zufferey, A., Giroudon, C., Nourredine, M., & Demily, C. (2025). Gender on the spectrum: Prevalence of gender diversity in autism spectrum disorder—a systematic review and meta-analysis. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0202>
- Botha, M. (2019). *Autistic community connectedness as a buffer against the effects of minority stress* [University of Surrey].
- Botha, M. (2021). Academic, activist, or advocate? Angry, entangled, and emerging: A critical reflection on autism knowledge production. *Frontiers in Psychology*, 12. <https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2021.727542/pdf>
- Botha, M. (2025). Critical realism, community psychology, and the curious case of autism: A philosophy and practice of science with social justice in mind. *J Community Psychol*, 53(1), e22764. <https://doi.org/10.1002/jcop.22764>
- Botha, M., Dibb, B., & Frost, D. M. (2020). "Autism is me": An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427-453. <https://doi.org/10.1080/09687599.2020.1822782>
- Botha, M., Dibb, B., & Frost, D. M. (2022). 'It's being a part of a grand tradition, a grand counter-culture which involves communities': A qualitative investigation of autistic community connectedness. *Autism*, 13623613221080248. <https://doi.org/10.1177/13623613221080248>
- Botha, M., & Frost, D. M. (2018). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health*, 10(1), 20-34. <https://doi.org/10.1177/2156869318804297>
- Botha, M., & Gillespie-Lynch, K. (2021). Come as you are: Examining autistic identity development and the neurodiversity movement through an intersectional lens. *Human Development*, 66, 93-112. <https://doi.org/10.1159/000524123>
- Botha, M., Hanlon, J., & Williams, G. L. (2021). Does language matter? Identity-first versus person-first language use in autism research: A response to vivanti. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-020-04858-w>
- Bottema-Beutel, K. (2024). Putting autism research in social contexts. *Autism*, 13623613241245642. <https://doi.org/10.1177/13623613241245642>
- Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3(1), 18-29. <https://doi.org/10.1089/aut.2020.0014>
- Bottini, S. B., Morton, H. E., Buchanan, K. A., & Gould, K. (2024). Moving from disorder to difference: A systematic review of recent language use in autism research. *Autism in Adulthood*, 6(2), 128-140. <https://doi.org/10.1089/aut.2023.0030>
- Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0071>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- Braun, V., & Clarke, V. (2024). Reporting guidelines for qualitative research: A values-based approach. *Qualitative Research in Psychology*, 1-40. <https://doi.org/10.1080/14780887.2024.2382244>
- Brede, J., Babb, C., Jones, C. R. G., Serpell, L., Hull, L., Adamson, J., Baker, H., Fox, J. R. E., & Mandy, W. (2024). The clinical characteristics of autistic women with restrictive eating disorders. *BJPsych Open*, 10(4), e131. <https://doi.org/10.1192/bjo.2024.65>

- Brice, S., Rodgers, J., Ingham, B., Mason, D., Wilson, C., Freeston, M., Le Couteur, A., & Parr, J. R. (2021). The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: Findings from UK surveys. *BMJ Open*, 11(3), e043336. <https://doi.org/10.1136/bmjopen-2020-043336>
- Brick, M. (2024). *Autistic-coded representation and autism stereotypes: Looking for the spectrum*. Lexington Books.
- Brickhill, R., Atherton, G., Piovesan, A., & Cross, L. (2023). Autism, thy name is man: Exploring implicit and explicit gender bias in autism perceptions. *PLoS One*, 18(8), e0284013. <https://doi.org/10.1371/journal.pone.0284013>
- Brosnan, M., & Camilleri, L. J. (2025). Neuro-affirmative support for autism, the double empathy problem and monotropism. *Front Psychiatry*, 16, 1538875. <https://doi.org/10.3389/fpsyt.2025.1538875>
- Bross, L. A., Huffman, J. M., & Hagiwara, M. (2022). Examining the special interest areas of autistic adults with a focus on their employment and mental health outcomes. *Journal of Vocational Rehabilitation*, 57(3), 289-305. <https://doi.org/10.3233/jvr-221218>
- Brown, E. (2023). Fawning, masking, and working as an intimacy professional on the autism spectrum. *Journal of Consent-Based Performance*, 2(2), 74-82. <https://journals.test.calstate.edu/jcbp/article/download/3862/3405>
- Brown, H. K., Taylor, C., Vigod, S. N., Dennis, C. L., Fung, K., Chen, S., Guttmann, A., Havercamp, S. M., Parish, S. L., Ray, J. G., & Lunskey, Y. (2023). Disability and in-hospital breastfeeding practices and supports in Ontario, Canada: A population-based study. *Lancet Public Health*, 8(1), e47-e56. [https://doi.org/10.1016/S2468-2667\(22\)00310-3](https://doi.org/10.1016/S2468-2667(22)00310-3)
- Browne, K., Lawson, W., McGarry, S., Scott, M., Girdler, S., & Milbourn, B. (2024). "Consistent support is good for my mental health"—exploring the lived experience of autistic mental health. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0141>
- Bungert, L., Li, C. E., Cardinaux, A. L., O'Brien, A. M., Cannon, J., Shkolnik, V., Gabrieli, J. D. E., Strang, J. F., & Sinha, P. (2024). Proportional overrepresentation of gender-diverse identities in two US-based autistic adult samples from the SPARK database. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0121>
- Bureau, R., & Clement, C. (2024). "Survival classes for a neurotypical world": What French autistic adults want and need after receiving an autism diagnosis. *Autism*, 28(4), 843-853. <https://doi.org/10.1177/13623613231183071>
- Burr, V. (2015). *Social constructionism*. Routledge.
- Burton, L., & Fox, C. (2022). Are families supported to come to terms with an autism diagnosis? A service evaluation of referrals to family therapy for young people with autism in one NHS trust. *Journal of Family Therapy*, 45(2), 154-166. <https://doi.org/10.1111/1467-6427.12419>
- Bury, S. M., Haschek, A., Wenzel, M., Spoor, J. R., & Hedley, D. (2024). Brief report: Learning about autism: Is the source of autism knowledge associated with differences in autism knowledge, autism identity, and experiences of stigma. *J Autism Dev Disord*, 54(11), 4346-4353. <https://doi.org/10.1007/s10803-022-05823-5>
- Bury, S. M., Jellett, R., Haschek, A., Wenzel, M., Hedley, D., & Spoor, J. R. (2022). Understanding language preference: Autism knowledge, experience of stigma and autism identity. *Autism*, 13623613221142383. <https://doi.org/10.1177/13623613221142383>
- Butler, J. (2006). *Gender trouble: Feminism and the subversion of identity*. Routledge.
- Butler, J. S. (1988). Performative acts and gender constitution: An essay in phenomenology and feminist theory. *Theatre Journal*, 40(4), 519-533. <https://web.stanford.edu/~eckert/Courses/1562018/Readings/Butler1988.pdf>
- Cage, E. (2020). Autism acceptance and mental health. In *Encyclopedia of autism spectrum disorders* (pp. 1-6). https://doi.org/10.1007/978-1-4614-6435-8_102427-1
- Cage, E., Botha, M., McDevitt, L., King, K. N., Biscoe, L., Tucker, K., & Pearson, A. (2022). Diagnosis as a new beginning not an end: A participatory photovoice study on navigating an autism diagnosis in adulthood.

- Cage, E., Botha, M., McDevitt, L., King, K. N., Biscoe, L., Tucker, K., & Pearson, A. (2024). Diagnosis as a new beginning not an end: A participatory photovoice study on navigating an autism diagnosis in adulthood. *Autism*, 13623613231220418. <https://doi.org/10.1177/13623613231220418>
- Cage, E., De Andres, M., & Mahoney, P. (2020). Understanding the factors that affect university completion for autistic people. *Research in Autism Spectrum Disorders*, 72. <https://doi.org/10.1016/j.rasd.2020.101519>
- Cage, E., Di Monaco, J., & Newell, V. (2019). Understanding, attitudes and dehumanisation towards autistic people. *Autism*, 23(6), 1373-1383. <https://doi.org/10.1177/1362361318811290>
- Cage, E., & Troxell-Whitman, Z. (2020). Understanding the relationships between autistic identity, disclosure, and camouflaging. *Autism in Adulthood*, 2(4), 334-338. <https://doi.org/10.1089/aut.2020.0016>
- Cai, R. Y., Love, A., Robinson, A., & Gibbs, V. (2023). The inter-relationship of emotion regulation, self-compassion, and mental health in autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0068>
- Cai, R. Y., Richdale, A. L., Dissanayake, C., Trollor, J., & Uljarevic, M. (2019). Emotion regulation in autism: Reappraisal and suppression interactions. *Autism*, 23(3), 737-749. <https://doi.org/10.1177/1362361318774558>
- Campbell, A. A., Karp, S. M., & Mogos, M. (2025). Feeding behaviors in infants and toddlers later diagnosed with autism spectrum disorder: A systematic review. *J Autism Dev Disord*, 55(5), 1788-1808. <https://doi.org/10.1007/s10803-024-06303-8>
- Camus, L., Macmillan, K., Rajendran, G., & Stewart, M. (2022). 'I too, need to belong': Autistic adults' perspectives on misunderstandings and well-being. https://osf.io/5mysh_v1/download/
- Camus, L., Rajendran, G., & Stewart, M. E. (2024). Social self-efficacy and mental well-being in autistic adults: Exploring the role of social identity. *Autism*, 28(5), 1258-1267. <https://doi.org/10.1177/13623613231195799>
- Canigual, R., Ward, J. A., & Hamilton, A. F. C. (2021). Effects of being watched on eye gaze and facial displays of typical and autistic individuals during conversation. *Autism*, 25(1), 210-226. <https://doi.org/10.1177/1362361320951691>
- Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making autism research inclusive by attending to intersectionality: A review of the research ethics literature. *Review Journal of Autism and Developmental Disorders*, 8, 22-36. https://www.pragmatichealthethics.ca/wp-content/uploads/2020/05/2020_Cascio_et_al-2020-Review_Journal_of_Autism_and_Developmental_Disorders.pdf
- CASP. (2018). *Critical appraisal skills programme qualitative checklist*. https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist2018_fillable_form.pdf
- Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *J Autism Dev Disord*, 50(10), 3638-3648. <https://doi.org/10.1007/s10803-019-04323-3>
- Castañeda, C. J. (2023). *Delayed and denied: A phenomenological investigation of women with autism and their experiences with late diagnosis* <https://ttu-ir.tdl.org/bitstreams/e9dfc214-832e-4b85-a6cd-82c429b9726d/download>
- Chahboun, S., Stenseng, F., & Page, A. G. (2022). The changing faces of autism: The fluctuating international diagnostic criteria and the resulting inclusion and exclusion-a Norwegian perspective. *Front Psychiatry*, 13, 787893. <https://doi.org/10.3389/fpsy.2022.787893>
- Chan, D. V., Doran, J. D., & Galobardi, O. D. (2023). Beyond friendship: The spectrum of social participation of autistic adults. *J Autism Dev Disord*, 53(1), 424-437. <https://doi.org/10.1007/s10803-022-05441-1>
- Chance, P. (1974). "After you hit a child you can't just get up and leave him; you are hooked to that kid". Conversations with Ivar Lovaas about self-mutilating children and how their parents make it worse. *Psychology Today*, 76(January), 76-84.

- Chanfreau, J. (2023). The persistence in gendering: Work-family policy in Britain since Beveridge. *Journal of Social Policy*, 52(4), 981-998. <https://doi.org/10.1017/S0047279422000125>
- Chang, J. P., Chou, W. J., Chiu, Y. N., Tsai, W. C., Shang, C. Y., Wu, Y. Y., & Gau, S. S. (2024). Mothering and mother-child interactions in the unaffected siblings of autistic children. *Dev Med Child Neurol*, 66(11), 1446-1456. <https://doi.org/10.1111/dmcn.15917>
- 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. <https://doi.org/10.1016/j.rasd.2022.102069>
- Chapman, R. (2020). The reality of autism: On the metaphysics of disorder and diversity. *Philosophical Psychology*, 33(6), 799-819. <https://doi.org/10.1080/09515089.2020.1751103>
- Chapman, R. (2021). Neurodiversity and the social ecology of mental functions. *Perspect Psychol Sci*, 1745691620959833. <https://doi.org/10.1177/1745691620959833>
- Chapman, R., & Botha, M. (2023). Neurodivergence-informed therapy. *Dev Med Child Neurol*, 65(3), 310-317. <https://doi.org/10.1111/dmcn.15384>
- Chapman, R., & Carel, H. (2022). Neurodiversity, epistemic injustice, and the good human life. *Journal of social philosophy*, 53, 614-631. <https://shura.shu.ac.uk/29834/1/josp.12456.pdf>
- Chapple, M., & Worsley, J. D. (2021). Commentary: Considering nomenclature for autism - aligning with the language preferences of the autistic community - a commentary on Kehinde et al. (2021). *Child Adolesc Ment Health*, 26(3), 284-285. <https://doi.org/10.1111/camh.12490>
- Charlton, R. A., Entecott, T., Belova, E., & Nwaordu, G. (2021). "It feels like holding back something you need to say": Autistic and non-autistic adults accounts of sensory experiences and stimming. *Research in Autism Spectrum Disorders*, 89. <https://doi.org/10.1016/j.rasd.2021.101864>
- Charlton, R. A., McQuaid, G. A., Bishop, L., Lee, N. R., & Wallace, G. L. (2023). Predictors of sleep quality for autistic people across adulthood. *Autism Res*. <https://doi.org/10.1002/aur.2891>
- Cheang, R. T., Skjevling, M., Blakemore, A. I., Kumari, V., & Puzzo, I. (2024). Do you feel me? Autism, empathic accuracy and the double empathy problem. *Autism*, 13623613241252320. <https://doi.org/10.1177/13623613241252320>
- Chen, B. B., & Yakubova, G. (2024). What do autistic youth and young adults want at work? A qualitative study of autistic individuals' views on key workplace supports. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0092>
- Chen, Y., Jenkins, C. A., Charlton, R. A., Happé, F., Mandy, W., & Stewart, G. R. (2024). "Utterly overwhelming"—a mixed-methods exploration of sensory processing differences and mental health experiences in middle-aged and older autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0031>
- Chen, Y., Xi, Z., Saunders, R., Simmons, D., Totsika, V., & Mandy, W. (2024). A systematic review and meta-analysis of the relationship between sensory processing differences and internalising/externalising problems in autism. *Clin Psychol Rev*, 114, 102516. <https://doi.org/10.1016/j.cpr.2024.102516>
- Chen, Y. L., Senande, L. L., Thorsen, M., & Patten, K. (2021). Peer preferences and characteristics of same-group and cross-group social interactions among autistic and non-autistic adolescents. *Autism*, 25(7), 1885-1900. <https://doi.org/10.1177/13623613211005918>
- Chow, C., & Cooper, K. (2024). What are the lived experiences of strengths in autistic individuals? A systematic review and thematic synthesis. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0172>
- Chown, N., Shaw, S., Doherty, M., Johnson, M., Krupa, J., Martin, N., & Brooker-Corcoran, M. (2023). General practitioner autism training and mandatory medical training: A cross-sectional study of gps' knowledge, attitudes and practices. *Canadian Journal of Educational and Social Studies*, 3(1). <https://doi.org/10.53103/cjess.v3i1.99>
- Cirigliaro, M., Chang, T. S., Arteaga, S. A., Pérez-Cano, L., Ruzzo, E. K., Gordon, A., Bicks, L. K., Jung, J.-Y., Lowe, J. K., & Wall, D. P. (2023). The contributions of rare inherited and polygenic

- risk to ASD in multiplex families. *Proceedings of the National Academy of Sciences*, 120(31), e2215632120. <https://www.pnas.org/doi/pdf/10.1073/pnas.2215632120>
- Clarke, J. (2025). *Stop the world I want to get off: A guide to understanding and supporting the recovery of autistic burnout in children and young people*. Jessica Kingsley Publishers.
- Cleary, M., West, S., Kornhaber, R., & Hungerford, C. (2023). Autism, discrimination and masking: Disrupting a recipe for trauma. *Issues Ment Health Nurs*, 44(9), 799-808. <https://doi.org/10.1080/01612840.2023.2239916>
- Cleary, M., West, S., & McLean, L. (2023). From 'refrigerator mothers' to empowered advocates: The evolution of the autism parent. *Issues Ment Health Nurs*, 44(1), 64-70. <https://doi.org/10.1080/01612840.2022.2115594>
- Clements, L., & Aiello, A. L. (2021). *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments*. <https://cerebra.org.uk/wp-content/uploads/2021/07/Final-Parent-Blame-Report-20-July-21-03.pdf>
- Clements, L., & Aiello, A. L. (2023). *The prevalence and impact of allegations of fabricated or induced illness (FII)*. <https://www.stgeorghouse.org/wp-content/uploads/2025/02/The-Prevalance-and-Impact-of-Allegations-of-Fabricated-or-Induced-Illness-FII.pdf>
- Clímaco, J. C. (2020). Análise das construções possíveis de maternidades nos estudos feministas e da deficiência. *Revista Estudos Feministas*, 28(1). <https://doi.org/10.1590/1806-9584-2020v28n154235>
- Collier, A. (1998). Language, practice and realism. In I. Parker (Ed.), *Social constructionism, discourse and realism* (pp. 47-58). Sage.
- Conner, C. M., Elias, R., Smith, I. C., & White, S. W. (2023). Emotion regulation and executive function: Associations with depression and anxiety in autism. *Res Autism Spectr Disord*, 101. <https://doi.org/10.1016/j.rasd.2023.102103>
- Cook, A., Ogden, J., & Winstone, N. (2017). Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings. *European Journal of Special Needs Education*, 33(3), 302-315. <https://doi.org/10.1080/08856257.2017.1312797>
- Cook, J., Crane, L., Bourne, L., Hull, L., & Mandy, W. (2021). Camouflaging in an everyday social context: An interpersonal recall study. *Autism*, 1362361321992641. <https://doi.org/10.1177/1362361321992641>
- Cook, J., Crane, L., Hull, L., Bourne, L., & Mandy, W. (2022). Self-reported camouflaging behaviours used by autistic adults during everyday social interactions. *Autism*, 26(2), 406-421. <https://doi.org/10.1177/13623613211026754>
- Cook, J., Hull, L., & Mandy, W. (2024). Improving diagnostic procedures in autism for girls and women: A narrative review. *Neuropsychiatr Dis Treat*, 20, 505-514. <https://doi.org/10.2147/NDT.S372723>
- Cook, J. M., Crane, L., & Mandy, W. (2023). Dropping the mask: It takes two. *Autism*, 13623613231183059. <https://doi.org/10.1177/13623613231183059>
- Cooper, K., & Russell, A. (2025). Insistence on sameness, repetitive negative thinking and mental health in autistic and non-autistic adults. *Autism*, 29(2), 424-434. <https://doi.org/10.1177/13623613241275468>
- Cooper, K., Russell, A. J., Lei, J., & Smith, L. G. (2023). The impact of a positive autism identity and autistic community solidarity on social anxiety and mental health in autistic young people. *Autism*, 27(3), 848-857. <https://doi.org/10.1177/13623613221118351>
- Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. (2021). "I'm proud to be a little bit different": The effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*, 51, 704-714. <https://link.springer.com/content/pdf/10.1007/s10803-020-04575-4.pdf>
- Corden, K., Brewer, R., & Cage, E. (2021). Personal identity after an autism diagnosis: Relationships with self-esteem, mental wellbeing, and diagnostic timing. *Front Psychol*, 12, 699335. <https://doi.org/10.3389/fpsyg.2021.699335>

- Coscini, N., Williams, K., Chew, D., Pang, K. C., O'Connell, M. A., & May, T. (2021). Association between early androgens and autistic traits: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*, 85, 101789. <https://www.sciencedirect.com/science/article/pii/S1750946721000647/pdf?md5=c6648fca9712a69ba01348968f498dc5&pid=1-s2.0-S1750946721000647-main.pdf>
- Cowell, R. L. (2024). Communicating diversity: (cognitive) ableism in information-seeking research. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0077>
- Craddock, E. (2024). Being a woman is 100% significant to my experiences of attention deficit hyperactivity disorder and autism: Exploring the gendered implications of an adulthood combined autism and attention deficit hyperactivity disorder diagnosis. *Qual Health Res*, 10497323241253412. <https://doi.org/10.1177/10497323241253412>
- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *J Autism Dev Disord*, 48(11), 3761-3772. <https://doi.org/10.1007/s10803-018-3639-1>
- Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021). Supporting newly identified or diagnosed autistic adults: An initial evaluation of an autistic-led programme. *J Autism Dev Disord*, 51(3), 892-905. <https://doi.org/10.1007/s10803-020-04486-4>
- Crane, L., Lui, L. M., Davies, J., & Pellicano, E. (2021). Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*, 25(4), 1161-1167. <https://doi.org/10.1177/1362361320981317>
- Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics *University of Chicago Legal Forum*, 1(8), 139-167. <https://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8>
- Crenshaw, K. W. (2017). *On intersectionality: Essential writings*. The New Press.
- Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage.
- Crompton, C. J., Hallett, S., McAuliffe, C., Stanfield, A. C., & Fletcher-Watson, S. (2022). "A group of fellow travellers who understand": Interviews with autistic people about post-diagnostic peer support in adulthood. *Front Psychol*, 13, 831628. <https://doi.org/10.3389/fpsyg.2022.831628>
- Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 24(6), 1438-1448. <https://doi.org/10.1177/1362361320908976>
- Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*, 24(7), 1704-1712. <https://doi.org/10.1177/1362361320919286>
- Cronshaw, G., & Midouhas, E. (2024). Harsh parenting and trajectories of emotional and behavioural difficulties in autistic children. *J Autism Dev Disord*, 54(12), 4637-4649. <https://doi.org/10.1007/s10803-023-06167-4>
- Crowson, S., Poole, D., Scargill, K., & Freeth, M. (2024). Understanding the post-diagnostic support priorities of autistic adults in the United Kingdom: A co-produced modified Delphi study. *Autism*, 28(4), 854-865. <https://doi.org/10.1177/13623613231196805>
- Cruz, S., Zubizarreta, S. C., Costa, A. D., Araujo, R., Martinho, J., Tubio-Fungueirino, M., Sampaio, A., Cruz, R., Carracedo, A., & Fernandez-Prieto, M. (2025). Is there a bias towards males in the diagnosis of autism? A systematic review and meta-analysis. *Neuropsychol Rev*, 35(1), 153-176. <https://doi.org/10.1007/s11065-023-09630-2>
- Cumin, J., Pelaez, S., & Mottron, L. (2021). Positive and differential diagnosis of autism in verbal women of typical intelligence: A Delphi study. *Autism*, 13623613211042719. <https://doi.org/10.1177/13623613211042719>
- Cummins, C., Pellicano, E., & Crane, L. (2020). Autistic adults' views of their communication skills and needs. *Int J Lang Commun Disord*, 55(5), 678-689. <https://doi.org/10.1111/1460-6984.12552>

- Curd, J., & Nguyễn, T. S. T. (2024). "I was always on the outside, watching quietly": Autistic women reflect on school experiences. *Humanities and Social Sciences Communications*, 11(1). <https://doi.org/10.1057/s41599-024-03632-y>
- Curnow, E., Maciver, D., Johnston, L., Murray, M., Johnstone-Cooke, V., Utley, I., Jenkins, N., Meff, T., Muggleton, J., & Rutherford, M. (2025). Learning from the experiences of autistic professionals working in health and education. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0168>
- Curnow, E., Rutherford, M., Maciver, D., Johnston, L., Prior, S., Boilson, M., Shah, P., Jenkins, N., & Meff, T. (2023). Mental health in autistic adults: A rapid review of prevalence of psychiatric disorders and umbrella review of the effectiveness of interventions within a neurodiversity informed perspective. *PLoS One*, 18(7), e0288275. <https://doi.org/10.1371/journal.pone.0288275>
- Cuthbertson, L. M., Robb, Y. A., & Blair, S. (2020). Theory and application of research principles and philosophical underpinning for a study utilising interpretative phenomenological analysis. *Radiography (Lond)*, 26(2), e94-e102. <https://doi.org/10.1016/j.radi.2019.11.092>
- Czech, H. (2018). Hans Asperger, national socialism, and "race hygiene" in Nazi-era Vienna. *Mol Autism*, 9, 29. <https://doi.org/10.1186/s13229-018-0208-6>
- Dababnah, S., Kim, I., & Shaia, W. E. (2022). 'I am so fearful for him': A mixed-methods exploration of stress among caregivers of black children with autism. *International Journal of Developmental Disabilities*, 68(5), 658–670. https://pmc.ncbi.nlm.nih.gov/articles/PMC9542792/pdf/YJDD_68_1870418.pdf
- Dai, X., Williams, G. J., Groeger, J. A., Jones, G., Brookes, K., Zhou, W., Hua, J., & Du, W. (2025). The role of circadian rhythms and sleep in the aetiology of autism spectrum disorder and attention-deficit/hyperactivity disorder: New evidence from bidirectional two-sample mendelian randomization analysis. *Autism*, 29(1), 76-86. <https://doi.org/10.1177/13623613241258546>
- Dai, Y., Chen, M., Deng, T., Huang, B., Ji, Y., Feng, Y., Liu, S., & Zhang, L. (2024). The importance of parenting self-efficacy and social support for family quality of life in children newly diagnosed with autism spectrum disorder: A one-year follow-up study. *Autism Res*, 17(1), 148-161. <https://doi.org/10.1002/aur.3061>
- Daniels, J. N. (2019). Disabled mothering? Outlawed, overlooked and severely prohibited: Interrogating ableism in motherhood. *Social Inclusion*, 7(1), 114-123. <https://doi.org/10.17645/si.v7i1.1551>
- Das, M., Tang, J., Ringland, K. E., & Piper, A. M. (2021). Towards accessible remote work: Understanding work-from-home practices of neurodivergent professionals. *Proc. ACM Hum. - Comput. Interact.*, 5(CSCW1), Article 183. <https://doi.org/10.1145/3449282>
- Davidsson, M., Ringstrom, F., Hagberg, B., Gillberg, C., & Billstedt, E. (2025). Adverse childhood experiences in children with neurodevelopmental disorders and their parents. *Nord J Psychiatry*, 79(3), 185-193. <https://doi.org/10.1080/08039488.2025.2469737>
- Davies, J., & Bagnall, C. (2024). "A good transition is just key": The views and experiences of disability support staff in supporting autistic students transition to university. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0076>
- Davies, J., Cooper, K., Killick, E., Sam, E., Healy, M., Thompson, G., Mandy, W., Redmayne, B., & Crane, L. (2024). Autistic identity: A systematic review of quantitative research. *Autism Res*, 17(5), 874-897. <https://doi.org/10.1002/aur.3105>
- Davies, J., Islaam, L., Carter, S., Redmayne, B., Cooper, K., Mandy, W., & Crane, L. (2024). Examining the support experiences of autistic young people with multiple marginalized identities in the United Kingdom. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0059>
- Davis, R., den Houting, J., Nordahl-Hansen, A., & Fletcher-Watson, S. (2022). Helping autistic children. In *The wiley-blackwell handbook of childhood social development* (pp. 729-746).
- de la Cuesta Benjumea, C. (2024). Assessing and achieving quality in qualitative research: Clues for researchers in training. *Invest Educ Enferm*, 42(1). <https://doi.org/10.17533/udea.iee.v42n1e02>
- DeBrabander, K. M., Morrison, K. E., Jones, D. R., Faso, D. J., Chmielewski, M., & Sasson, N. J. (2019). Do first impressions of autistic adults differ between autistic and nonautistic observers? *Autism in Adulthood*, 1(4), 250-257. <https://doi.org/10.1089/aut.2019.0018>

- Del Bianco, T., Lockwood Estrin, G., Lautarescu, A., Oakley, B. F., Eaton, E., Terčon, J., Douglas, S., Plas, J. R. D., Belton, D., Loth, E., Doherty, M., & Jones, E. J. H. (2025). Examining neurodiversity and inclusion in neuroscience research networks: A case study of the AIMS-2-TRIALS autism research consortium. *Open Research Europe*, 5. <https://doi.org/10.12688/openreseurope.19394.1>
- Dell'Osso, L., Amatori, G., Giovannoni, F., Massimetti, E., Cremone, I. M., & Carpita, B. (2024). Rumination and altered reactivity to sensory input as vulnerability factors for developing post-traumatic stress symptoms among adults with autistic traits. *CNS Spectr*, 29(2), 119-125. <https://doi.org/10.1017/S1092852924000014>
- Dell'Osso, L., & Carpita, B. (2022). What misdiagnoses do women with autism spectrum disorder receive in the DSM-5? *CNS Spectr*, 1-2. <https://doi.org/10.1017/S1092852922000037>
- Dell'Osso, L., Massoni, L., Battaglini, S., De Felice, C., Nardi, B., Amatori, G., Cremone, I. M., & Carpita, B. (2023). Emotional dysregulation as a part of the autism spectrum continuum: A literature review from late childhood to adulthood. *Frontiers in Psychiatry*, 14, 1234518. <https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsy.2023.1234518/pdf>
- Demetriou, E. A., Pepper, K. L., Park, S. H., Pellicano, L., Song, Y. J. C., Naismith, S. L., Hickie, I. B., Thomas, E. E., & Guastella, A. J. (2021). Autism spectrum disorder: An examination of sex differences in neuropsychological and self-report measures of executive and non-executive cognitive function. *Autism*, 25(8), 2223-2237. <https://doi.org/10.1177/13623613211014991>
- Deniz, E., & Toseeb, U. (2023). A longitudinal study of sibling bullying and mental health in autistic adolescents: The role of self-esteem. *Autism Res*, 16(8), 1533-1549. <https://doi.org/10.1002/aur.2987>
- Devnani, P. A., & Hegde, A. U. (2015). Autism and sleep disorders. *Journal of Pediatric Neurosciences*, 10(4), 304-307. <https://doi.org/10.4103/1817-1745.174438>
- Diemer, M. C., Gerstein, E. D., & Regester, A. (2022). Autism presentation in female and black populations: Examining the roles of identity, theory, and systemic inequalities. *Autism*, 13623613221113501. <https://doi.org/10.1177/13623613221113501>
- Dira, P. M. M., Machailo, R. J., & Scholtz, S. (2024). Caregivers' voices: From the world of autism spectrum disorder. *Curationis*, 47(1), e1-e11. <https://doi.org/10.4102/curationis.v47i1.2519>
- DoE. (2023). *A guide for parents on school behaviour and exclusion*. Department of Education. <https://www.gov.uk/government/publications/school-exclusions-guide-for-parents/a-guide-for-parents-on-school-behaviour-and-exclusion#where-to-get-support>
- DoH. (2014). *Think autism - fulfilling and rewarding lives. The strategy for autistic adults in England: An update*. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/301492/Think Autism -Autism Strategy-colour contrast version.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/301492/Think_Autism_-_Autism_Strategy-colour_contrast_version.pdf)
- DoH. (2015). *Statutory guidance for local authorities and NHS organisations to support implementation of the adult autism strategy*. <https://www.gov.uk/government/uploads/system/uploads/attachmentdata/file/422338/autism-guidance.pdf>
- DoH, & DoE. (2021). *The national strategy for autistic children, young people and adults: 2021 to 2026*. Retrieved 08/06/2023 from <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026#introduction>
- Doherty, M., McCowan, S., & Shaw, S. C. (2023). Autistic space: A novel framework for meeting the needs of autistic people in healthcare settings. *Br J Hosp Med (Lond)*, 84(4), 1-9. <https://doi.org/10.12968/hmed.2023.0006>
- Doherty, M., Neilson, S., O'Sullivan, J., Carravallah, L., Johnson, M., Cullen, W., & Shaw, S. C. K. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: A cross-sectional study. *BMJ Open*, 12(2), e056904. <https://doi.org/10.1136/bmjopen-2021-056904>

- Doherty, M., Neilson, S. D., O'Sullivan, J. D., Carravallah, L., Johnson, M., Cullen, W., & Gallagher, L. (2020). Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. *medRxiv*. <https://doi.org/10.1101/2020.04.01.20050336>
- Donovan, J., Chiatti, B. D., McKeever, A., Bloch, J. R., Gonzales, M. S., & Birati, Y. (2023). "Yes, I can bond." Reflections of autistic women's mothering experiences in the early postpartum period. *Womens Health (Lond)*, 19, 17455057231175312. <https://doi.org/10.1177/17455057231175312>
- Douglas, P., Runswick-Cole, K., Ryan, S., & Fogg, P. (2021). Mad mothering: Learning from the intersections of madness, mothering, and disability. *Journal of Literary & Cultural Disability Studies*, 15(1), 39-56. https://ora.ox.ac.uk/objects/uuid:19f1c5fd-1dcd-4f29-a2f4-1e172a4bf522/download_file?file_format=&safe_filename=Douglas+et+al+2021+mad+mothering+learning.pdf&type_of_work=Journal+article
- Douglas, P. N., & Klar, E. (2019). Beyond disordered brains and mother blame: Critical issues in autism and mothering. In L. O. Hallstein, A. O'Reilly, & M. Vandenbeld Giles (Eds.), *Routledge motherhood companion*. Routledge.
- Douglas, S., & Sedgewick, F. (2023). Experiences of interpersonal victimization and abuse among autistic people. *Autism*, 13623613231205630. <https://doi.org/10.1177/13623613231205630>
- Dowley, B. (2016). The development and importance of the autistic voice in understanding autism and enhancing services. *Good Autism Practice*, 17(1), 48-53.
- Doyle, N. (2020). Neurodiversity at work: A biopsychosocial model and the impact on working adults. *Br Med Bull*, 135(1), 108-125. <https://doi.org/10.1093/bmb/ldaa021>
- Doyle, N., McDowall, A., & Waseem, U. (2022). Intersectional stigma for autistic people at work: A compound adverse impact effect on labor force participation and experiences of belonging. *Autism in Adulthood*, 4(4), 340-356. <https://doi.org/10.1089/aut.2021.0082>
- Dubreucq, J., Plasse, J., Gabayet, F., Faraldo, M., Blanc, O., Chereau, I., Cervello, S., Couhet, G., Demily, C., Guillard-Bouhet, N., Gouache, B., Jaafari, N., Legrand, G., Legros-Lafarge, E., Pommier, R., Quiles, C., Straub, D., Verdoux, H., Vignaga, F.,...Franck, N. (2020). Self-stigma in serious mental illness and autism spectrum disorder: Results from the rehabase national psychiatric rehabilitation cohort. *Eur Psychiatry*, 63(1), e13. <https://doi.org/10.1192/j.eurpsy.2019.12>
- Dudas, R. B., Lovejoy, C., Cassidy, S., Allison, C., Smith, P., & Baron-Cohen, S. (2017). The overlap between autistic spectrum conditions and borderline personality disorder. *PLoS One*, 12(9), e0184447. <https://doi.org/10.1371/journal.pone.0184447>
- Dugdale, A. S., Thompson, A. R., Leedham, A., Beail, N., & Freeth, M. (2021). Intense connection and love: The experiences of autistic mothers. *Autism : the international journal of research and practice*, 25(7), 1973-1984. <https://doi.org/https://dx.doi.org/10.1177/13623613211005987>
- Dunn, D. (2022). Accepting the monsters. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0015>
- Dupuis, A., Mudiyaanselage, P., Burton, C. L., Arnold, P. D., Crosbie, J., & Schachar, R. J. (2022). Hyperfocus or flow? Attentional strengths in autism spectrum disorder [Original Research]. *Frontiers in Psychiatry*, 13. <https://doi.org/10.3389/fpsy.2022.886692>
- Duvekot, J., van der Ende, J., Verhulst, F. C., Slappendel, G., van Daalen, E., Maras, A., & Greaves-Lord, K. (2017). Factors influencing the probability of a diagnosis of autism spectrum disorder in girls versus boys. *Autism*, 21(6), 646-658. <https://doi.org/10.1177/1362361316672178>
- Dwyer, P. (2020, Jul). *Autism and Asperger's in the Nazi era*. Retrieved 7 from <https://www.ncbi.nlm.nih.gov/pubmed/30887409>
- Dwyer, P., Acevedo, S. M., Brown, H. M., Grapel, J., Jones, S. C., Nachman, B. R., Raymaker, D. M., & Williams, Z. J. (2021). An expert roundtable discussion on experiences of autistic autism researchers. *Autism in Adulthood*, 3(3), 209-220. <https://doi.org/10.1089/aut.2021.29019.rtb>
- Dwyer, P., Sillas, A., Prieto, M., Camp, E., Nordahl, C. W., & Rivera, S. M. (2024). Hyper-focus, sticky attention, and springy attention in young autistic children: Associations with sensory behaviors and cognitive ability. *Autism Res*, 17(8), 1677-1695. <https://doi.org/10.1002/aur.3174>
- Dwyer, P., Williams, Z. J., Lawson, W. B., & Rivera, S. M. (2024). A trans-diagnostic investigation of attention, hyper-focus, and monotropism in autism, attention dysregulation hyperactivity

- development, and the general population. *Neurodiversity*, 2.
<https://doi.org/10.1177/27546330241237883>
- Dyck, E., & Russell, G. (2020). Challenging psychiatric classification: Healthy autistic diversity and the neurodiversity movement. In *Healthy minds in the twentieth century* (pp. 167-187).
https://doi.org/10.1007/978-3-030-27275-3_8
- Easler, J. K., Taylor, T. M., Roper, S. O., Yorgason, J. B., & Harper, J. M. (2022). Uplifts, respite, stress, and marital quality for parents raising children with Down syndrome or autism. *Intellect Dev Disabil*, 60(2), 145-162. <https://doi.org/10.1352/1934-9556-60.2.145>
- Eaton, J. (2024). *Autism missed and misdiagnosed: Identifying, understanding and supporting diverse autistic identities*. Jessica Kingsley Publishers.
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In W. Stainton-Rogers & C. Willig (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179-194). Sage.
- Edwards, C., Love, A. M., Cai, R. Y., Heyworth, M., Johnston, A., Aldridge, F., & Gibbs, V. (2025). "I'm not feeling alone in my experiences": How newly diagnosed autistic adults engage with a neurodiversity-affirming "welcome pack". *Autism*, 13623613251335070.
<https://doi.org/10.1177/13623613251335070>
- Edwards, C., Love, A. M. A., Jones, S. C., Cai, R. Y., Nguyen, B. T. H., & Gibbs, V. (2023). 'Most people have no idea what autism is': Unpacking autism disclosure using social media analysis. *Autism*, 13623613231192133. <https://doi.org/10.1177/13623613231192133>
- Eidelman, A. I. (2022). Challenges to the autistic mother who wishes to breastfeed [Editorial]. *Breastfeeding Medicine: The Official Journal of the Academy of Breastfeeding Medicine*, 17(12), 979-980. <https://doi.org/https://dx.doi.org/10.1089/bfm.2022.29228.editorial>
- Evans, J. A., Krumrei-Mancuso, E. J., & Rouse, S. V. (2023). What you are hiding could be hurting you: Autistic masking in relation to mental health, interpersonal trauma, authenticity, and self-esteem. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0115>
- Fallon, M. J., Luczynski, K. C., Rodriguez, N. M., Felty, C., & Rahaman, J. A. (2025). A preliminary analysis of teaching children with autism spectrum disorder self-protection skills for bullying situations. *J Appl Behav Anal*, 58(2), 287-302. <https://doi.org/10.1002/jaba.2938>
- Farag, F., Sims, A., Strudwick, K., Carrasco, J., Waters, A., Ford, V., Hopkins, J., Whitlingum, G., Absoud, M., & Kelly, V. B. (2022). Avoidant/restrictive food intake disorder and autism spectrum disorder: Clinical implications for assessment and management. *Dev Med Child Neurol*, 64(2), 176-182. <https://doi.org/10.1111/dmcn.14977>
- Farsinejad, A., Russell, A., & Butler, C. (2022). Autism disclosure – the decisions autistic adults make. *Research in Autism Spectrum Disorders*, 93. <https://doi.org/10.1016/j.rasd.2022.101936>
- Fennell, L. C. P., & Johnson, S. A. (2022). Examination of professional biases about autism: How can we do better? *Clin Neuropsychol*, 36(5), 1094-1115.
<https://doi.org/10.1080/13854046.2021.1958922>
- Ferenc, K., Platos, M., Byrka, K., & Krol, M. E. (2023). Looking through rainbow-rimmed glasses: Taking neurodiversity perspective is related to subjective well-being of autistic adults. *Autism*, 27(5), 1348-1361. <https://doi.org/10.1177/13623613221135818>
- Fernandez-Prieto, M., Moreira, C., Cruz, S., Campos, V., Martinez-Regueiro, R., Taboada, M., Carracedo, A., & Sampaio, A. (2021). Executive functioning: A mediator between sensory processing and behaviour in autism spectrum disorder. *J Autism Dev Disord*, 51(6), 2091-2103.
<https://doi.org/10.1007/s10803-020-04648-4>
- Field, S. L., Williams, M. O., Jones, C. R. G., & Fox, J. R. E. (2024). A meta-ethnography of autistic people's experiences of social camouflaging and its relationship with mental health. *Autism*, 13623613231223036. <https://doi.org/10.1177/13623613231223036>
- Finch, T. L., Mackintosh, J., Petrou, A., McConachie, H., Le Couteur, A., Garland, D., & Parr, J. R. (2022). "We couldn't think in the box if we tried. We can't even find the damn box": A qualitative study of the lived experiences of autistic adults and relatives of autistic adults. *PLoS One*, 17(3), e0264932. <https://doi.org/10.1371/journal.pone.0264932>

- Fine, M., & Asch, A. (1988). *Women with disabilities : Essays in psychology, culture, and politics*. Temple University Press.
- Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing and Society*, 25(4), 601-621.
<https://doi.org/10.1017/s0144686x05003600>
- Finley, L. (2002). 'Outing' the researcher: The provenance, process, and practice of reflexivity. . *Qualitative Health Research*, 12(4). <https://doi.org/10.1177/104973202129120052>
- Fisher, E., MacLennan, K., Mullally, S., & Rodgers, J. (2025). Neuro-normative epistemic injustice – consequences for the UK education crisis and school anxiety. *Neurodiversity*, 3.
<https://doi.org/10.1177/27546330251353565>
- Fletcher-Randle, J. E. (2022). Where are all the autistic parents? A thematic analysis of autistic parenting discourse within the narrative of parenting and autism in online media. *Studies in Social Justice*, 16(2), 389-406.
<https://journals.library.brocku.ca/index.php/SSJ/article/view/2701/2935>
- Fletcher-Watson, S. (2024a). Reporting participatory methods and author positionality in autism. *Autism*, 28(8), 1869-1871. <https://doi.org/10.1177/13623613241266950>
- Fletcher-Watson, S. (2024b). What's in a name? The costs and benefits of a formal autism diagnosis. *Autism*, 28(2), 257-262. <https://doi.org/10.1177/13623613231213300>
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943-953. <https://doi.org/10.1177/1362361318786721>
- Fletcher, A. J. (2017). Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194.
<https://doi.org/10.1080/13645579.2016.1144401>
- Folstein, S., & Rutter, M. (1977). Infantile autism: A genetic study of 21 twin pairs. *J Child Psychol Psychiatry*, 18(4), 297-321. <https://doi.org/10.1111/j.1469-7610.1977.tb00443.x>
- Fombonne, E., & Zuckerman, K. E. (2021). Clinical profiles of black and white children referred for autism diagnosis. *Journal of autism and developmental disorders*, 1-11.
https://www.researchgate.net/profile/Katharine-Zuckerman/publication/350983528_Clinical_Profiles_of_Black_and_White_Children_Referred_for_Autism_Diagnosis/links/62335e5b548e2b163749baae/Clinical-Profiles-of-Black-and-White-Children-Referred-for-Autism-Diagnosis.pdf
- Fong, V., Gardiner, E., & Iarocci, G. (2021). Satisfaction with informal supports predicts resilience in families of children with autism spectrum disorder. *Autism*, 25(2), 452-463.
<https://doi.org/10.1177/1362361320962677>
- Forbes, P. A. G., & Hamilton, A. F. C. (2020). Brief report: Autistic adults assign less weight to affective cues when judging others' ambiguous emotional states. *J Autism Dev Disord*, 50(8), 3066-3070.
<https://doi.org/10.1007/s10803-020-04410-w>
- Foster, S., Ackerman, R. A., Wilks, C., Dodd, M., Calderon, R. M., Ropar, D., Fletcher-Watson, S., Crompton, C. J., & Sasson, N. (2024). Rapport in same and mixed neurotype groups of autistic and non-autistic adults. <https://doi.org/https://doi.org/10.31219/osf.io/efvbc>
- Foucault, M. (1965). *Madness and civilization; a history of insanity in the age of reason*. Pantheon Books.
- Foucault, M. (1991). *Discipline and punish: The birth of the prison*. Penguin.
- Frazier, T. W., Whitehouse, A. J., Leekam, S. R., Carrington, S. J., Alvares, G. A., Evans, D. W., Hardan, A. Y., & Uljarević, M. (2024). Reliability of the commonly used and newly-developed autism measures. *Journal of Autism and Developmental Disorders*, 54(6), 2158-2169.
- French, B., & Cassidy, S. (2024). "Going through life on hard mode"—the experience of late diagnosis of autism and/or ADHD: A qualitative study. *Autism in Adulthood*.
<https://doi.org/10.1089/aut.2024.0085>
- Freudenberger, H. J. (1977). *The staff burn-out syndrome*. Drug Abuse Council.

- Friedman, A., Paltoglou, A., & Sorte, R. (2024). A qualitative exploration of the experiences of self-diagnosed autistic women and gender-diverse individuals who are not pursuing an autism diagnosis. *Neurodiversity*, 2. <https://doi.org/10.1177/27546330241307828>
- Frith, U. (1991). *Autism and Asperger syndrome* (U. Frith, Ed.). Cambridge University Press. <https://doi.org/10.1017/CBO9780511526770>
- Frizell, C. A. (2024). Re: "'I've spent my whole life striving to be normal': Internalized stigma and perceived impact of diagnosis in autistic adults" by Huang et al.: Late diagnosis illuminated- perspectives on autism resilience and complexity. *Autism Adulthood*, 6(2), 247-248. <https://doi.org/10.1089/aut.2023.0210>
- Frost, N. (2011). *Qualitative research methods in psychology: Combining core approaches*. McGraw-Hill Education.
- Frost, N. (2016). *Practising research: Why you're always part of the research process even when you think you're not*. Palgrave.
- Fulton, R., Readon, E., Kate, R., & Jones, R. (2020). Sensory trauma: Autism, sensory difference and the daily experience of fear. https://www.researchgate.net/profile/Emma_Reardon2/publication/351918786_Sensory_Trauma_-_autism_sensory_difference_and_the_daily_experience_of_fear/links/60b002e6a6fdcc647ee3367f/Sensory-Trauma-autism-sensory-difference-and-the-daily-experience-of-fear.pdf
- Gadamer, H.-G. (2013). *Truth and method*. Bloomsbury Publishing Plc.
- Galan-Vera, I. Z., Robles-Bello, M. A., Sarhani-Robles, A., & Valencia-Naranjo, N. (2025). Experiences and coping strategies of parents with children diagnosed with autism spectrum disorder in early care with emphasis on social skills and family cultural values: A qualitative study. *Arch Psychiatr Nurs*, 56, 151864. <https://doi.org/10.1016/j.apnu.2025.151864>
- Galvin, J., Aguolu, P., Amos, A., Bayne, F., Hamza, F., & Alcock, L. (2024). Self-compassion, camouflaging, and mental health in autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0110>
- Galvin, J., Howes, A., & Richards, G. (2024). Longitudinal associations between autistic traits, self-compassion, anxiety and depression in autistic and non-autistic adults without intellectual disability. *J Autism Dev Disord*, 54(12), 4571-4583. <https://doi.org/10.1007/s10803-023-06157-6>
- Gara, S. K., Chhetri, A. G., Alrjoob, M., Abbasi, S. A. A., & Rutkofsky, I. H. (2020). The sensory abnormalities and neuropsychopathology of autism and anxiety. *Cureus*, 12(5).
- Garcia-Molina, I. (2024). "When I need help, I ask my friends": Experiences of Spanish autistic women when disclosing their late diagnosis to family and friends. *Front Psychol*, 15, 1342352. <https://doi.org/10.3389/fpsyg.2024.1342352>
- Garcia-Molina, I., & Cortes-Calvo, M. (2025). "Until I had my son, I did not realise that these characteristics could be due to autism": Motherhood and family experiences of Spanish autistic mothers. *Autism Adulthood*, 7(3), 303-311. <https://doi.org/10.1089/aut.2023.0013>
- Garcia-Simon, M. I., Del Mar Navarro-Jimenez, E., Martinez-Ortigosa, A., Roperio-Padilla, C., Roman, P., & Rodriguez-Arrastia, M. (2025). Experiences of females with late diagnosis of autism: Descriptive qualitative study. *Nurs Res*. <https://doi.org/10.1097/NNR.0000000000000825>
- Gardner, M., Suplee, P. D., Bloch, J., & Lecks, K. (2016). Exploratory study of childbearing experiences of women with Asperger syndrome [Article]. *Nursing for Women's Health*, 20(1), 28-37. <https://doi.org/10.1016/j.nwh.2015.12.001>
- Garfinkel, H. (1987). *Studies in ethnomethodology*. Prentice Hall.
- Garg, A., & Garg, A. (2022). The other side of motherhood. *International Journal*, 5(5), 617. <http://ijmscr.com/asset/images/uploads/16656232394813.pdf>
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, 14(3), 1-32. <https://doi.org/10.1353/nwsa.2003.0005>
- Garland-Thomson, R. (2005). Feminist disability studies. *Signs*, 30(2), 1567-1587. <https://doi.org/10.1086/423352>

- Garland-Thomson, R. (2017). *Extraordinary bodies: Figuring physical disability in American culture and literature*. Columbia University Press.
- Geelhand, P., Papastamou, F., Jaspard, S., & Kissine, M. (2025). Autistic adults display different verbal behavior only in mixed-neurotype interactions: Evidence from a referential communication task. *Autism*, 29(5), 1129-1142. <https://doi.org/10.1177/13623613241298376>
- Gellini, H., & Marczak, M. (2023). "I always knew I was different": Experiences of receiving a diagnosis of autistic spectrum disorder in adulthood—a meta-ethnographic systematic review. *Review Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s40489-023-00356-8>
- Gemma, N. (2021). Reconceptualising 'reasonable adjustments' for the successful employment of autistic women. *Disability & Society*, 1-19. <https://doi.org/10.1080/09687599.2021.1971065>
- Genovese, A. C., Singh, S. C., Casubhoy, I., & Hellings, J. A. (2023). Gender diverse autistic young adults: A mental health perspective. *Arch Sex Behav*, 52(3), 1339-1343. <https://doi.org/10.1007/s10508-022-02443-z>
- Gentles, S. J., McLaughlin, J., & Schneider, M. A. (2024). Stress among caregivers of autistic children: Conceptual analysis and verification using two qualitative datasets. *PLoS One*, 19(10), e0312391. <https://doi.org/10.1371/journal.pone.0312391>
- George, R., & Stokes, M. A. (2017). Gender identity and sexual orientation in autism spectrum disorder. *Autism : the international journal of research and practice*, 1362361317714587. <http://journals.sagepub.com/doi/full/10.1177/1362361317714587>
- Gernsbacher, M. A., & Yergeau, M. (2019). Empirical failures of the claim that autistic people lack a theory of mind. *Arch Sci Psychol*, 7(1), 102-118. <https://doi.org/10.1037/arc0000067>
- Ghanouni, P., & Quirke, S. (2023). Resilience and coping strategies in adults with autism spectrum disorder. *J Autism Dev Disord*, 53(1), 456-467. <https://doi.org/10.1007/s10803-022-05436-y>
- Ghanouni, P., Raphael, R., Seaker, L., & Casey, A. (2024). How to build resiliency in autistic individuals: An implication to advance mental health. *BMC Psychol*, 12(1), 420. <https://doi.org/10.1186/s40359-024-01916-1>
- Ghirardi, L., Kuja-Halkola, R., Butwicka, A., Martin, J., Larsson, H., D'Onofrio, B. M., Lichtenstein, P., & Taylor, M. J. (2021). Familial and genetic associations between autism spectrum disorder and other neurodevelopmental and psychiatric disorders. *J Child Psychol Psychiatry*, 62(11), 1274-1284. <https://doi.org/10.1111/jcpp.13508>
- Gibbs, V., Hudson, J. L., & Pellicano, E. (2023). Poly-victimization of autistic adults: An investigation of individual-level correlates. *Autism Res*, 16(12), 2336-2349. <https://doi.org/10.1002/aur.3031>
- Gibbs, V., & Pellicano, E. (2023). 'Maybe we just seem like easy targets': A qualitative analysis of autistic adults' experiences of interpersonal violence. *Autism*, 13623613221150375. https://discovery.ucl.ac.uk/id/eprint/10164483/2/Pellicano_ACCEPTED%20Autistic%20adults%20experiences%20of%20interpersonal%20violence%20FINAL%20%20Clean.pdf
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Stanford University Press.
- Gilmore, D., Radford, D., Haas, M. K., Shields, M., Bishop, L., & Hand, B. (2023). Building community and identity online: A content analysis of highly viewed #autism TikTok videos. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0019>
- Glasby, J., Tew, J., & Fenton, S.-J. (2021). UK mental health policy and practice. In *Mind, state and society: Social history of psychiatry and mental health in Britain 1960–2010* (pp. 93-102). Cambridge University Press.
- Glynne-Owen, R. (2010). Early intervention and autism: The impact of positivism and the call for change. *The International Journal of Children's Rights*, 18(3), 405-416. <https://doi.org/10.1163/157181810X497431>
- Goffman, E. (1959). *The presentation of self in everyday life*. Penguin.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Penguin Books.
- Gonçalves Garcia, S., da Silveira Simões-Pires, C., Acosta Brum, J., & Centurion Cabral, J. (2025). Taking off the mask: Investigating autism diagnosis and camouflaging in adult women. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0150>

- Gong, Y., Du, Y., Li, H., Zhang, X., An, Y., & Wu, B. L. (2015). Parenting stress and affective symptoms in parents of autistic children. *Sci China Life Sci*, 58(10), 1036-1043. <https://doi.org/10.1007/s11427-012-4293-z>
- Gore, K., Hayward, S. M., Flower, R. L., Gilbert, M., & Barbaro, J. (2024). "Maybe no one knows we need help": Understanding the experiences of autistic working mothers in Australia. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0089>
- Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism: The International Journal of Research & Practice*, 21(6), 703-705. <https://doi.org/10.1177/1362361317706174>
- Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis?: Girls and women on the autism spectrum. *Good Autism Practice*, 12(1), pp34.
- Granieri, J. E., McNair, M. L., Gerber, A. H., Reifler, R. F., & Lerner, M. D. (2020). Atypical social communication is associated with positive initial impressions among peers with autism spectrum disorder. *Autism*, 24(7), 1841-1848. <https://doi.org/10.1177/1362361320924906>
- Grant, A., Griffiths, C., Williams, K., & Brown, A. (2024). "It felt like I had an old fashioned telephone ringing in my breasts": An online survey of UK autistic birthing parents' experiences of infant feeding. *Matern Child Nutr*, 20(1), e13581. <https://doi.org/10.1111/mcn.13581>
- Grant, A., Jones, S., Williams, K., Leigh, J., & Brown, A. (2022). Autistic women's views and experiences of infant feeding: A systematic review of qualitative evidence. *Autism*, 13623613221089374. <https://doi.org/10.1177/13623613221089374>
- Grant, A., & Kara, H. (2021). Considering the autistic advantage in qualitative research: The strengths of autistic researchers. *Contemporary Social Science*, 16(5), 589-603. <https://doi.org/10.1080/21582041.2021.1998589>
- Grant, A., Turner, S., Shaw, S. C. K., Williams, K., Morgan, H., Ellis, R., & Brown, A. (2024). "I am afraid of being treated badly if I show it": A cross-sectional study of healthcare accessibility and autism health passports among UK autistic adults. *PLoS One*, 19(5), e0303873. <https://doi.org/10.1371/journal.pone.0303873>
- Gratton, F. V., Strang, J. F., Song, M., Cooper, K., Kallitsounaki, A., Lai, M. C., Lawson, W., van der Miesen, A. I. R., & Wimmis, H. E. (2023). The intersection of autism and transgender and nonbinary identities: Community and academic dialogue on research and advocacy. *Autism Adulthood*, 5(2), 112-124. <https://doi.org/10.1089/aut.2023.0042>
- Gray, S. M., McMorris, C. A., Mudry, T. E., & McCrimmon, A. W. (2024). An exploration of diagnostic identity for autistic individuals: A systematic review of existing literature. *Research in Autism Spectrum Disorders*, 114. <https://doi.org/10.1016/j.rasd.2024.102394>
- Green, K., Weir, E., Wright, L., Allison, C., & Baron-Cohen, S. (2025). Autistic and transgender/gender diverse people's experiences of health and healthcare. *Mol Autism*, 16(1), 4. <https://doi.org/10.1186/s13229-024-00634-0>
- Green, S. A., & Wood, E. T. (2019). The role of regulation and attention in atypical sensory processing. *Cogn Neurosci*, 10(3), 160-162. <https://doi.org/10.1080/17588928.2019.1592141>
- Greene, R. K., Rutter, T. M., Phelps, R. A., Olsen, E. K., Harmon, R., & Moyer, D. N. (2024). Diagnostic assessment of autism spectrum disorder in transgender and gender diverse youth. *Clin Neuropsychol*, 1-22. <https://doi.org/10.1080/13854046.2024.2331272>
- Greenlee, J. L., Piro-Gambetti, B., Putney, J., Papp, L. M., & Hartley, S. L. (2022). Marital satisfaction, parenting styles, and child outcomes in families of autistic children. *Fam Process*, 61(2), 941-961. <https://doi.org/10.1111/famp.12708>
- Grey, B., Dallos, R., & Stancer, R. (2021). Feeling 'like you're on ... a prison ship' – understanding the caregiving and attachment narratives of parents of autistic children. <https://doi.org/10.1177/26344041211000202>. *Human Systems: Therapy, Culture and Attachments*, 1(1), 96-114. <https://doi.org/10.1177/26344041211000202>
- Griffiths, S., Allison, C., Kenny, R., Holt, R., Smith, P., & Baron-Cohen, S. (2019). The vulnerability experiences quotient (veg): A study of vulnerability, mental health and life satisfaction in autistic adults. *Autism Res*, 12(10), 1516-1528. <https://doi.org/10.1002/aur.2162>

- Grinker, R. R. (2010). Commentary: On being autistic, and social. *Ethos*, 38(1), 205-218. <https://doi.org/10.1111/j.1548-1352.2010.01087.x>
- Grove, R., Clapham, H., Moodie, T., Gurrin, S., & Hall, G. (2023). 'Living in a world that's not about us': The impact of everyday life on the health and wellbeing of autistic women and gender diverse people [Research Support, Non-U.S. Gov't]. *Women's health*, 19, 17455057231189542. <https://doi.org/https://dx.doi.org/10.1177/17455057231189542>
- Gullon-Scott, F., & Long, C. (2022). Fill and perplexing presentations: What is the evidence base for and against current guidelines, and what are the implications for social services? *British Journal of Social Work*, 52(7), 4040-4056. <https://academic.oup.com/bjsw/article-pdf/52/7/4040/46578661/bcac037.pdf>
- Gur, A., Meir, Y. B., Edelstein, M., Nagar, M., Rokach, O., Reich, A., & Hindi, T. N. (2024). Family resilience in families of children with autism spectrum disorders: Ecological systems theory perspective. *Intellect Dev Disabil*, 62(6), 474-485. <https://doi.org/10.1352/1934-9556-62.6.474>
- Gurba, A. N., McNair, M. L., Hargreaves, A., Scheerer, N. E., Ng, C. S. M., & Lerner, M. D. (2024). Editorial: Break the stigma: Autism. The future of research on autism stigma - towards multilevel, contextual and global understanding. *Front Psychiatry*, 15, 1504429. <https://doi.org/10.3389/fpsyt.2024.1504429>
- Gurbuz, E., Hanley, M., & Riby, D. M. (2019). University students with autism: The social and academic experiences of university in the UK. *Journal of autism and developmental disorders*, 49, 617-631. <https://link.springer.com/content/pdf/10.1007/s10803-018-3741-4.pdf>
- Gurbuz, E., Riby, D. M., South, M., & Hanley, M. (2024). Associations between autistic traits, depression, social anxiety and social rejection in autistic and non-autistic adults. *Sci Rep*, 14(1), 9065. <https://doi.org/10.1038/s41598-024-59532-3>
- Hacking, I. (1995). The looping effects of human kinds. In D. Sperber, D. Premack, & A. J. Premack (Eds.), *Causal cognition: A multidisciplinary approach* Oxford University Press.
- Hacking, I. (2009). Autistic autobiography. *Philos Trans R Soc Lond B Biol Sci*, 364(1522), 1467-1473. <https://doi.org/10.1098/rstb.2008.0329>
- Halsall, J., Clarke, C., & Crane, L. (2021). "Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators. *Autism*, 25(7), 2074-2086. <https://doi.org/10.1177/13623613211012819>
- Hamdani, Y., Kassee, C., Walker, M., Lunsby, Y., Gladstone, B., Sawyer, A., Ameis, S. H., Desarkar, P., Szatmari, P., & Lai, M. C. (2023). Roadblocks and detours on pathways to a clinical diagnosis of autism for girls and women: A qualitative secondary analysis. *Womens Health (Lond)*, 19, 17455057231163761. <https://doi.org/10.1177/17455057231163761>
- Hampton, S., Allison, C., Aydin, E., Baron-Cohen, S., & Holt, R. (2022). Autistic mothers' perinatal well-being and parenting styles. *Autism*, 26(7), 1805-1820. <https://doi.org/10.1177/13623613211065544>
- Hampton, S., Allison, C., Baron-Cohen, S., & Holt, R. (2023). Autistic people's perinatal experiences II: A survey of childbirth and postnatal experiences. *J Autism Dev Disord*, 53(7), 2749-2763. <https://doi.org/10.1007/s10803-022-05484-4>
- Hampton, S., Man, J., Allison, C., Aydin, E., Baron-Cohen, S., & Holt, R. (2021). A qualitative exploration of autistic mothers' experiences II: Childbirth and postnatal experiences. *Autism*, 13623613211043701. <https://doi.org/10.1177/13623613211043701>
- Hampton, S., Man, J., Allison, C., Aydin, E., Baron-Cohen, S., & Holt, R. (2022). A qualitative exploration of autistic mothers' experiences II: Childbirth and postnatal experiences. *Autism*, 26(5), 1165-1175. https://pmc.ncbi.nlm.nih.gov/articles/PMC9340136/pdf/10.1177_13623613211043701.pdf
- Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res*, 15(1), 12-26. <https://doi.org/10.1002/aur.2652>
- Han, E., Scior, K., Grace, K., Heath, E., Dufresne, S., & Crane, L. (2024). 'Who, when, how to share': Pilot study of a new disclosure decision-making programme for autistic adults. *Autism*, 13623613231221685. <https://doi.org/10.1177/13623613231221685>

- Han, E., Scior, K., Heath, E., Umagami, K., & Crane, L. (2023). Development of stigma-related support for autistic adults: Insights from the autism community. *Autism*, 27(6), 1676-1689. <https://doi.org/10.1177/13623613221143590>
- Hand, B. N., Gilmore, D., DeVassie, H., Longo, A., Juckett, L., Hanks, C., Haverkamp, S. M., & Coury, D. (2024). Development of prepare for autistic adults: An adult autism training for resident physicians designed with autistic adults and family members. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0137>
- Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3), 575-599. <https://doi.org/10.2307/3178066>
- Harmens, M., Sedgewick, F., & Hobson, H. (2021). The quest for acceptance: A blog-based study of autistic women's experiences and well-being during autism identification and diagnosis. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2021.0016>
- Harmens, M., Sedgewick, F., & Hobson, H. (2022). Autistic women's diagnostic experiences: Interactions with identity and impacts on well-being. *Womens Health (Lond)*, 18, 17455057221137477. <https://doi.org/10.1177/17455057221137477>
- Harrold, A., Keating, K., Larkin, F., & Setti, A. (2024). The association between sensory processing and stress in the adult population: A systematic review. *Applied Psychology: Health and Well-Being*, 16(4), 2536-2566. <https://iaap-journals.onlinelibrary.wiley.com/doi/pdf/10.1111/aphw.12554>
- Harrop, C., Tomaszewski, B., Putnam, O., Klein, C., Lamarche, E., & Klinger, L. (2024). Are the diagnostic rates of autistic females increasing? An examination of state-wide trends. *J Child Psychol Psychiatry*. <https://doi.org/10.1111/jcpp.13939>
- Hartley, G., Sirois, F., Purrington, J., & Rabey, Y. (2023). Adverse childhood experiences and autism: A meta-analysis. *Trauma Violence Abuse*, 15248380231213314. <https://doi.org/10.1177/15248380231213314>
- Hartman, D., O'Donnell-Killen, T., Doyle, J. K., Kavanagh, M., Day, A., & Azevedo, J. (2023). *The adult autism assessment handbook. A neurodiversity-affirmative approach*. Jessica Kingsley Publishers.
- Hartung, C. M., & Widiger, T. A. (1998). Gender differences in the diagnosis of mental disorders: Conclusions and controversies of the DSM-IV. *Psychological Bulletin*, 123(3), 260. <https://doi.org/10.1037/0033-2909.123.3.260>
- Hasson, L., Keville, S., Gallagher, J., Onagbesan, D., & Ludlow, A. K. (2024). Inclusivity in education for autism spectrum disorders: Experiences of support from the perspective of parent/carers, school teaching staff and young people on the autism spectrum. *Int J Dev Disabil*, 70(2), 201-212. <https://doi.org/10.1080/20473869.2022.2070418>
- Hatton, V. A., & Lee, M. X. (2021). An evaluation of the online post-diagnostic groups facilitated by the autism spectrum condition service at Gloucestershire Health and Care NHS. *Advances in Autism*, 8(4), 319-331. <https://doi.org/10.1108/aia-08-2021-0035>
- Hayes, J., Ford, T., McCabe, R., & Russell, G. (2022). Autism diagnosis as a social process. *Autism*, 26(2), 488-498. <https://doi.org/10.1177/13623613211030392>
- Hayward, S. M., McVilly, K. R., & Stokes, M. A. (2020). Sources and impact of occupational demands for autistic employees. *Research in Autism Spectrum Disorders*, 76, 101571. <https://www.sciencedirect.com/science/article/pii/S1750946720300611/pdf?md5=83c77da0938fe0a72c8b420b2ddd62e3&pid=1-s2.0-S1750946720300611-main.pdf>
- Heidegger, M. (1962). *Being and time*, 1927. Harper.
- Henderson, L. M., St Clair, M., Knowland, V., van Rijn, E., Walker, S., & Gaskell, M. G. (2023). Stronger associations between sleep and mental health in adults with autism: A UK biobank study. *J Autism Dev Disord*, 53(4), 1543-1559. <https://doi.org/10.1007/s10803-021-05382-1>
- Hens, K., & Van Goidsenhoven, L. (2023). Developmental diversity: Putting the development back into research about developmental conditions. *Frontiers in Psychiatry*, 13, 2994. <https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsy.2022.986732/pdf>
- Hernández González, O., González Fernández, D., Spencer Contreras, R., Gillespie-Smith, K., & Jara Rojas, E. (2024). The childbearing and mental health experiences of autistic mothers: A

- systematic review. *International Journal of Developmental Disabilities*, 1-15.
<https://doi.org/10.1080/20473869.2024.2353456>
- Heyworth, M., Brett, S., den Houting, J., Magiati, I., Steward, R., Urbanowicz, A., Stears, M., & Pellicano, E. (2023). "I'm the family ringmaster and juggler": Autistic parents' experiences of parenting during the COVID-19 pandemic. *Autism in Adulthood*, 5(1), 24-36.
<https://pmc.ncbi.nlm.nih.gov/articles/PMC10024268/pdf/aut.2021.0097.pdf>
- Higgins, E. T. (2012). Regulatory focus theory. *Handbook of theories of social psychology*, 1, 483-504.
- Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #autisticburnout. *Autism*, 25(8), 2356-2369. <https://doi.org/10.1177/13623613211019858>
- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bolte, S. (2016). Premature mortality in autism spectrum disorder. *Br J Psychiatry*, 208(3), 232-238.
<https://doi.org/10.1192/bjp.bp.114.160192>
- Hollingworth, D., Ferguson, L., Schaub, J., & Kempson-Byrne, S. (2023). *Autism and parental blame: A systematic literature review*.
- Horton, E., Goldschmied, A. Z., Knops, M. J. J., Brownhill, L. A., Bycroft, A., Lloyd, A., Tones, D., Wiltshire, B., Toro, C. T., & Jutley-Neilson, J. (2024). Empowering voices: Fostering reflective dialogue and redefining research dynamics in participatory approaches with the autistic community. *Journal of Participatory Research Methods*, 5(3).
<https://doi.org/10.35844/001c.122455>
- Hosozawa, M., Sacker, A., & Cable, N. (2021). Timing of diagnosis, depression and self-harm in adolescents with autism spectrum disorder. *Autism*, 25(1), 70-78.
<https://doi.org/10.1177/1362361320945540>
- Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism*, 23(7), 1871-1876. <https://doi.org/10.1177/1362361318823902>
- Howard, P. L., & Sedgewick, F. (2021). 'Anything but the phone!': Communication mode preferences in the autism community. *Autism*, 25(8), 2265-2278. <https://doi.org/10.1177/13623613211014995>
- HRA. (2017). *UK policy framework for health and social care research*. <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>
- Huang, Y., Arnold, S. R. C., Foley, K. R., & Trollor, J. N. (2024). A qualitative study of adults' and support persons' experiences of support after autism diagnosis. *J Autism Dev Disord*, 54(3), 1157-1170. <https://doi.org/10.1007/s10803-022-05828-0>
- Huang, Y., Hwang, Y. I. J., Arnold, S. R. C., Lawson, L. P., Richdale, A. L., & Trollor, J. N. (2022). Autistic adults' experiences of diagnosis disclosure. *J Autism Dev Disord*, 52(12), 5301-5307.
<https://doi.org/10.1007/s10803-021-05384-z>
- Huang, Y., Trollor, J. N., Foley, K.-R., & Arnold, S. R. C. (2023). "I've spent my whole life striving to be normal": Internalized stigma and perceived impact of diagnosis in autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0066>
- Huisman, B., Noens, I., Steensma, T. D., Kreukels, B. P. C., & van der Miesen, A. I. R. (2024). Autism traits in transgender and gender-diverse adults seeking gender-affirming medical treatment. *International Journal of Transgender Health*, 1-17.
<https://doi.org/10.1080/26895269.2024.2368077>
- Hull, L., Levy, L., Lai, M. C., Petrides, K. V., Baron-Cohen, S., Allison, C., Smith, P., & Mandy, W. (2021). Is social camouflaging associated with anxiety and depression in autistic adults? *Mol Autism*, 12(1), 13. <https://doi.org/10.1186/s13229-021-00421-1>
- 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. *J Autism Dev Disord*, 47(8), 2519-2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. *Review Journal of Autism and Developmental Disorders*, 7(4), 306-317.
<https://doi.org/10.1007/s40489-020-00197-9>

- Hume, R., & Burgess, H. (2020). "I'm human after all": Autism, trauma, and affective empathy. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0013>
- Humm, M. (1995). *Practicing feminist criticism: An introduction*. Prentice Hall.
- Humphrey, N., & Lewis, S. (2008). Make me normal' the views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1), 23-46.
https://www.researchgate.net/profile/Neil-Humphrey-2/publication/5670942_Make_me_normal'/links/55714e1708aee701d61cc0ac/Make-me-normal.pdf
- Hunt, A. D., & Procyshyn, T. L. (2024). Changing perspectives on autism: Overlapping contributions of evolutionary psychiatry and the neurodiversity movement. *Autism Res*, 17(3), 459-466.
<https://doi.org/10.1002/aur.3078>
- Hussein, A. (2021). *A participatory research approach to understanding the experiences of black, Asian and minority ethnic (bame) autistic young people* University of East London].
- Hutson, P., & Hutson, J. (2023). Autism in females: Understanding the overlooked diagnoses, unique challenges, and recommendations. *Journal of Clinical & Medical Images*, 3(3).
<https://digitalcommons.lindenwood.edu/cgi/viewcontent.cgi?article=1494&context=faculty-research-papers>
- Hwang, S. K., & Heslop, P. (2023). Autistic parents' personal experiences of parenting and support: Messages from an online focus group. *The British Journal of Social Work*, 53(1), 276-295.
<https://researchportal.northumbria.ac.uk/files/70954708/PURE.pdf>
- Hwang, Y. I. J., Arnold, S., Srasuebkul, P., & Trollor, J. (2020). Understanding anxiety in adults on the autism spectrum: An investigation of its relationship with intolerance of uncertainty, sensory sensitivities and repetitive behaviours. *Autism*, 24(2), 411-422.
<https://doi.org/10.1177/1362361319868907>
- ICO. (2018). *Guide to the General Data Protection Regulation (GDPR)*. <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/>
- IPSEA. (2025). *Exclusion from school*. Retrieved 13/06/2025 from
<https://www.ipsea.org.uk/pages/category/exclusion-from-school>
- Jadav, N., & Bal, V. H. (2022). Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research. *Autism Res*.
<https://doi.org/10.1002/aur.2808>
- Jamal, W., Cardinaux, A., Haskins, A. J., Kjølgaard, M., & Sinha, P. (2021). Reduced sensory habituation in autism and its correlation with behavioral measures. *Journal of Autism and Developmental Disorders*, 51, 3153-3164.
https://dspace.mit.edu/bitstream/handle/1721.1/136861/10803_2020_4780_ReferencePDF.pdf?sequence=1&isAllowed=n
- Jason, G. J. (2025). Selling eugenic killing: The Nazi propaganda campaign to support the liquidation of the disabled. <https://philarchive.org/archive/JASSEK>
- Jedrzejewska, A., & Dewey, J. (2022). Camouflaging in autistic and non-autistic adolescents in the modern context of social media. *J Autism Dev Disord*, 52(2), 630-646.
<https://doi.org/10.1007/s10803-021-04953-6>
- Jellet, R., & Muggleton, J. (2022). Implications of applying "clinically significant impairment" to autism assessment: Commentary on six problems encountered in clinical practice. *Journal of autism and developmental disorders*, 52(3), 1412-1421.
<https://link.springer.com/content/pdf/10.1007/s10803-021-04988-9.pdf>
- Jeong, H., & Othman, J. (2016). Using interpretative phenomenological analysis from a realist perspective. *The Qualitative Report*, 21(3), 558-570.
https://www.researchgate.net/profile/Hyeseung-Jeong/publication/298972470_Using_Interpretative_Phenomenological_Analysis_from_a_Realist_Perspective/links/56edecf208aea35d5b9954c3/Using-Interpretative-Phenomenological-Analysis-from-a-Realist-Perspective.pdf
- Jones, D. R., Botha, M., Ackerman, R. A., King, K., & Sasson, N. J. (2023). Non-autistic observers both detect and demonstrate the double empathy problem when evaluating interactions between

- autistic and non-autistic adults. *Autism*, 13623613231219743. <https://doi.org/10.1177/13623613231219743>
- Jones, D. R., Nicolaidis, C., Ellwood, L. J., Garcia, A., Johnson, K. R., Lopez, K., & Waisman, T. C. (2020). An expert discussion on structural racism in autism research and practice. *Autism Adulthood*, 2(4), 273-281. <https://doi.org/10.1089/aut.2020.29015.drj>
- Jones, S. C. (2022). Autistics working in academia: What are the barriers and facilitators? *Autism*, 13623613221118158. <https://doi.org/10.1177/13623613221118158>
- Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2021). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-021-04998-7>
- Jones, S. C., Gordon, C. S., & Mizzi, S. (2023). Representation of autism in fictional media: A systematic review of media content and its impact on viewer knowledge and understanding of autism. *Autism*, 27(8), 2205-2217. <https://doi.org/10.1177/13623613231155770>
- Junttila, M., Kielinen, M., Jussila, K., Joskitt, L., Mantymaa, M., Ebeling, H., & Mattila, M. L. (2024). The traits of autism spectrum disorder and bullying victimization in an epidemiological population. *Eur Child Adolesc Psychiatry*, 33(4), 1067-1080. <https://doi.org/10.1007/s00787-023-02228-2>
- Jurkevithz, R., Campbell, M., & Morgan, L. (2020). *Spectrum women: Autism and parenting*. Jessica Kingsley Publishers.
- Kadiri, F. (2022). Autism spectrum disorder: The state of play. *Journal of Psychology and Behavior Studies*, 2(2), 05-10. <https://www.academia.edu/download/88929499/3180.pdf>
- Kallianes, V., & Rubenfeld, P. (1997). Disabled women and reproductive rights. *Disability & Society*, 12(2), 203-222. <https://doi.org/10.1080/09687599727335>
- Kallitsounaki, A., & Williams, D. M. (2022). Autism spectrum disorder and gender dysphoria/incongruence. A systematic literature review and meta-analysis. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-022-05517-y>
- Kandeh, M. S., Kandeh, M. K., Martin, N., & Krupa, J. (2020). Autism in black, Asian and minority ethnic communities: A report on the first Autism Voice UK symposium. *Advances in Autism*, 6(2), 165-175. <https://doi.org/10.1108/aia-12-2018-0051>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250. http://mail.neurodiversity.com/library_kanner_1943.pdf
- Kanner, L. (1944). Early infantile autism. *Journal of Paediatrics*, 25(3), 211-217. [https://doi.org/10.1016/S0022-3476\(44\)80156-1](https://doi.org/10.1016/S0022-3476(44)80156-1)
- Kanner, L. (1949). Problems of nosology and psychodynamics of early infantile autism. *The American Journal of Orthopsychiatry*, 19, 416-426. <https://doi.org/10.1111/j.1939-0025.1949.tb05441.x>
- Kaplan, S. (2024). *The ones that got away: The role of eugenicists in the sustainment of medical atrocities in Nazi Germany*
- Kapp, S. K. (2022). Models of helping and coping with autism. In *The Routledge international handbook of critical autism studies* (pp. 255-269). Routledge.
- Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*, 23(7), 1782-1792. <https://doi.org/10.1177/1362361319829628>
- Keating, C. T., Hickman, L., Geelhand, P., Takahashi, T., Leung, J., Monk, R., Schuster, B., Rybicki, A., Girolamo, T. M., Clin, E., Papastamou, F., Belenger, M., Eigsti, I. M., Cook, J. L., Kosaka, H., Osu, R., Okamoto, Y., & Sowden-Carvalho, S. (2024). Cross-cultural variation in experiences of acceptance, camouflaging and mental health difficulties in autism: A registered report. *PLoS One*, 19(3), e0299824. <https://doi.org/10.1371/journal.pone.0299824>
- Kelly, C., Sharma, S., Jieman, A.-T., & Ramon, S. (2024). Sense-making narratives of autistic women diagnosed in adulthood: A systematic review of the qualitative research. *Disability & Society*, 39(3), 663-695. <https://doi.org/10.1080/09687599.2022.2076582>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462. <https://doi.org/10.1177/1362361315588200>

- Kenny, L., Remington, A., & Pellicano, E. (2024). Everyday executive function issues from the perspectives of autistic adolescents and their parents: Theoretical and empirical implications. *Autism*, 13623613231224093. <https://doi.org/10.1177/13623613231224093>
- Keshavarz, S., & Esmaeilpour, K. (2025). Relationship between social anxiety and separation anxiety symptoms with insistence on sameness with the mediating role of sensory hypersensitivity. *BMC Psychol*, 13(1), 62. <https://doi.org/10.1186/s40359-025-02369-w>
- Keville, S., Mills, M., & Ludlow, A. K. (2024). Exploring mothers' experiences of accessing an education health and care plan (EHCP) for an autistic child attending mainstream school in the United Kingdom. *International Journal of Developmental Disabilities*, 1-12. <https://doi.org/10.1080/20473869.2023.2298606>
- Khasakhala, E., Bota, K., Ayaga, G., Sichari, M., Wesonga, B., & Kokonya, D. (2023). Comorbidity of mental health and autism spectrum disorder: Perception of practitioners in management of their challenging behaviour. *International Journal of Developmental Disabilities*, 69(3), 386-397. <https://doi.org/10.1080/20473869.2023.2203531>
- Kiep, M., Spek, A., Ceulemans, E., & Noens, I. (2025). Sensory processing and executive functioning in autistic adults. *J Autism Dev Disord*, 55(6), 2075-2084. <https://doi.org/10.1007/s10803-023-06008-4>
- Kim, E. J., Skinner, T., & Parish, S. L. (2019). A study on intersectional discrimination in employment against disabled women in the UK. *Disability & Society*, 35(5), 715-737. <https://doi.org/10.1080/09687599.2019.1702506>
- Kim, S. Y., & Bottema-Beutel, K. (2019). Negotiation of individual and collective identities in the online discourse of autistic adults. *Autism in Adulthood*, 1(1), 69-78. <https://doi.org/10.1089/aut.2018.0029>
- King, D. K. (1988). Multiple jeopardy, multiple consciousness: The context of a black feminist ideology. *Signs: Journal of Women in Culture and Society*, 14(1), 42-72. <https://doi.org/10.1086/494491>
- Kirby, A. V., Little, L. M., Schultz, B., & Baranek, G. T. (2015). Observational characterization of sensory interests, repetitions, and seeking behaviors. *Am J Occup Ther*, 69(3), 6903220010p6903220011-6903220019. <https://doi.org/10.5014/ajot.2015.015081>
- Kniola, A., Ludwig, N. N., Singh, V., Bradley, C., Carpenter, L., Dillon, E. F., Kanne, S., Kim, S. H., Parish-Morris, J., Snyder, L. G., Consortium, S., & Wodka, E. L. (2024). Delayed milestones and demographic factors relate to the accuracy of autism screening in females using spoken language. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-024-06579-w>
- Knoll, K. R. (2012). *Feminist disability studies: Theoretical debates, activism, identity politics and coalition building* [University of Washington]. Washington. https://digital.lib.washington.edu/researchworks/bitstream/handle/1773/20505/Knoll_washington_0250E_10341.pdf?sequence=1&isAllowed=y
- Koffer Miller, K. H., Cooper, D. S., Song, W., & Shea, L. L. (2022). Self-reported service needs and barriers reported by autistic adults: Differences by gender identity. *Research in Autism Spectrum Disorders*, 92. <https://doi.org/10.1016/j.rasd.2022.101916>
- Kotagal, S., Malow, B., Spruyt, K., Wang, G., Bolanos Almeida, C. E., Tavera Saldana, L. M., Blunden, S., Narang, I., Ipsiroglu, O. S., Bruni, O., Strazisar, B. G., Simakajornboon, N., Nunes, M. L., & Cortese, S. (2024). Melatonin use in managing insomnia in children with autism and other neurogenetic disorders - an assessment by the international pediatric sleep association (ipsa). *Sleep Med*, 119, 222-228. <https://doi.org/10.1016/j.sleep.2024.04.008>
- Koteyko, N., Van Driel, M., Billan, S., Barros Pena, B., & Vines, J. (2024). Stigma management strategies of autistic social media users. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0095>
- Kourti, M. (2021a). A critical realist approach on autism: Ontological and epistemological implications for knowledge production in autism research. *Front Psychol*, 12, 713423. <https://doi.org/10.3389/fpsyg.2021.713423>
- Kourti, M. (2021b). *Working with autistic transgender and non-binary people: Research, practice, and experience*. Jessica Kingsley Publishers.

- Kteily, N. S., & Landry, A. P. (2022). Dehumanization: Trends, insights, and challenges. *Trends in Cognitive Sciences*, 26(3), 222-240. [https://www.cell.com/trends/cognitive-sciences/abstract/S1364-6613\(21\)00311-9](https://www.cell.com/trends/cognitive-sciences/abstract/S1364-6613(21)00311-9)
- Kulasinghe, K., Whittingham, K., & Mitchell, A. E. (2022). Emotional availability in the mother-child relationship for families of young children with autism spectrum disorder in Australia: A cross-sectional survey. *Res Dev Disabil*, 131, 104365. <https://doi.org/10.1016/j.ridd.2022.104365>
- Kung, K. T. F. (2024). Autistic traits, gender minority stress, and mental health in transgender and non-binary adults. *J Autism Dev Disord*, 54(4), 1389-1397. <https://doi.org/10.1007/s10803-022-05875-7>
- Kuzminski, R., Black, M. H., Bölte, S., Lawson, W., Falkmer, M., Philips, S., Girdler, S., & Milbourn, B. (2025). Using photovoice to capture the quality of life of the Australian autistic community. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0178>
- Lai, M. C., Amestoy, A., Bishop, S., Brown, H. M., Giwa Onaiwu, M., Halladay, A., Harrop, C., Hotez, E., Huerta, M., Kelly, A., Miller, D., Nordahl, C. W., Ratto, A. B., Saulnier, C., Siper, P. M., Sohl, K., Zwaigenbaum, L., & Goldman, S. (2023). Improving autism identification and support for individuals assigned female at birth: Clinical suggestions and research priorities. *Lancet Child Adolesc Health*, 7(12), 897-908. [https://doi.org/10.1016/S2352-4642\(23\)00221-3](https://doi.org/10.1016/S2352-4642(23)00221-3)
- LaManna, J. B., & Quelly, S. B. (2020). After gestational diabetes: An overlooked care transition in primary care. *The Journal for Nurse Practitioners*, 16(5), 319-323. [https://www.npjjournal.org/article/S1555-4155\(20\)30050-7/pdf](https://www.npjjournal.org/article/S1555-4155(20)30050-7/pdf)
- Lamash, L., Gutman, Y., Meyer, S., & Gal, E. (2025). Aligning perspectives: Autism identity, independence, participation, and quality of life in autistic adolescents through self and parental reports. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-025-06836-6>
- Lamash, L., Sagie, D., Selanikyo, E., Meyer, S., & Gal, E. (2024). Autism identity in young adults and the relationships with participation, quality of life, and well-being. *Research in Autism Spectrum Disorders*, 111. <https://doi.org/10.1016/j.rasd.2023.102311>
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120. <https://doi.org/10.1191/1478088706qp062oa>
- Lawson, W. B. (2020). Adaptive morphing and coping with social threat in autism: An autistic perspective. *Journal of Intellectual Disability-Diagnosis and Treatment*, 8(3), 519-526. https://researchers.mq.edu.au/files/164977020/Publisher_version.pdf
- Leachman, C., Nichols, E. S., Al-Saoud, S., & Duerden, E. G. (2024). Anxiety in children and adolescents with autism spectrum disorder: Behavioural phenotypes and environmental factors. *BMC Psychol*, 12(1), 534. <https://doi.org/10.1186/s40359-024-02044-6>
- Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Front Psychol*, 12, 635690. <https://doi.org/10.3389/fpsyg.2021.635690>
- Lee, E. A. L., Scott, M., Black, M. H., D'Arcy, E., Tan, T., Sheehy, L., Bolte, S., & Girdler, S. (2024). "He sees his autism as a strength, not a deficit now": A repeated cross-sectional study investigating the impact of strengths-based programs on autistic adolescents. *J Autism Dev Disord*, 54(5), 1656-1671. <https://doi.org/10.1007/s10803-022-05881-9>
- Lee, J., & Barger, B. (2024). Factors predicting poor mental and physical health in parents of children with autism spectrum disorder: Results from 2016 to 2019 National Survey of Children's Health. *J Autism Dev Disord*, 54(3), 915-930. <https://doi.org/10.1007/s10803-022-05870-y>
- Lee, J. Y. S., Whittingham, K., Olson, R., & Mitchell, A. E. (2025). "Their happiness, not neurotypical success": Autistic adults reflect on the parenting of autistic children. *J Autism Dev Disord*, 55(1), 339-352. <https://doi.org/10.1007/s10803-023-06188-z>
- Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, 24(1), 135-146. <https://doi.org/10.1177/1362361319853442>

- Lei, J., Brosnan, M., Ashwin, C., & Russell, A. (2020). Evaluating the role of autistic traits, social anxiety, and social network changes during transition to first year of university in typically developing students and students on the autism spectrum. *J Autism Dev Disord*, 50(8), 2832-2851. <https://doi.org/10.1007/s10803-020-04391-w>
- Lei, J., Cooper, K., & Hollocks, M. J. (2024). Psychological interventions for autistic adolescents with co-occurring anxiety and depression: Considerations linked to autism social identity and masking. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0005>
- Leitner, Y. (2014). The co-occurrence of autism and attention deficit hyperactivity disorder in children—what do we know? *Frontiers in human neuroscience*, 8, 268. <https://www.frontiersin.org/journals/human-neuroscience/articles/10.3389/fnhum.2014.00268/pdf>
- Lenker, K. P., Li, Y., Fernandez-Mendoza, J., Mayes, S. D., & Calhoun, S. L. (2025). Autism spectrum disorder phenotypes based on sleep dimensions and core autism symptoms. *Journal of autism and developmental disorders*, 1-13. <https://link.springer.com/content/pdf/10.1007/s10803-025-06822-y.pdf>
- Lewis, L. F., & Stevens, K. (2023). The lived experience of meltdowns for autistic adults. *Autism*, 27(6), 1817-1825. <https://doi.org/10.1177/13623613221145783>
- Li, J. L., Washington-Nortey, M., Kifle, T. H., Cotier, F., & Hoekstra, R. A. (2025). The role of extended family members in the lives of autistic individuals and their parents: A systematic review and meta-synthesis. *Clin Child Fam Psychol Rev*, 28(2), 507-539. <https://doi.org/10.1007/s10567-025-00525-7>
- Liang, K., Lai Lam, K. K., Huang, L., Lin, X., Wang, Z., Liu, H., & Chi, P. (2025). Self-compassion, mental health, and parenting: Comparing parents of autistic and non-autistic children. *Autism*, 29(1), 53-63. <https://doi.org/10.1177/13623613241286683>
- Libster, N., Harwood, R., Meacham, K., & Kasari, C. (2024). "I do my best to do right by her": Autistic motherhood and the experience of raising a non-autistic adolescent daughter [Research Support, U.S. Gov't, P.H.S.]. *Autism*, 28(6), 1357-1368. <https://doi.org/https://dx.doi.org/10.1177/13623613241241577>
- Licence, L., Oliver, C., Moss, J., & Richards, C. (2020). Prevalence and risk-markers of self-harm in autistic children and adults. *J Autism Dev Disord*, 50(10), 3561-3574. <https://doi.org/10.1007/s10803-019-04260-1>
- Lieneman, C., Guastello, A., Munson, M., Barthle-Herrera, M., Bailey, B., Higham, M., Druskin, L. R., & McNeil, C. B. (2024). Conceptualizing co-occurring autism spectrum disorder, obsessive-compulsive disorder, and gender diversity in adolescents: A narrative review. *Journal of Indian Association for Child and Adolescent Mental Health*, 20(2), 97-110. <https://doi.org/10.1177/09731342241252560>
- Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S., Trollor, J., Yudell, M., & Pellicano, E. (2023). "Peas in a pod": Oral history reflections on autistic identity in family and community by late-diagnosed adults. *J Autism Dev Disord*, 53(3), 1146-1161. <https://doi.org/10.1007/s10803-022-05667-z>
- Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S. R., Trollor, J. N., Yudell, M., & Pellicano, E. (2022). 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*, 26(6), 1395-1408. <https://doi.org/10.1177/13623613211050694>
- Lim, A., Young, R. L., & Brewer, N. (2022). Autistic adults may be erroneously perceived as deceptive and lacking credibility. *J Autism Dev Disord*, 52(2), 490-507. <https://doi.org/10.1007/s10803-021-04963-4>
- Lin, C. Y., Wu, Y. L., Chien, Y. L., & Gau, S. S. (2025). Quality of life and clinical correlates in cognitively-able autistic adults: A special focus on sensory characteristics and perceived parental support. *J Formos Med Assoc*, 124(2), 157-163. <https://doi.org/10.1016/j.jfma.2024.03.022>
- Lin, X., Su, X., Huang, S., Liu, Z., Yu, H., Wang, X., Lin, L., Cao, M., Li, X., & Jing, J. (2023). Association between maternal parenting styles and behavioral problems in children with ASD: Moderating

- effect of maternal autistic traits. *Front Psychiatry*, 14, 1107719.
<https://doi.org/10.3389/fpsyt.2023.1107719>
- Linden, A., Best, L., Elise, F., Roberts, D., Branagan, A., Tay, Y. B. E., Crane, L., Cusack, J., Davidson, B., Davidson, I., Hearst, C., Mandy, W., Rai, D., Smith, E., & Gurusamy, K. (2023). Benefits and harms of interventions to improve anxiety, depression, and other mental health outcomes for autistic people: A systematic review and network meta-analysis of randomised controlled trials. *Autism*, 27(1), 7-30. <https://doi.org/10.1177/13623613221117931>
- Lindsay, S., Osten, V., Rezai, M., & Bui, S. (2021). Disclosure and workplace accommodations for people with autism: A systematic review. *Disabil Rehabil*, 43(5), 597-610.
<https://doi.org/10.1080/09638288.2019.1635658>
- Livingston, L. A. (2021). Substance use, coping, and compensation in autism. *The Lancet Psychiatry*, 8(8), 641-642. [https://doi.org/10.1016/s2215-0366\(21\)00205-4](https://doi.org/10.1016/s2215-0366(21)00205-4)
- Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: A qualitative study. *The Lancet Psychiatry*, 6(9), 766-777.
[https://doi.org/10.1016/s2215-0366\(19\)30224-x](https://doi.org/10.1016/s2215-0366(19)30224-x)
- Ljubicic, M., Sare, S., & Kolcic, I. (2025). Sleep quality and evening salivary cortisol levels in association with the psychological resources of parents of children with developmental disorders and type 1 diabetes. *J Autism Dev Disord*, 55(4), 1481-1494. <https://doi.org/10.1007/s10803-024-06269-7>
- Lockwood Estrin, G., Milner, V., Spain, D., Happe, F., & Colvert, E. (2021). Barriers to autism spectrum disorder diagnosis for young women and girls: A systematic review. *Review Journal of Autism and Developmental Disorders*, 8(4), 454-470. <https://doi.org/https://dx.doi.org/10.1007/s40489-020-00225-8>
- Long, C., Eaton, J., Russell, S., Gullon-Scott, F., & Bilson, A. (2022). *Fabricated or induced illness and perplexing presentations: Abbreviated practice guide for social work practitioners*.
https://basw.co.uk/sites/default/files/resources/fabricated_or_induced_illness_-_a_practice_guide_for_social_workers.pdf
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry*, 56(6), 466-474. <https://doi.org/10.1016/j.jaac.2017.03.013>
- Lopez, K. (2022). Intersectionality on the horizon: Exploring autism in adulthood from a unique vantage point. *Autism in Adulthood*, 4(4), 255-257. <https://doi.org/10.1089/aut.2022.29023.editorial>
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The autism diagnostic observation schedule—generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205-223. <https://doi.org/10.1023/A:1005592401947>
- Losada-Puente, L., Bana, M., & Asorey, M. J. F. (2022). Family quality of life and autism spectrum disorder: Comparative diagnosis of needs and impact on family life. *Res Dev Disabil*, 124, 104211. <https://doi.org/10.1016/j.ridd.2022.104211>
- Loth, E. (2023). Does the current state of biomarker discovery in autism reflect the limits of reductionism in precision medicine? Suggestions for an integrative approach that considers dynamic mechanisms between brain, body, and the social environment. *Frontiers in Psychiatry*, 14, 1085445. <https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsyt.2023.1085445/pdf>
- Lotter, V. (1966). Epidemiology of autistic conditions in young children. *Social Psychiatry*, 1(3).
<https://link.springer.com/content/pdf/10.1007/BF00584048.pdf>
- Lovaas, O. I., Berberich, J. P., Perloff, B. F., & Schaeffer, B. (1966). Acquisition of imitative speech by schizophrenic children. *Science*, 151(3711), 705-707.
<https://www.science.org/doi/epdf/10.1126/science.151.3711.705>
- Lovaas, O. I., Schreibman, L., & Koegel, R. L. (1974). A behavior modification approach to the treatment of autistic children. *Journal of Autism and Childhood Schizophrenia*, 4(2), 111-129.
https://www.researchgate.net/profile/Robert-Koegel/publication/18685897_A_behavior_modification_approach_to_the_treatment_of_autistic

[children/links/55a4223d08ae81aec912e69e/A-behavior-modification-approach-to-the-treatment-of-autistic-children.pdf](https://doi.org/10.1089/aut.2023.0005)

- Love, A. M. A., Cai, R. Y., Edwards, C., & Gibbs, V. (2023). Exploring identity importance for autistic adults and associations with disclosure experiences: A brief report. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0005>
- Love, A. M. A., Edwards, C., Cai, R. Y., & Gibbs, V. (2023). Using experience sampling methodology to capture disclosure opportunities for autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0090>
- Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, 8(12), 1713-1721. <https://doi.org/10.1016/j.rasd.2014.09.009>
- Luymes, N. J., Redquest, B. K., Rollo, L., & Fletcher, P. C. (2023). "They say 'we don't have resources! We don't have EAs [educational assistants]! We can't handle your kids!': Mothers' perspectives on their autistic children's school experiences. *Journal on Developmental Disabilities*, 28(2).
- MacLennan, K., Woolley, C., and sensory, E., Heasman, B., Starns, J., George, B., & Manning, C. (2022). "It is a big spider web of things": Sensory experiences of autistic adults in public spaces. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0024>
- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91(1), 1-20. <https://doi.org/10.1348/000712600161646>
- Mahabala, K. Y., Dutt, A., Shenoy, R., Lee, Y., Thimmaiah, C., Bhat, S., Nayak, A., & Rao, A. (2025). A scoping review on parental/caregiver challenges in maintaining oral hygiene among children with autism spectrum disorder. *Int J Paediatr Dent*, 35(3), 566-576. <https://doi.org/10.1111/ipd.13268>
- Mailick, M., Bennett, T., DaWalt, L. S., Durkin, M. S., Forbes, G., Howlin, P., Lord, C., Zaidman-Zait, A., Zwaigenbaum, L., Bal, V., Bishop, S., Chiang, C. H., DiMartino, A., Freitag, C. M., Georgiades, S., Hollocks, M., Lai, M. C., Maenner, M. J., Powell, P. S.,...Halladay, A. (2025). Expanding research on contextual factors in autism research: What took us so long? *Autism Res*, 18(4), 710-716. <https://doi.org/10.1002/aur.3312>
- Malacrida, C. (2009). Performing motherhood in a disablist world: Dilemmas of motherhood, femininity and disability. *International Journal of Qualitative Studies in Education*, 22(1), 99-117. <https://doi.org/10.1080/09518390802581927>
- Malacrida, C. (2019). Mothering and disability: From eugenics to newgenics. In *Routledge handbook of disability studies* (pp. 467-478). Routledge.
- Mallett, R., & Runswick-Cole, K. (2014). *Approaching disability: Critical issues and perspectives*. Routledge.
- Mallipeddi, N. V., & VanDaalen, R. A. (2021). Intersectionality within critical autism studies: A narrative review. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2021.0014>
- Mandy, W., Pellicano, L., St Pourcain, B., Skuse, D., & Heron, J. (2018). The development of autistic social traits across childhood and adolescence in males and females [Developmental Disorders & Autism 3250]. *Journal of Child Psychology and Psychiatry*, 59(11), 1143-1151. <https://doi.org/http://dx.doi.org/10.1111/jcpp.12913> (Child Psychology & Psychiatry & Allied Disciplines)
- Mannion, A., & Leader, G. (2013). Comorbidity in autism spectrum disorder: A literature review. *Research in Autism Spectrum Disorders*, 7(12), 1595-1616. <https://doi.org/https://doi.org/10.1016/j.rasd.2013.09.006>
- Mannion, A., & Leader, G. (2023). Relationship between child sleep problems in autism spectrum disorder and parent mental health and well-being. *Sleep Med*, 109, 4-10. <https://doi.org/10.1016/j.sleep.2023.05.009>
- Mannion, A., Whelan, S., & Leader, G. (2024). An examination of sleep problems and parental well-being, comparing families with and without autistic children. *Research in Autism Spectrum Disorders*, 117. <https://doi.org/10.1016/j.rasd.2024.102462>

- Manoli, D. S., & State, M. W. (2021). Autism spectrum disorder genetics and the search for pathological mechanisms. *American Journal of Psychiatry*, 178(1), 30-38.
<https://psychiatryonline.org/doi/pdf/10.1176/appi.ajp.2020.20111608>
- Mansour, H., Gillions, A., Brown, J., Pattenden, A., Hartley, S., Patel, S., James, S., Styles, M., Mandy, W., Stott, J., & O'Nions, E. (2025). 'It's designed for someone who is not me': A reflexive thematic analysis of the unmet healthcare support needs in UK autistic adults aged 65 years and over. *Autism*, 29(3), 754-765. <https://doi.org/10.1177/13623613241291081>
- Mantzas, J., Richdale, A. L., & Dissanayake, C. (2022). A conceptual model of risk and protective factors for autistic burnout. *Autism Res*, 15(6), 976-987. <https://doi.org/10.1002/aur.2722>
- Marriott, E., Stacey, J., Hewitt, O. M., & Verkuil, N. E. (2022). Parenting an autistic child: Experiences of parents with significant autistic traits. *J Autism Dev Disord*, 52(7), 3182-3193.
<https://doi.org/10.1007/s10803-021-05182-7>
- Marshall, T. (2015). *I am aspie woman: The unique characteristics, traits and gifts of adult females on the autism spectrum*. Tania A Marshall.
- Martin, K. B., Haltigan, J. D., Ekas, N., Prince, E. B., & Messinger, D. S. (2020). Attachment security differs by later autism spectrum disorder: A prospective study. *Developmental Science*, 23(5), e12953. <https://doi.org/https://doi.org/10.1111/desc.12953>
- Martin, N. (2020). University through the eyes of autistic students and staff. In *Neurodiversity reader*.
<https://openresearch.lsbu.ac.uk/download/decefd5b528d4d955128cf529ede48c1dc679e66265a8af31ecc021e5111a9db/122823/Neurodiversity%20Reader%20Chapter%2026.pdf>
- Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., Brown, T., Woodbury-Smith, M., Wilson, C., Finch, T., & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. *Autism*, 25(3), 774-785.
<https://doi.org/10.1177/1362361321993709>
- Mason, D., Stewart, G. R., Capp, S. J., & Happé, F. (2022). Older age autism research: A rapidly growing field, but still a long way to go. *Autism in Adulthood*, 4(2), 164-172.
<https://pmc.ncbi.nlm.nih.gov/articles/PMC9645679/pdf/aut.2021.0041.pdf>
- Maw, K. J., Beattie, G., & Burns, E. J. (2024). Cognitive strengths in neurodevelopmental disorders, conditions and differences: A critical review. *Neuropsychologia*, 197, 108850.
<https://doi.org/10.1016/j.neuropsychologia.2024.108850>
- May, T., & Perry, B. (2017). *Reflexivity: The essential guide*. Sage.
- Maye, M., Boyd, B. A., Martinez-Pedraza, F., Halladay, A., Thurm, A., & Mandell, D. S. (2022). Biases, barriers, and possible solutions: Steps towards addressing autism researchers under-engagement with racially, ethnically, and socioeconomically diverse communities. *J Autism Dev Disord*, 52(9), 4206-4211. <https://doi.org/10.1007/s10803-021-05250-y>
- Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism*, 18(3), 223-232. <https://doi.org/10.1177/1362361312474121>
- McAuliffe, C., Walsh, R. J., & Cage, E. (2023). "My whole life has been a process of finding labels that fit": A thematic analysis of autistic LGBTQIA+ identity and inclusion in the LGBTQIA+ community. *Autism Adulthood*, 5(2), 127-138. <https://doi.org/10.1089/aut.2021.0074>
- McCarty, M. J., & Brumback, A. C. (2021). Rethinking stereotypes in autism. *Semin Pediatr Neurol*, 38, 100897. <https://doi.org/10.1016/j.spen.2021.100897>
- McCauley, J. B., Pickles, A., Huerta, M., & Lord, C. (2020). Defining positive outcomes in more and less cognitively able autistic adults. *Autism Res*, 13(9), 1548-1560. <https://doi.org/10.1002/aur.2359>
- McGonigle, J. J., Venkat, A., Beresford, C., Campbell, T. P., & Gabriels, R. L. (2014). Management of agitation in individuals with autism spectrum disorders in the emergency department. *Child and Adolescent Psychiatric Clinics*, 23(1), 83-95. <https://doi.org/10.1016/j.chc.2013.08.003>
- McKee, K. (2009). Post-Foucauldian governmentality: What does it offer critical social policy analysis? *Critical Social Policy*, 29(3), 465-486. <https://doi.org/10.1177/0261018309105180>
- McKinlay, J., Wilson, C., Hendry, G., & Ballantyne, C. (2022). "It feels like sending your children into the lions' den" - a qualitative investigation into parental attitudes towards ASD inclusion, and the

- impact of mainstream education on their child. *Res Dev Disabil*, 120, 104128.
<https://doi.org/10.1016/j.ridd.2021.104128>
- McKinlay, M., Thorpe, D., Cage, E., Grainger, C., Jasper, C., & Stewart, M. (2025). A systematic review: Which psycho-social-environmental factors do autistic students identify as being important for positive experiences in mainstream secondary school? *Autism*, 29(3), 566-578.
<https://doi.org/10.1177/13623613241285974>
- McLean, K. J., Eack, S. M., & Bishop, L. (2021). The impact of sleep quality on quality of life for autistic adults. *Res Autism Spectr Disord*, 88. <https://doi.org/10.1016/j.rasd.2021.101849>
- McMunn, A., Xue, B., Di Gessa, G., & Lacey, R. (2024). Sandwich care in the UK: How common is it and who is doing it. In.
- McQuaid, G. A., Lee, N. R., & Wallace, G. L. (2022). Camouflaging in autism spectrum disorder: Examining the roles of sex, gender identity, and diagnostic timing. *Autism*, 26(2), 552-559.
<https://doi.org/10.1177/13623613211042131>
- McQuaid, G. A., Pelphrey, K. A., Bookheimer, S. Y., Dapretto, M., Webb, S. J., Bernier, R. A., McPartland, J. C., Van Horn, J. D., & Wallace, G. L. (2021). The gap between IQ and adaptive functioning in autism spectrum disorder: Disentangling diagnostic and sex differences. *Autism*, 25(6), 1565-1579. <https://doi.org/10.1177/1362361321995620>
- McQuaid, G. A., Ratto, A. B., Jack, A., Khuu, A., Smith, J. V., Duane, S. C., Clawson, A., Lee, N. R., Verbalis, A., Pelphrey, K. A., Kenworthy, L., Wallace, G. L., & Strang, J. F. (2024). Gender, assigned sex at birth, and gender diversity: Windows into diagnostic timing disparities in autism. *Autism*, 13623613241243117. <https://doi.org/10.1177/13623613241243117>
- McQuaid, G. A., Strang, J., & Jack, A. (2022). Borderline personality and late, missed, and misdiagnosis in female autism: A review of the literature.
<https://files.osf.io/v1/resources/t37vj/providers/osfstorage/6238e6698b90a6069eae4a35?action=download&direct&version=1>
- McVey, A. J., Jones, D. R., Waisman, T. C., Raymaker, D. M., Nicolaidis, C., & Maddox, B. B. (2023). Mindshift in autism: A call to professionals in research, clinical, and educational settings. *Front Psychiatry*, 14, 1251058. <https://doi.org/10.3389/fpsyt.2023.1251058>
- Meeussen, L., & Van Laar, C. (2018). Feeling pressure to be a perfect mother relates to parental burnout and career ambitions. *Front Psychol*, 9, 2113. <https://doi.org/10.3389/fpsyg.2018.02113>
- Megari, K., Frantzezou, C. K., Polyzopoulou, Z. A., & Tzouni, S. K. (2024). Neurocognitive features in childhood and adulthood in autism spectrum disorder: A neurodiversity approach. *Int J Dev Neurosci*, 84(6), 471-499. <https://doi.org/10.1002/jdn.10356>
- Mehta, R. (2025). Extended kangaroo mother care - examining the utility of skin-to-skin contact over the first year of life. *Infant Behav Dev*, 79, 102055. <https://doi.org/10.1016/j.infbeh.2025.102055>
- Merleau-Ponty, M. (2012). *Phenomenology of perception*. Routledge.
- Mesa, S., & Hamilton, L. G. (2022). "We are different, that's a fact, but they treat us like we're different-er": Understandings of autism and adolescent identity development. *Advances in Autism*, 8(3), 217-231.
<http://ray.yorksj.ac.uk/id/eprint/5367/1/Mesa%20%26%20Hamilton%20%282021%29.pdf>
- Micai, M., Fatta, L. M., Gila, L., Caruso, A., Salvitti, T., Fulceri, F., Ciaramella, A., D'Amico, R., Del Giovane, C., Bertelli, M., Romano, G., Schunemann, H. J., & Scattoni, M. L. (2023). Prevalence of co-occurring conditions in children and adults with autism spectrum disorder: A systematic review and meta-analysis. *Neurosci Biobehav Rev*, 155, 105436.
<https://doi.org/10.1016/j.neubiorev.2023.105436>
- Miller, D., Rees, J., & Pearson, A. (2021). "Masking is life": Experiences of masking in autistic and nonautistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0083>
- Miller, E., Farrington, P., & Taylor, B. (1999). MMR vaccination and autism. *The Lancet*, 354(9182), 950.
[https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(05\)75697-X.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(05)75697-X.pdf)
- Milner, V., Colvert, E., Hull, L., Cook, J., Ali, D., Mandy, W., & Happe, F. (2023). Does camouflaging predict age at autism diagnosis? A comparison of autistic men and women. *Autism Res*.
<https://doi.org/10.1002/aur.3059>

- Milner, V., Mandy, W., Happe, F., & Colvert, E. (2022). Sex differences in predictors and outcomes of camouflaging: Comparing diagnosed autistic, high autistic trait and low autistic trait young adults. *Autism*, 13623613221098240. <https://doi.org/10.1177/13623613221098240>
- Milner, V., McIntosh, H., Colvert, E., & Happe, F. (2019). A qualitative exploration of the female experience of autism spectrum disorder (ASD). *J Autism Dev Disord*, 49(6), 2389-2402. <https://doi.org/10.1007/s10803-019-03906-4>
- Milosevic, S., Brookes-Howell, L., Randell, E., Williams-Thomas, R., Delport, S., Busse, M., Gillespie, D., Ahuja, A. S., McKigney, A. M., Glarou, E., & McNamara, R. (2022). Understanding the support experiences of families of children with autism and sensory processing difficulties: A qualitative study. *Health Expectations*, 25(3), 1118-1130. <https://doi.org/https://doi.org/10.1111/hex.13465>
- Milton, D. (2017). *A mismatch of salience: Explorations of the nature of autism from theory to practice*. Pavilion Press.
- Milton, D., Gurbuz, E., & Lopez, B. (2022). The 'double empathy problem': Ten years on. *Autism*, 26(8), 1901-1903. <https://doi.org/10.1177/13623613221129123>
- Milton, D., Heasman, B., & Sheppard, E. (2018). Double empathy. In F. Volkmar (Ed.), *Encyclopedia of autism spectrum disorders*. Springer.
- Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18(7), 794-802. <https://doi.org/10.1177/1362361314525281>
- Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27(6), 883-887. <https://doi.org/10.1080/09687599.2012.710008>
- Mittertreiner, E. J., Ng-Cordell, E., McVey, A. J., & Kerns, C. M. (2024). Research methods at the intersection of gender diversity and autism: A scoping review. *Autism*, 13623613241245595. <https://doi.org/10.1177/13623613241245595>
- Mo, K., Sadoway, T., Bonato, S., Ameis, S. H., Anagnostou, E., Lerch, J. P., Taylor, M. J., & Lai, M. C. (2021). Sex/gender differences in the human autistic brains: A systematic review of 20 years of neuroimaging research. *Neuroimage Clin*, 32, 102811. <https://doi.org/10.1016/j.nicl.2021.102811>
- Mo, S., Viljoen, N., & Sharma, S. (2021). The impact of socio-cultural values on autistic women: An interpretative phenomenological analysis. *Autism*, 13623613211037896. <https://doi.org/10.1177/13623613211037896>
- Mokoena, N., & Kern, A. (2022). Experiences of siblings to children with autism spectrum disorder. *Front Psychiatry*, 13, 959117. <https://doi.org/10.3389/fpsy.2022.959117>
- Montaque, I., Dallos, R., & McKenzie, B. (2018). "It feels like something difficult is coming back to haunt me": An exploration of 'meltdowns' associated with autistic spectrum disorder from a parental perspective. *Clin Child Psychol Psychiatry*, 23(1), 125-139. <https://doi.org/10.1177/1359104517730114>
- Moore, H. L., Cassidy, S., & Rodgers, J. (2024). Exploring the mediating effect of camouflaging and the moderating effect of autistic identity on the relationship between autistic traits and mental wellbeing. *Autism Res*, 17(7), 1391-1406. <https://doi.org/10.1002/aur.3073>
- Moore, I., Morgan, G., & Howard, C. (2024). Constructions of "female autism" in professional practices: A Foucauldian discourse analysis. *Feminism & Psychology*. <https://doi.org/10.1177/09593535241283325>
- Moore, I., Morgan, G., Welham, A., & Russell, G. (2022). The intersection of autism and gender in the negotiation of identity: A systematic review and metasynthesis. *Feminism & Psychology*. <https://doi.org/10.1177/09593535221074806>
- Morgan, H., Durman, E., & Henry, K. (2024). *Supporting autistic people through pregnancy and childbirth*. Jessica Kingsley Publishers.
- Morgan, R. (2023). How do adolescent autistic girls construct selfconcept and social identity? A discourse analysis. *Educational Psychology in Practice*, 39(2), 178-200. <https://www.tandfonline.com/doi/epdf/10.1080/02667363.2023.2181316?needAccess=true>

- Morris-Rosendahl, D. J., & Crocq, M. A. (2020). Neurodevelopmental disorders-the history and future of a diagnostic concept. *Dialogues Clin Neurosci*, 22(1), 65-72.
<https://doi.org/10.31887/DCNS.2020.22.1/macrocq>
- Morris, I. F., Sykes, J. R., Paulus, E. R., Dameh, A., Razzaque, A., Esch, L. V., Gruenig, J., & Zelazo, P. D. (2025). Beyond self-regulation: Autistic experiences and perceptions of stimming. *Neurodiversity*, 3. <https://doi.org/10.1177/27546330241311096>
- Morris, J. (1991). 'Us' and 'them'? Feminist research, community care and disability. *Critical Social Policy*, 11(33), 22-39. <https://doi.org/1177/026101839101103302>
- Morris, J. (1996). *Encounters with strangers: Feminism and disability*. The Women's Press.
- Morrison, K. E., DeBrabander, K. M., Jones, D. R., Faso, D. J., Ackerman, R. A., & Sasson, N. J. (2020). Outcomes of real-world social interaction for autistic adults paired with autistic compared to typically developing partners. *Autism*, 24(5), 1067-1080.
<https://doi.org/10.1177/1362361319892701>
- Morsa, B. (2023). *On psychoanalysis'(mis) formulation of autistic children*.
https://play.google.com/store/books/details?id=8GquEAAAOBAJ&rdid=book-8GquEAAAOBAJ&rdot=1&source=gbs_vpt_read&pcampaignid=books_booksearch_viewport
- Morton, H. E. (2021). Assessment of bullying in autism spectrum disorder: Systematic review of methodologies and participant characteristics. *Review Journal of Autism and Developmental Disorders*, 8(4), 482-497. <https://link.springer.com/article/10.1007/s40489-020-00232-9>
- Moser, C., Smith DaWalt, L., Burke, M. M., & Taylor, J. L. (2024). Emerging adulthood in autism: Striving for independence or interdependence? *Autism*, 28(6), 1325-1327.
<https://doi.org/10.1177/13623613241245647>
- Moser, C. A., & Kalton, G. (1985). *Survey methods in social investigation*. Routledge.
- Mullally, S. L., & Connolly, S. E. (2025). "I felt shamed and blamed": An exploration of the parental lived experience of school distress. *Front Psychiatry*, 16, 1489316.
<https://doi.org/10.3389/fpsyt.2025.1489316>
- Muniandy, M., Richdale, A. L., Arnold, S. R. C., Trollor, J. N., & Lawson, L. P. (2025). Brief report: Longitudinal role of coping strategies on mental health outcomes in autistic youth and adults. *J Autism Dev Disord*, 55(3), 1146-1155. <https://doi.org/10.1007/s10803-023-05953-4>
- Munroe, A., & Dunleavy, M. (2023). Recognising autism in girls within the education context: Reflecting on the internal presentation and the diagnostic criteria. *Irish Educational Studies*, 42(4), 561-581.
<https://doi.org/10.1080/03323315.2023.2260371>
- Murphy, S. (2021). The pros and cons of being an autistic parent. *Good Autism Practice (GAP)*, 22(1), 87-96. <https://www.ingentaconnect.com/content/bild/gap/2021/00000022/00000001/art00009>
- Murray, D., Lesser, M., & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9(2), 139-156. <https://doi.org/10.1177/1362361305051398>
- Murray, D., Milton, D., Green, J., & Bervoets, J. (2023). The human spectrum: A phenomenological enquiry within neurodiversity. *Psychopathology*, 56(3), 220-230.
<https://doi.org/10.1159/000526213>
- Musetti, A., Zagaria, A., Pezzi, M., Fante, C., Dioni, B., Raffin, C., Manari, T., Lenzo, V., & De Luca Picione, R. (2024). Parental quality of life, child adjustment and adult attachment in parents of children and adolescents with autism spectrum disorder. *Res Dev Disabil*, 146, 104684.
<https://doi.org/10.1016/j.ridd.2024.104684>
- Nah, Y. H., & Tan, J. W. (2021). The effect of diagnostic labels on teachers' perceptions of behaviours of students with autism spectrum disorder. *Br J Educ Psychol*, 91(1), 315-327.
<https://doi.org/10.1111/bjep.12368>
- Nakic Rados, S., Hairston, I., & Handelzalts, J. E. (2024). The concept analysis of parent-infant bonding during pregnancy and infancy: A systematic review and meta-synthesis. *J Reprod Infant Psychol*, 42(2), 142-165. <https://doi.org/10.1080/02646838.2022.2162487>
- NAO. (2024). *Support for children and young people with special educational needs*.
<https://www.nao.org.uk/reports/support-for-children-and-young-people-with-special-educational-needs/>

- Narvekar, N., Carter Leno, V., Pasco, G., Begum Ali, J., Johnson, M. H., Charman, T., Jones, E. J. H., & Team, S. (2024). The roles of sensory hyperreactivity and hyporeactivity in understanding infant fearfulness and emerging autistic traits. *J Child Psychol Psychiatry*, 65(8), 1022-1036. <https://doi.org/10.1111/jcpp.13941>
- NAS. (2024). *My health passport*. National Autistic Society. Retrieved 20/11/2024 from <https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport>
- Natri, H. M., Abubakare, O., Asasumasu, K., Basargekar, A., Beaud, F., Botha, M., Bottema-Beutel, K., Brea, M. R., Brown, L. X. Z., Burr, D. A., Cobbaert, L., Dabbs, C., Denome, D., Rosa, S. D. R., Doherty, M., Edwards, B., Edwards, C., Liszk, S. E., Elise, F.,...Zisk, A. H. (2023). Anti-ableist language is fully compatible with high-quality autism research: Response to singer et al. (2023). *Autism Res*, 16(4), 673-676. <https://doi.org/10.1002/aur.2928>
- Nayyar, J. M., Stapleton, A. V., Guerin, S., & O'Connor, C. (2024). Exploring lived experiences of receiving a diagnosis of autism in adulthood: A systematic review. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0152>
- Nayyar, J. M., Stapleton, A. V., Guerin, S., & O'Connor, C. (2025). Exploring lived experiences of receiving a diagnosis of autism in adulthood: A systematic review. *Autism in Adulthood*, 7(1), 1-12.
- NCT. (2016). *Difficulties with baby bonding affect a third of UK mums*. <https://www.nct.org.uk/about-us/media/news/difficulties-baby-bonding-affect-third-uk-mums>
- Nemati, S., Shojaeian, N., Bardel, M., Deetjen-Ruiz, R., Khani, Z., & McHugh, L. (2024). Exploring the variables of the psychological well-being of mothers of children with autism spectrum disorder through self-compassion and psychological hardiness. *J Autism Dev Disord*, 54(10), 3739-3744. <https://doi.org/10.1007/s10803-023-06077-5>
- Neufeld, J., Hederos Eriksson, L., Hammarsten, R., Lundin Remnelius, K., Tillmann, J., Isaksson, J., & Bolte, S. (2021). The impact of atypical sensory processing on adaptive functioning within and beyond autism: The role of familial factors. *Autism*, 25(8), 2341-2355. <https://doi.org/10.1177/13623613211019852>
- Neville, F., Sedgewick, F., McClean, S., White, J., & Bray, I. (2024). Reacting, retreating, regulating, and reconnecting: How autistic adults in the United Kingdom use time alone for well-being. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0148>
- NHS. (2024). *Autism statistics, October 2023 to September 2024 publication, part of autism waiting time statistics*. NHS England Digital. Retrieved 29/12/2024 from <https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/october-2023-to-september-2024>
- NHSE. (2023). *A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards*. <https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/>
- NICE. (2012). *Autism spectrum disorder in adults: Diagnosis and management (cg142)*. <https://www.nice.org.uk/guidance/cg142/resources/autism-spectrum-disorder-in-adults-diagnosis-and-management-pdf-35109567475909>
- NICE. (2017). *Autism spectrum disorder in under 19s: Recognition, referral and diagnosis. Clinical guideline [cg128]*. <https://www.nice.org.uk/guidance/cg128>
- Nichol, A. (2025). Critical realism: Explaining causal mechanisms that underpin events, entities, and (inter) actions in coaching. In *Research methods in sports coaching* (pp. 86-94). Routledge.
- NIHR. (2019). *What is public involvement in research?* <https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>
- Nimante, D., Laganovska, E., & Osgood, R. (2023). To tell or not to tell - disclosure of autism in the workplace. *Int J Dev Disabil*, 69(3), 414-423. <https://doi.org/10.1080/20473869.2023.2193489>
- Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, 18(3), 369-386. <https://eprints.bbk.ac.uk/id/eprint/44551/3/44551.pdf>

- Nocon, A. S., Roestorf, A., & Menéndez, L. M. G. (2022). Positive psychology in neurodiversity: An investigation of character strengths in autistic adults in the United Kingdom in a community setting. *Research in Autism Spectrum Disorders*, 99. <https://doi.org/10.1016/j.rasd.2022.102071>
- Norris, J. E., Harvey, R., & Hull, L. (2024). Post-diagnostic support for adults diagnosed with autism in adulthood in the UK: A systematic review with narrative synthesis. *Autism*, 13623613241273073. <https://doi.org/10.1177/13623613241273073>
- Northrup, J. B., Hartman, A. G., MacKenzie, K. T., Sivathasan, S., Eldeeb, S., & Mazefsky, C. A. (2024). Emotion dysregulation in autism: Severity and correlates in early childhood. *Autism Res*, 17(12), 2662-2675. <https://doi.org/10.1002/aur.3264>
- Nyrenius, J., Eberhard, J., Ghaziuddin, M., Gillberg, C., & Billstedt, E. (2023). The 'lost generation' in adult psychiatry: Psychiatric, neurodevelopmental and sociodemographic characteristics of psychiatric patients with autism unrecognised in childhood. *BJPsych Open*, 9(3), e89. <https://doi.org/10.1192/bjo.2023.13>
- O'Neill, S., & O'Donnell, G. M. (2024). Identifying autistic children: Priorities for research arising from a systematic review of parents' experiences of the assessment process. *Autism*, 13623613241243107. <https://doi.org/10.1177/13623613241243107>
- O'Nions, E., Petersen, I., Buckman, J. E. J., Charlton, R., Cooper, C., Corbett, A., Happe, F., Manthorpe, J., Richards, M., Saunders, R., Zanker, C., Mandy, W., & Stott, J. (2023). Autism in England: Assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *Lancet Reg Health Eur*, 29, 100626. <https://doi.org/10.1016/j.lanepe.2023.100626>
- O'Reilly, M., Lester, J. N., & Kiyimba, N. (2020). Autism in the twentieth century: An evolution of a controversial condition. In *Healthy minds in the twentieth century* (pp. 137-165). https://doi.org/10.1007/978-3-030-27275-3_7
- Oakley, A. (1979). *From here to maternity: Becoming a mother*. Penguin.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Macmillan.
- Onabanjo, D. (2024). Navigating the social and healthcare sector: Experiences and perspectives of ethnic minority family members/designated care givers of individuals with developmental disorders within the social and healthcare systems. *International Journal of Developmental Disabilities*, 1-18. <https://doi.org/10.1080/20473869.2024.2324530>
- Onaiwu, M. G. (2023). *A neurodiversity and gentle parenting journey...in color*. <https://awnnetwork.org/wp-content/uploads/2023/11/A-Neurodiversity-and-Gentle-Parenting-Journey-in-Color.final.pdf>
- ONS. (2019). *What is the difference between sex and gender*. https://backup.ons.gov.uk/wp-content/uploads/sites/3/2019/02/What-is-the-difference-between-sex-and-gender_-1.pdf
- Oswald, A. C. (2025). *Bioinformatics analysis of genes connected to autism spectrum* [Walsh University].
- Overland, E., Hauge, A. L., Orm, S., Oie, M. G., Skogli, E. W., Pellicano, E., & Andersen, P. N. (2024). "I have to charge my social battery": Perspectives from autistic young adults on quality of life. *Autism*, 28(6), 1369-1381. <https://doi.org/10.1177/13623613241245578>
- Oyserman, D., Uskul, A. K., Yoder, N., Neese, R. M., & Williams, D. R. (2007). Unfair treatment and self-regulatory focus. *Journal of experimental social psychology*, 43, 505-512. https://deepblue.lib.umich.edu/bitstream/handle/2027.42/89950/oyserman_uskul_yoder_et_al..pdf?sequence=1
- Oz, B., Yuksel, T., & Nasiroglu, S. (2020). Depression-anxiety symptoms and stigma perception in mothers of children with autism spectrum disorder. *Noro psikiyatri arsivi*, 57(1), 50-55. <https://doi.org/https://dx.doi.org/10.29399/npa.23655>
- Packer, M. J., & Addison, R. B. (1989). *Entering the circle: Hermeneutic investigation in psychology*. University of New York Press.
- Page, S. D., Clark, L., Souders, M. C., Pinto-Martin, J. A., & Deatrick, J. A. (2025). Family management of common sleep disturbances among children with autism: Implications for pediatric nursing research and practice. *J Pediatr Nurs*, 82, 160-169. <https://doi.org/10.1016/j.pedn.2025.03.006>

- Pagnier, M., & Moualla, M. (2024). The autistic parenting journey: A systematic review of qualitative evidence and thematic meta-synthesis. *Autism in Adulthood*.
<https://doi.org/10.1089/aut.2024.0176>
- Pajo, B. (2018). *Introduction to research methods. A hands-on approach*. Sage.
- Parfitt, C. (2023). *On the spectrum and in the room: The role of identity and empowerment in autistic women's recovery from psychological trauma*
https://era.ed.ac.uk/bitstream/handle/1842/40572/ParfittC_2023.pdf?sequence=1
- Paricos, A., Sturrock, A., Twomey, K., & Leadbitter, K. (2024). "I'm not mad, bad, and dangerous ... simply wired differently": Exploring factors contributing to good quality of life with autistic women. *Research in Autism Spectrum Disorders*, 112. <https://doi.org/10.1016/j.rasd.2024.102338>
- Paris, K., Lodestone, A. Z., Houser, M., & Lewis, L. F. (2025). "Shutdowns are like you're stuck on the blue screen of death": A metaphor analysis of autistic shutdowns. *Autism in Adulthood*.
<https://www.liebertpub.com/doi/pdf/10.1089/aut.2024.0193>
- Parry, H., & Mee, S. (2022). Working with female adults living with autism in secure inpatient services. *Nursing Times*, 118(1), 34-37. <https://www.nursingtimes.net/learning-disabilities/working-with-female-adults-living-with-autism-in-secure-inpatient-services-04-01-2022/>
- Patra, A. H., Bonefas, K., & Markenscoff-Papadimitriou, E. (2025). "Teaching the biology of neurodiversity for social change". *Dev Biol*, 524, 190-198.
<https://doi.org/10.1016/j.ydbio.2025.05.016>
- Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood*, 3(1), 52-60.
<https://doi.org/10.1089/aut.2020.0043>
- Pearson, A., & Rose, K. (2023). *Autistic masking: Understanding identity management and the role of stigma*. Pavilion Publishing and Media Ltd.
- Pearson, A., Rose, K., Mitchell, A., Joseph, W., Douglas, S., Sedgewick, F., & Botha, M. (2024). "It's not a physical prison but you can't get out": How autistic adults make sense of the experience of intimate violence and abuse. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0145>
- Pearson, A., Rose, K., & Rees, J. (2023). 'I felt like I deserved it because I was autistic': Understanding the impact of interpersonal victimisation in the lives of autistic people. *Autism*, 27(2), 500-511.
<https://doi.org/10.1177/13623613221104546>
- Peat, G., Rodriguez, A., & Smith, J. (2019). Interpretive phenomenological analysis applied to healthcare research. *Evidence Based Nursing*, 22(1), 7-9. <https://doi.org/10.1136/ebnurs-2018-103017>
- Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from 'normal science' to neurodiversity in autism science. *J Child Psychol Psychiatry*, 63(4), 381-396.
<https://doi.org/10.1111/jcpp.13534>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756-770.
<https://doi.org/10.1177/1362361314529627>
- Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Heyworth, M., Clapham, H., & Yudell, M. (2021). "I knew she'd get it, and get me": Participants' perspectives of a participatory autism research project. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2021.0039>
- Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). Understanding suicide risk in autistic adults: Comparing the interpersonal theory of suicide in autistic and non-autistic samples. *J Autism Dev Disord*, 50(10), 3620-3637.
<https://doi.org/10.1007/s10803-020-04393-8>
- Pender, R., Fearon, P., Heron, J., & Mandy, W. (2020). The longitudinal heterogeneity of autistic traits: A systematic review. *Research in Autism Spectrum Disorders*, 79.
<https://doi.org/10.1016/j.rasd.2020.101671>
- Perez Velazquez, J. L., & Galan, R. F. (2013). Information gain in the brain's resting state: A new perspective on autism. *Front Neuroinform*, 7, 37. <https://doi.org/10.3389/fninf.2013.00037>

- Perry, E., Mandy, W., Hull, L., & Cage, E. (2021). Understanding camouflaging as a response to autism-related stigma: A social identity theory approach. *J Autism Dev Disord*.
<https://doi.org/10.1007/s10803-021-04987-w>
- Phung, J., Penner, M., Pirlot, C., & Welch, C. (2021). What I wish you knew: Insights on burnout, inertia, meltdown, and shutdown from autistic youth. *Front. Psychol.*, 12, 741421.
<https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2021.741421/pdf>
- Piening, S., van Balkom, I. D. C., Stapert, A. F., Henning, D., Greaves-Lord, K., Davids, L., Castelein, S., & Groen, Y. (2023). Perspectives on autism spectrum disorder diagnosis, symptoms, treatment and gender roles: A qualitative study of similarities and differences between sexes. *Int J Environ Res Public Health*, 20(24). <https://doi.org/10.3390/ijerph20247183>
- Pietkiewicz, I. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychological Journal*, 20(1).
<https://doi.org/10.14691/cppj.20.1.7>
- Pilgrim, D. (2014). *Understanding mental health: A critical realist exploration*. Routledge.
- Plank, I. S., Tepest, R., Vogeley, K., & Falter-Wagner, C. M. (2025). The influence of interpersonal synchrony and autism on impressions of dyadic interactions: A preregistered study. *Mol Autism*, 16(1), 34. <https://doi.org/10.1186/s13229-025-00668-y>
- Pocock, D. (2024). What is real? What is knowledge? In D. Pocock (Ed.), *Expanding the limits of individual and family therapies: A critical realist approach* (pp. 25-51). Springer Nature Switzerland. https://doi.org/10.1007/978-3-031-76309-0_2
- Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism*, 11(1), 3.
<https://doi.org/http://dx.doi.org/10.1186/s13229-019-0304-2>
- Porter, N., Loveland, K. A., Honda, H., & Yamane, T. (2025). What is a good mother of children with autism? A cross-cultural comparison between the U.S. and Japan. *J Autism Dev Disord*, 55(2), 739-751. <https://doi.org/10.1007/s10803-023-06232-y>
- Poulsen, R., Tan, D. W., Sowman, P. F., McAlpine, D., & Pellicano, E. (2025). Auditory environments influence the link between autistic traits and quality of life. *Sci Rep*, 15(1), 10612.
<https://doi.org/10.1038/s41598-025-94585-y>
- Poulsen, R., Williams, Z., Dwyer, P., Pellicano, E., Sowman, P. F., & McAlpine, D. (2024). How auditory processing influences the autistic profile: A review. *Autism Res*, 17(12), 2452-2470.
<https://doi.org/10.1002/aur.3259>
- Powell, T., & Acker, L. (2015). Adults' experience of an Asperger syndrome diagnosis. *Focus on Autism and Other Developmental Disabilities*, 31(1), 72-80. <https://doi.org/10.1177/1088357615588516>
- Precious, K. (2024). *Achieving policy change on autism: Lessons from self-advocates in England*. E. Publishing.
- Price, D. (2022). *Unmasking autism*. Monoray.
- Prince, D. E. (2010). An exceptional path: An ethnographic narrative reflecting on autistic parenthood from evolutionary, cultural, and spiritual perspectives. *Ethos*, 38(1), 56-68.
<https://doi.org/10.1111/j.1548-1352.2009.01081.x>
- Pryke-Hobbes, A., Davies, J., Heasman, B., Livesey, A., Walker, A., Pellicano, E., & Remington, A. (2023). The workplace masking experiences of autistic, non-autistic neurodivergent and neurotypical adults in the UK. *PLoS One*, 18(9), e0290001.
<https://doi.org/10.1371/journal.pone.0290001>
- Purdie-Vaughns, V., & Eibach, R. P. (2008). Intersectional invisibility: The distinctive advantages and disadvantages of multiple subordinate-group identities. *Sex Roles*, 59(5-6), 377-391.
<https://doi.org/10.1007/s11199-008-9424-4>
- Putnam, O. C., Eddy, G., Crowley LaPoint, S., Swisher, M., & Harrop, C. (2025). "I'm excited to have my voice heard": Understanding autism research participation from the perspective of autistic women, non-binary adults, and parents of autistic girls. *Neurodiversity*, 3.
<https://doi.org/10.1177/27546330251324007>

- Putnam, O. C., Eddy, G., Goldblum, J., Swisher, M., & Harrop, C. (2023). How autistic adults' priorities for autism research differ by gender identity: A mixed-methods study. *Womens Health (Lond)*, 19, 17455057231160342. <https://doi.org/10.1177/17455057231160342>
- Pyszkowska, A., Nowacki, A., & Celban, J. (2025). The daydream spectrum: The role of emotional dysregulation, internalized stigma and self-esteem in maladaptive daydreaming among adults with ADHD, ASD, and double diagnosis. *J Atten Disord*, 29(1), 53-69. <https://doi.org/10.1177/10870547241290901>
- Rabba, A. S., Smith, J., Hall, G., Alexander, V., Batty, K., Datta, P., Goodall, E., Heyworth, M., Lamb, S., Lawson, W., Lilley, R., Reid, K., Syeda, N., & Pellicano, E. (2025). 'I'm sick of being the problem': Autistic mothers' experiences of interacting with schools for their autistic children. *Autism*, 29(4), 1034-1046. <https://doi.org/10.1177/13623613241297223>
- Radev, S., Freeth, M., & Thompson, A. R. (2024a). How healthcare systems are experienced by autistic adults in the United Kingdom: A meta-ethnography. *Autism*, 13623613241235531. <https://doi.org/10.1177/13623613241235531>
- Radev, S., Freeth, M., & Thompson, A. R. (2024b). 'I'm not just being difficult . . . I'm finding it difficult': A qualitative approach to understanding experiences of autistic parents when interacting with statutory services regarding their autistic child. *Autism*, 28(6), 1394-1404. <https://doi.org/10.1177/13623613231212794>
- Radulski, E. M. (2022). Conceptualising autistic masking, camouflaging, and neurotypical privilege: Towards a minority group model of neurodiversity. *Human Development*, 66(2), 113-127. <https://doi.org/10.1159/000524122>
- Rasmussen, P. D. (2023). 'I was never broken-I just don't fit in this world.' A case report series of misdiagnosed women with higher functioning ASD. *Nord J Psychiatry*, 77(4), 352-359. <https://doi.org/10.1080/08039488.2022.2112973>
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism Adulthood*, 2(2), 132-143. <https://doi.org/10.1089/aut.2019.0079>
- RCPCH. (2020). *Assessment and management of adults and children in cases of fabricated or induced illness (FII)*. https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwjnJ7BoMuOAXXGYEEAHZFSK1IQFnoECAkQAQ&url=https%3A%2F%2Fwww.rcpsych.ac.uk%2Fdocs%2Fdefault-source%2Fimproving-care%2Fbetter-mh-policy%2Fcollege-reports%2Fcr223.pdf%3Fsfvrsn%3D658db320_2&usq=AOvVaw3cpT5xrSsd_Cmv2kSld9HE&opi=89978449
- RCPCH. (2021). *Perplexing presentations (PP)/fabricated or induced illness (FII) in children, RCPCH guidance: Last updated 2009, and updated February 2021*. <https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjW65zdoMuOAXUuUKEAHViLBOMQFnoECBYQAQ&url=https%3A%2F%2Fchildprotection.rcpch.ac.uk%2Fwp-content%2Fuploads%2Fsites%2F6%2F2021%2F03%2FPerplexing-Presentations-FII-Guidance.pdf&usq=AOvVaw2fSfEVITB8BOGaCCoFa7jX&opi=89978449>
- Rea, H. M., Oien, R. A., Shic, F., Webb, S. J., & Ratto, A. B. (2022). Sex differences on the ADOS-2. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-022-05566-3>
- Redvaldsen, D. (2024). *A history of British eugenics since 1865*. Springer.
- Reid, M., Delgado, D., Heinly, J., Kiernan, B., Shapiro, S., Morgan, L., Maddox, B., & Jager-Hyman, S. (2024). Suicidal thoughts and behaviors in people on the autism spectrum. *Curr Psychiatry Rep*, 26(11), 563-572. <https://doi.org/10.1007/s11920-024-01533-0>
- Reuben, K. E., Stanzone, C. M., & Singleton, J. L. (2021). Interpersonal trauma and posttraumatic stress in autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0073>
- Rhodes, M., & Seeley-Wait, E. (2025). Misunderstood, excluded, and othered: Lay constructions of autistic women. *Feminism & Psychology*. <https://doi.org/10.1177/09593535241306535>

- Riccio, A., Kapp, S. K., Jordan, A., Dorelien, A. M., & Gillespie-Lynch, K. (2021). How is autistic identity in adolescence influenced by parental disclosure decisions and perceptions of autism? *Autism*, 25(2), 374-388. <https://doi.org/10.1177/1362361320958214>
- Richdale, A. L., Lawson, L. P., Chalmers, A., Uljarevic, M., Morris, E. M. J., Arnold, S. R. C., & Trollor, J. N. (2023). Pathways to anxiety and depression in autistic adolescents and adults. *Depress Anxiety*, 2023, 5575932. <https://doi.org/10.1155/2023/5575932>
- Richdale, A. L., Shui, A. M., Lampinen, L. A., & Katz, T. (2024). Sleep disturbance and other co-occurring conditions in autistic children: A network approach to understanding their inter-relationships. *Autism Res*. <https://doi.org/10.1002/aur.3233>
- Ridgway, K., Cooke, K., Demmer, D. H., Hooley, M., Westrupp, E., & Stokes, M. A. (2024). Camouflaging autism in pursuit of friendship and intimate relationships: A systematic review. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0160>
- Riebel, M., Bureau, R., Rohmer, O., Clement, C., & Weiner, L. (2025). Self-compassion as an antidote to self-stigma and shame in autistic adults. *Autism*, 29(6), 1569-1584. <https://doi.org/10.1177/13623613251316965>
- Rifai, O. M., Fletcher-Watson, S., Jiménez-Sánchez, L., & Crompton, C. J. (2021). Investigating markers of rapport in autistic and nonautistic interactions. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2021.0017>
- Rim, S. J., Kwak, K., & Park, S. (2023). Risk of psychiatric comorbidity with autism spectrum disorder and its association with diagnosis timing using a nationally representative cohort. *Research in Autism Spectrum Disorders*, 104. <https://doi.org/10.1016/j.rasd.2023.102134>
- Rippon, G. (2024). Differently different?: A commentary on the emerging social cognitive neuroscience of female autism. *Biol Sex Differ*, 15(1), 49. <https://doi.org/10.1186/s13293-024-00621-3>
- Robinson, E. B., Lichtenstein, P., Anckarsäter, H., Happé, F., & Ronald, A. (2013). Examining and interpreting the female protective effect against autistic behavior [Article]. *Proceedings of the National Academy of Sciences of the United States of America*, 110(13), 5258-5262. <https://doi.org/10.1073/pnas.1211070110>
- Rodgaard, E. M., Jensen, K., Miskowiak, K. W., & Mottron, L. (2021). Childhood diagnoses in individuals identified as autistics in adulthood. *Mol Autism*, 12(1), 73. <https://doi.org/10.1186/s13229-021-00478-y>
- Rodríguez-Zafra, A., & Garcia-Molina, I. (2025). "It's all theatre and my mask unintentionally broke": Conscious camouflaging in Spanish autistic women and non-binary individuals with late detection. *Research in Autism*, 126. <https://doi.org/10.1016/j.reia.2025.202643>
- Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron-Cohen, S. (2021). Association of race/ethnicity and social disadvantage with autism prevalence in 7 million school children in England. *JAMA Pediatr*, e210054. <https://doi.org/10.1001/jamapediatrics.2021.0054>
- Romualdez, A. M., Heasman, B., Walker, Z., Davies, J., & Remington, A. (2021). "People might understand me better": Diagnostic disclosure experiences of autistic individuals in the workplace. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0063>
- Romualdez, A. M., Walker, Z., & Remington, A. (2021). Autistic adults' experiences of diagnostic disclosure in the workplace: Decision-making and factors associated with outcomes. *Autism Dev Lang Impair*, 6, 23969415211022955. <https://doi.org/10.1177/23969415211022955>
- Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-5 and beyond. *J Autism Dev Disord*, 51(12), 4253-4270. <https://doi.org/10.1007/s10803-021-04904-1>
- Rosqvist, H. B., Chown, N., & Stenning, A. (2020). *Neurodiversity studies: A new critical paradigm*. Routledge.
- Ross, A., Grove, R., & McAloon, J. (2023). The relationship between camouflaging and mental health in autistic children and adolescents. *Autism Res*, 16(1), 190-199. <https://doi.org/10.1002/aur.2859>

- Rum, Y., Genzer, S., Golan, O., Allison, C., Baron-Cohen, S., & Perry, A. (2025). Empathy and interest towards an autistic person and the effect of disclosing the diagnosis. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-025-06802-2>
- Runswick-Cole, K. (2014). 'Us' and 'them': The limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society*, 29(7), 1117-1129. <https://doi.org/10.1080/09687599.2014.910107>
- Runswick-Cole, K., Mallett, R., & Timimi, S. (2016). *Re-thinking autism: Diagnosis, identity and equality*. Jessica Kingsley Publishers.
- Russell, A. S., McFayden, T. C., McAllister, M., Liles, K., Bittner, S., Strang, J. F., & Harrop, C. (2025). Who, when, where, and why: A systematic review of "late diagnosis" in autism. *Autism Res*, 18(1), 22-36. <https://doi.org/10.1002/aur.3278>
- Russell, G. (2021). *The rise of autism: Risk and resistance in the age of diagnosis*. Routledge.
- Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A., & Ford, T. (2022). Time trends in autism diagnosis over 20 years: A UK population-based cohort study. *J Child Psychol Psychiatry*, 63(6), 674-682. <https://doi.org/10.1111/jcpp.13505>
- Sagar, E. (2024). "You're just so weird and crazy": Recounting my lived experiences as a PhD scholar in India. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0109>
- Sagar, E., Khera, S. N., & Garg, N. (2023). "I wish they'd just let us be": Experiences of Indian autistic individuals around stimming behaviors at the workplace. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0096>
- Samra, R., & Hankivsky, O. (2021). Adopting an intersectionality framework to address power and equity in medicine. *The Lancet*, 397(10277), 857-859. [https://doi.org/10.1016/s0140-6736\(20\)32513-7](https://doi.org/10.1016/s0140-6736(20)32513-7)
- Sandin, S., Yip, B. H. K., Yin, W., Weiss, L. A., Dougherty, J. D., Fass, S., Constantino, J. N., Hailin, Z., Turner, T. N., Marrus, N., Gutmann, D. H., Sanders, S. J., & Christoffersson, B. (2024). Examining sex differences in autism heritability. *JAMA Psychiatry*. <https://doi.org/10.1001/jamapsychiatry.2024.0525>
- Sapiets, S. J., Hastings, R. P., & Totsika, V. (2024). Predictors of access to early support in families of children with suspected or diagnosed developmental disabilities in the United Kingdom. *J Autism Dev Disord*, 54(4), 1628-1641. <https://doi.org/10.1007/s10803-023-05996-7>
- Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep*, 7, 40700. <https://doi.org/10.1038/srep40700>
- Sasson, N. J., & Morrison, K. E. (2019). First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism*, 23(1), 50-59. <https://doi.org/10.1177/1362361317729526>
- Saxe, A. (2017). The theory of intersectionality: A new lens for understanding the barriers faced by autistic women. *Canadian Journal of Disability Studies*, 6(4), 153-178. <https://doi.org/10.15353/cjds.v6i4.386>
- Scattoni, M. L., Micai, M., Ciaramella, A., Salvitti, T., Fulceri, F., Fatta, L. M., Poustka, L., Diehm, R., Iskrov, G., Stefanov, R., Guillon, Q., Roge, B., Staines, A., Sweeney, M. R., Boilson, A. M., Leosdottir, T., Saemundsen, E., Moilanen, I., Ebeling, H.,...Schendel, D. (2021). Real-world experiences in autistic adult diagnostic services and post-diagnostic support and alignment with services guidelines: Results from the asdeu study. *J Autism Dev Disord*, 51(11), 4129-4146. <https://doi.org/10.1007/s10803-021-04873-5>
- Schiltz, H., Gohari, D., Park, J., & Lord, C. (2023). A longitudinal study of loneliness in autism and other neurodevelopmental disabilities: Coping with loneliness from childhood through adulthood. *Autism*, 13623613231217337. <https://doi.org/10.1177/13623613231217337>
- Schiltz, H. K., McVey, A. J., van Dyk, I. S., Adler, E. J., & Van Hecke, A. V. (2023). Brief report: Links between nonconformity to gender norms, autistic features, and internalizing symptoms in a non-clinical college sample. *J Autism Dev Disord*, 53(4), 1717-1725. <https://doi.org/10.1007/s10803-021-05033-5>

- Schulz, S. E., Luszczowski, M., Hannah, K. E., & Stevenson, R. A. (2023). Sensory gating in neurodevelopmental disorders: A scoping review. *Research on Child and Adolescent Psychopathology*, 51(7), 1005-1019. <https://doi.org/10.1007/s10802-023-01058-9>
- Scott, M., & Sedgewick, F. (2021). 'I have more control over my life': A qualitative exploration of challenges, opportunities, and support needs among autistic university students. *Autism Dev Lang Impair*, 6, 23969415211010419. <https://doi.org/10.1177/23969415211010419>
- Secchi, I., Petigas, L., Cuenod, A., Klauser, P., Kapp, C., Novatti, A., & Armando, M. (2023). Case report: Treatment-resistant depression, multiple trauma exposure and suicidality in an adolescent female with previously undiagnosed autism spectrum disorder. *Front Psychiatry*, 14, 1151293. <https://doi.org/10.3389/fpsyt.2023.1151293>
- Sedgewick, F., & Douglas, S. (2023). *Understanding autistic relationships across the lifespan: Family, friends, lovers and others*. Routledge.
- Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in the social motivation and friendship experiences of autistic and non-autistic adolescents [Article]. *Journal of Autism and Developmental Disorders*, 46(4), 1297-1306. <https://doi.org/10.1007/s10803-015-2669-1>
- Sedgewick, F., Hull, L., & Ellis, H. (2022). *Autism and masking: How and why people do it, and the impact it can have*. Jessica Kingsley Publishers.
- Seers, K., & Hogg, R. (2022). "Fake it 'till you make it": Authenticity and wellbeing in late diagnosed autistic women. *Feminism & Psychology*, 33(1), 23-41. <https://doi.org/10.1177/09593535221101455>
- Seers, K., & Hogg, R. C. (2021). 'You don't look autistic': A qualitative exploration of women's experiences of being the 'autistic other'. *Autism*, 1362361321993722. <https://doi.org/10.1177/1362361321993722>
- Sekulowicz, M., Kwiatkowski, P., Manor-Binyamini, I., Boron-Krupinska, K., & Cieslik, B. (2022). The effect of personality, disability, and family functioning on burnout among mothers of children with autism: A path analysis. *International journal of environmental research and public health*, 19(3). <https://doi.org/https://dx.doi.org/10.3390/ijerph19031187>
- Shakespeare, J. (2015). *Practical implications for primary care of the NICE guideline CG192: Antenatal and postnatal mental health*. R. C. o. G. Practitioners. <https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjzdXGocuOAXW3QUEAHXyOPG0QFnoECBqQAQ&url=https%3A%2F%2Fgpifn.org.uk%2Fwp-content%2Fuploads%2F2016%2F08%2Frcgp-ten-top-tips-nice-guidance-june-2015.pdf&usq=AOvVaw2mhHL2n1um-W4NKeeVw0ex&opi=89978449>
- Shaw, S. C., Carravallah, L., Johnson, M., O'Sullivan, J., Chown, N., Neilson, S., & Doherty, M. (2023). Barriers to healthcare and a 'triple empathy problem' may lead to adverse outcomes for autistic adults: A qualitative study. *Autism*, 13623613231205629. <https://doi.org/10.1177/13623613231205629>
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63-75. <https://doi.org/10.3233/EFI-2004-22201>
- Sherriff, A., Stewart, R., Macpherson, L. M. D., Kidd, J. B. R., Henderson, A., Cairns, D., & Conway, D. I. (2023). Child oral health and preventive dental service access among children with intellectual disabilities, autism and other educational additional support needs: A population-based record linkage cohort study. *Community Dent Oral Epidemiol*, 51(3), 494-502. <https://doi.org/10.1111/cdoe.12805>
- Shinebourne, P. (2011). The theoretical underpinnings of interpretative phenomenological analysis (IPA). *Existential Analysis*, 22(1), 16-32. www.researchgate.net/profile/Jacob_Stein/post/How_would_you_articulate_the_difference_between_hermeneutics_and_interpretive_phenomenology/attachment/59d6484479197b80779a2f53/AS:466208202989569@1488164105524/download/The+Theoretical+Underpinnings+of+Interpretative+Phenomenological+Analysis+%28IPA%29+Shinebourne+2011.pdf

- Shishehfar, S., Kashani Vahid, L., Vakili, S., & Azizi, M. (2024). Modelling the impact of caregiving burden on psychological distress with the mediating role of social support among mothers of children with autism spectrum disorder. *Journal of Assessment and Research in Applied Counseling*, 6(2), 169-176. <https://doi.org/10.61838/kman.jarac.6.2.21>
- Sibeoni, J., Massoutier, L., Valette, M., Manolios, E., Verneuil, L., Speranza, M., & Revah-Levy, A. (2022). The sensory experiences of autistic people: A metasynthesis. *Autism*, 13623613221081188. <https://doi.org/10.1177/13623613221081188>
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *J Am Acad Child Adolesc Psychiatry*, 47(8), 921-929. <https://doi.org/10.1097/CHI.0b013e318179964f>
- Simpson, H. (2019). Disability, neurodiversity, and feminism. *Journal of Feminist Scholarship*, 16(Fall), 81-83. <https://doi.org/10.23860/jfs.2019.16.10>
- Sinclair, J. (2013). Why I dislike "person first" language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2). <https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjD7OLtoCuOAXUSVUEAHbkSF-0QFnoECAkQAAQ&url=https%3A%2F%2Fblogs.exeter.ac.uk%2Fexploringdiagnosis%2Ffiles%2F2017%2F03%2FSinclair-Why-I-Dislike-First-Person-Language.pdf&usq=AOvVaw2qFVcYAI3VNPuYH4xgLL5Jl&opi=89978449>
- Sinclair, J. M. A., Aslan, B., Agabio, R., Anilkumar, A., Brosnan, M., Day, E., Dowling, N. A., Flood, C., Grant, J. E., Halliday, R., Hofvander, B., Howes, L., Moseley, R., Myers, B., O'Connor, V., Shaya, G., Thomas, S., Robinson, J., & Chamberlain, S. R. (2023). Identifying the most important research, policy and practice questions for substance use, problematic alcohol use and behavioural addictions in autism (saba-a): A priority setting partnership. *Compr Psychiatry*, 124, 152393. <https://doi.org/10.1016/j.comppsy.2023.152393>
- Singer, J. (1999). Why can't you be normal for once in your life? From a problem with no name to the emergence of a new category of difference. In M. Corker & S. French (Eds.), *Disability discourse* (pp. 59-67). Open University Press.
- Skafle, I., Gabarron, E., & Nordahl-Hansen, A. (2024). Social media shaping autism perception and identity. *Autism*, 13623613241230454. <https://doi.org/10.1177/13623613241230454>
- SMC. (2020). *Measuring poverty 2020: A report of the social metrics commission*. <https://socialmetricscommission.org.uk/wp-content/uploads/2020/06/Measuring-Poverty-2020-Web.pdf>
- Smit, S., & Hopper, J. (2023). Love, joy, and a lens of childhood trauma: Exploring factors that impact the mental health and well-being of autistic parents via iterative phenomenological analysis. *Autism in Adulthood*, 5(1), 63-75. <https://pmc.ncbi.nlm.nih.gov/articles/PMC10024273/pdf/aut.2021.0101.pdf>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54. <https://doi.org/10.1191/1478088704qp004oa>
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9-27. <https://www.tandfonline.com/doi/epdf/10.1080/17437199.2010.510659?needAccess=true>
- Smith, J. A. (2015). *Qualitative psychology: A practical guide to research methods*. Sage.
- Smith, J. A. (2018). Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis. *Qualitative Research in Psychology*, 16(2), 166-181. <https://doi.org/10.1080/14780887.2018.1540648>
- Smith, J. A., Flowers, P., & Larkin, M. (2012). *Interpretative phenomenological analysis: Theory, method and research*. Sage Publishing Ltd.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (pp. 22-54). Sage.

- Smith, J. V., McQuaid, G. A., Wallace, G. L., Neuhaus, E., Lopez, A., Ratto, A. B., Jack, A., Khuu, A., Webb, S. J., Verbalis, A., Pelphrey, K. A., & Kenworthy, L. (2024). Time is of the essence: Age at autism diagnosis, sex assigned at birth, and psychopathology. *Autism*, 13623613241249878. <https://doi.org/10.1177/13623613241249878>
- Smith, R. S., & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome. *J Autism Dev Disord*, 43(4), 891-910. <https://doi.org/10.1007/s10803-012-1633-6>
- Smooth, W. G. (2013). Intersectionality from theoretical framework to policy intervention. In A. R. Wilson (Ed.), *Situating intersectionality* (pp. 11-41). Palgrave Macmillan.
- Snyder, M. (1987). *Public appearances, private realities: The psychology of self-monitoring*. WH Freeman/Times Books/Henry Holt & Co.
- Soden, P. A., Bhat, A., Anderson, A. K., & Friston, K. (2025). The meltdown pathway: A multidisciplinary account of autistic meltdowns. *Psychological review*. <https://discovery.ucl.ac.uk/id/eprint/10209395/1/The%20meltdown%20pathway.pdf>
- Sommers, L., Papadopoulos, N., Fuller-Tyszkiewicz, M., Sciberras, E., McGillivray, J., Howlin, P., & Rinehart, N. (2025). The connection between sleep problems and emotional and behavioural difficulties in autistic children: A network analysis. *J Autism Dev Disord*, 55(4), 1159-1171. <https://doi.org/10.1007/s10803-024-06298-2>
- South, M., Beck, J. S., Lundwall, R., Christensen, M., Cutrer, E. A., Gabrielsen, T. P., Cox, J. C., & Lundwall, R. A. (2020). Unrelenting depression and suicidality in women with autistic traits. *Journal of Autism and Developmental Disorders*, 50(10), 3606-3619. <https://doi.org/http://dx.doi.org/10.1007/s10803-019-04324-2>
- Spaeth, E., & Pearson, A. (2023). A reflective analysis on neurodiversity and student wellbeing: Conceptualising practical strategies for inclusive practice., 11(2), . *Journal of Perspectives in Applied Academic Practice*, 11(2), 109-120. <https://jpaap.ac.uk/JPAAP/article/download/517/662>
- Spain, D., Stewart, G. R., Mason, D., Robinson, J., Capp, S. J., Gillan, N., Ensum, I., & Happe, F. (2022). Autism diagnostic assessments with children, adolescents, and adults prior to and during the COVID-19 pandemic: A cross-sectional survey of professionals. *Front Psychiatry*, 13, 789449. <https://doi.org/10.3389/fpsyt.2022.789449>
- Spain, D., Zivrali Yarar, E., & Happe, F. (2020). Social anxiety in adults with autism: A qualitative study. *Int J Qual Stud Health Well-being*, 15(1), 1803669. <https://doi.org/10.1080/17482631.2020.1803669>
- St John, B. M., & Ausderau, K. K. (2024). The characterization of feeding challenges in autistic children. *Autism*, 13623613241227518. <https://doi.org/10.1177/13623613241227518>
- St John, T., Woods, S., Bode, T., Ritter, C., & Estes, A. (2022). A review of executive functioning challenges and strengths in autistic adults. *Clin Neuropsychol*, 36(5), 1116-1147. <https://doi.org/10.1080/13854046.2021.1971767>
- Standley, E., & Kaufman, R. (2024). Nazi influence on contemporary understandings of autism. In. Stewart, G. R., Corbett, A., Ballard, C., Creese, B., Aarsland, D., Hampshire, A., Charlton, R. A., & Happe, F. (2021). The mental and physical health profiles of older adults who endorse elevated autistic traits. *J Gerontol B Psychol Sci Soc Sci*, 76(9), 1726-1737. <https://doi.org/10.1093/geronb/gbaa112>
- Stewart, G. R., Leoni, M., Charlton, R. A., Pickard, H. R., & Happe, F. (2023). A qualitative study of autistic adults' quality of life during the COVID-19 pandemic and lockdowns. *Autism Adulthood*, 5(3), 311-324. <https://doi.org/10.1089/aut.2022.0035>
- Strand, L. R. (2017). Charting relations between intersectionality theory and the neurodiversity paradigm. *Disability Studies Quarterly*, 37(2). <https://dsq-sds.org/index.php/dsq/article/view/5374/4647>
- Strang, J. F., van der Miesen, A. I. R., Fischbach, A. L., Wolff, M., Harris, M. C., & Klomp, S. E. (2023). Common intersection of autism and gender diversity in youth. *Child and Adolescent Psychiatric Clinics of North America*. <https://doi.org/10.1016/j.chc.2023.06.001>

- Sturrock, A., Adams, C., & Freed, J. (2021). A subtle profile with a significant impact: Language and communication difficulties for autistic females without intellectual disability. *Frontiers in Psychology*, 12. <https://doi.org/10.3389/fpsyg.2021.621742>
- Suckle, E. K. (2021). DSM-5 and challenges to female autism identification. *J Autism Dev Disord*, 51(2), 754-759. <https://doi.org/10.1007/s10803-020-04574-5>
- Suhrheinrich, J., Haine-Schlagel, R., Chlebowski, C., Lee, J., & Brookman-Frazee, L. (2024). Participatory training: Highlighting the need for a more inclusive and interdisciplinary approach to training. *Autism*, 28(10), 2425-2429. <https://doi.org/10.1177/13623613241280011>
- Summer, J., & Adavadar, P. (2023). *Autism and sleep*. Sleep Foundation. www.sleepfoundation.org/physical-health/autism-and-sleep
- Sunagawa, M. (2023). How much of my true self can i show? Social adaptation in autistic women: A qualitative study. *BMC Psychol*, 11(1), 144. <https://doi.org/10.1186/s40359-023-01192-5>
- Suplee, P., Gardner, M., Bloch, J., & Lecks, K. (2014). Childbearing experiences of women with Asperger syndrome. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing*, 43(Supp 1). <https://onlinelibrary.wiley.com/doi/pdf/10.1111/1552-6909.12455>
- Sutcliffe-Khan, F., Larkin, F., & Hamilton, L. (2024). Parents' and professionals' views on autistic motherhood using a participatory research design [Article]. *Current Psychology*, 43(25), 21792-21807. <https://doi.org/10.1007/s12144-024-05999-2>
- Suvarna, V., Farrell, L., Adams, D., Emerson, L. M., & Paynter, J. (2025). Differing relationships between parenting stress, parenting practices and externalising behaviours in autistic children. *Autism*, 29(3), 711-725. <https://doi.org/10.1177/13623613241287569>
- Sweetmore, V. (2022). Mental health nursing and autism: I am a mental health nurse so why did it take me so long to realize I'm autistic? *J Psychiatr Ment Health Nurs*, 29(6), 770-773. <https://doi.org/10.1111/jpm.12762>
- Szechy, K. A., & O'Donnell, L. A. (2025). Autism knowledge matters: Perceptions of an autistic employee's competency and attitudes toward workplace social inclusion. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0261>
- Szechy, K. A., Turk, P. D., & O'Donnell, L. A. (2023). Autism and employment challenges: The double empathy problem and perceptions of an autistic employee in the workplace. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0046>
- Szulc, J. M. (2023). Towards more inclusive qualitative research: The practice of interviewing neurominorities. *Labour and Industry*, 33(2), 179-187.
- Taboas, A., Doepke, K., & Zimmerman, C. (2023). Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism*, 27(2), 565-570. <https://doi.org/10.1177/13623613221130845>
- Takeda, T., Makinodan, M., Toritsuka, M., & Iwata, N. (2024). Impacts of adverse childhood experiences on individuals with autism spectrum disorder. *Curr Opin Neurobiol*, 89, 102932. <https://doi.org/10.1016/j.conb.2024.102932>
- Talcer, M. C., Duffy, O., & Pedlow, K. (2021). A qualitative exploration into the sensory experiences of autistic mothers [Psychological & Physical Disorders 3200]. *Journal of Autism and Developmental Disorders*, No-Specified. <https://doi.org/https://dx.doi.org/10.1007/s10803-021-05188-1> (Journal of Autism & Childhood Schizophrenia)
- Tarasenko-Struc, A. (2024). The wrong of eugenic sterilization. *Journal of Bioethical Inquiry*, 1-15. <https://philpapers.org/archive/TARTWO.pdf>
- Taylor, E. C., Livingston, L. A., Clutterbuck, R. A., Callan, M. J., & Shah, P. (2023). Psychological strengths and well-being: Strengths use predicts quality of life, well-being and mental health in autism. *Autism*, 13623613221146440. <https://doi.org/10.1177/13623613221146440>
- Taylor, E. C., Livingston, L. A., Clutterbuck, R. A., Shah, P., & Payne, C. (2020). Psychometric concerns with the 10-item autism-spectrum quotient (AQ10) as a measure of trait autism in the general population. *Experimental Results*, 1. <https://doi.org/10.1017/exp.2019.3>
- Taylor, J. L. (2021). Transforming care for people with intellectual disabilities and autism in England. *The Lancet Psychiatry*, 8(11), 942-944.

https://researchportal.northumbria.ac.uk/files/56971817/TransformingCare_2021_08_19_Lancet_Psychiatry_ACCEPTED.pdf

- Thapar, A., & Rutter, M. (2021). Genetic advances in autism. *J Autism Dev Disord*, 51(12), 4321-4332. <https://doi.org/10.1007/s10803-020-04685-z>
- Thom-Jones, S., Brownlow, C., & Abel, S. (2024). Experiences of autistic parents, from conception to raising adult children: A systematic review of the literature. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0181>
- Thom-Jones, S., Melgaard, I., & Gordon, C. S. (2024). Autistic women's experience of motherhood: A qualitative analysis of Reddit. *Journal of Autism & Developmental Disorders*, 26, 26. <https://doi.org/https://dx.doi.org/10.1007/s10803-024-06312-7>
- Thomas, C. (1997). The baby and the bathwater: Disabled women and motherhood in social context. *Sociology of Health & Illness*, 19(5), 622-643. <https://doi.org/10.1111/j.1467-9566.1997.tb00423.x>
- Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Open University Press.
- Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research*, 6(1), 22-36. <https://sjdr.se/articles/152/files/submission/proof/152-1-529-1-10-20171113.pdf>
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 1-10. <https://link.springer.com/content/pdf/10.1186/1471-2288-8-45.pdf>
- Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, 77. <https://doi.org/10.1016/j.rasd.2020.101598>
- Tien, I., Pearson, A., Sozeri, S., & Seers, K. (2025). "Only boys can be autistic": A qualitative exploration of gender stereotype and socialization on the diagnostic journey. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0178>
- Tien, I., Wolpe, S., Pearson, A., & Seers, K. (2025). "Creating a socially acceptable version of myself": A qualitative thematic analysis of the female and nonbinary experience of navigating the autism diagnostic system. *Neurodiversity*, 3, 27546330241306380. <https://journals.sagepub.com/doi/pdf/10.1177/27546330241306380>
- Timimi, S. (2011). Autism is not a scientifically valid or clinically useful diagnosis. *BMJ*, 343. <https://doi.org/10.1136/bmj.d5105>
- Timimi, S., Gardner, N., & McCabe, B. (2011). *The myth of autism: Medicalising men's and boys' social and emotional competence*. Palgrave Macmillan.
- Timmons, S., McGinnity, F., & Carroll, E. (2024). Ableism differs by disability, gender and social context: Evidence from vignette experiments. *Br J Soc Psychol*, 63(2), 637-657. <https://doi.org/10.1111/bjso.12696>
- Tomaszewski, B., Klein, C. B., Meyer, A. T., Lamarche, E., & Klinger, L. G. (2025). Developmental trajectories of adaptive behavior from toddlerhood to middle adulthood in autism. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0036>
- Trew, S. (2024). Made to feel different: Families perspectives on external responses to autism and the impacts on family well-being and relationships. *Autism*, 13623613231221684. <https://doi.org/10.1177/13623613231221684>
- Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G. L., & Brugha, T. (2021). Autism identification across ethnic groups: A narrative review. *Advances in Autism*, 7(3), 241-255. https://www.researchgate.net/profile/Samuel-Joseph-Tromans/publication/343514001_AIA_Ethnicity_Narrative_Review_2020pdf/data/5f2da246a6fdc ccc43b2e2d5/AIA-Ethnicity-Narrative-Review-2020.pdf
- Tromans, S. J., Teece, L., Saunders, C., McManus, S., & Brugha, T. (2024). Characteristics and primary care experiences of people who self-report as autistic: A probability sample survey of adults registered with primary care services in England. *BMJ Open*, 14(9), e081388. <https://doi.org/10.1136/bmjopen-2023-081388>

- Tromans, S. J., Tyrer, F., Gullon-Scott, F., Cooper, S.-A., McManus, S., & Brugha, T. S. (2024). The epidemiology of autism spectrum disorders in adulthood. In *Adolescents and adults with autism spectrum disorders* (pp. 385-404). Springer.
- Trundle, G., Alexander, Z., & Chester, V. (2025). Put autistic women and girls at the heart: Exploring the experiences of autistic women during diagnostic assessments in the UK. *Advances in Autism*, 11(2), 100-113. <https://doi.org/10.1108/aia-08-2024-0055>
- Trundle, G., Jones, K. A., Ropar, D., & Egan, V. (2023). Prevalence of victimisation in autistic individuals: A systematic review and meta-analysis. *Trauma Violence Abuse*, 24(4), 2282-2296. <https://doi.org/10.1177/15248380221093689>
- Trunk, P., Choi, B., & Rowe, M. L. (2024). Surveying autistic mothers about their parenting practices related to children's early language development [In Press]. *Autism in Adulthood*. <https://doi.org/https://dx.doi.org/10.1089/aut.2024.0138>
- Tsirgiotis, J. M., Young, R. L., & Weber, N. (2021). A mixed-methods investigation of diagnostician sex/gender-bias and challenges in assessing females for autism spectrum disorder. *J Autism Dev Disord*. <https://doi.org/10.1007/s10803-021-05300-5>
- Tsou, Y. T., Nasri, M., Li, B., Blijd-Hoogewys, E. M. A., Baratchi, M., Koutamanis, A., & Rieffe, C. (2024). Social connectedness and loneliness in school for autistic and allistic children. *Autism*, 13623613241259932. <https://doi.org/10.1177/13623613241259932>
- TUC. (2019). *Bullying at work*. <https://www.tuc.org.uk/sites/default/files/Bullying%20at%20Work%202019.pdf>
- Turner, M., & Beresford, P. (2005). *User controlled research: Its meanings and potential: Report summary*. <http://www.invo.org.uk/wp-content/uploads/2011/12/UserConRpt081205.pdf>
- Turner, T. K. M. (2023). *An exploration of the worklife experiences of autistic women in the UK* [University of Hertfordshire].
- Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding stigma in autism: A narrative review and theoretical model. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2021.0005>
- Turowetz, J. (2022). Interaction order and the labeling of disorder: How parents mobilize personal knowledge in the clinic to resist medicalization of their children's behavior. *Soc Sci Med*, 294, 114719. <https://doi.org/10.1016/j.socscimed.2022.114719>
- Turowetz, J., Wiscons, L. Z., & Maynard, D. W. (2024). Disorder or difference? How clinician-patient interaction and patient age shape the process and meaning of autism diagnosis. *Social Health Illn*, 46(S1), 171-188. <https://doi.org/10.1111/1467-9566.13611>
- Ugiagbe, I. M., Allan, H. T., Traynor, M., & Collins, L. (2025). Thinking theoretically in nursing research—positionality and reflexivity in an interpretative phenomenological analysis (IPA) study. *Nursing Inquiry*, 32(1), e12684.
- Ujii, Y., & Takahashi, K. (2022). Associations between self-reported social touch avoidance, hypersensitivity, and autistic traits: Results from questionnaire research among typically developing adults. *Personality and Individual Differences*, 184, 111186. <https://doi.org/https://doi.org/10.1016/j.paid.2021.111186>
- UNICEF/NHS. (2022). *Off to the best start*. www.unicef.org.uk/babyfriendly/wp-content/uploads/sites/2/2022/10/Breastfeeding-leaflet.pdf
- UPIAS. (1976). *Fundamental principles of disability*. <https://disabledpeoplesarchive.com/wp-content/uploads/sites/39/2021/01/001-FundamentalPrinciplesOfDisability-UPIAS-DA-22Nov1975.pdf>
- Vaidya, C. J., & Klein, C. (2022). Comorbidity of attention-deficit hyperactivity disorder and autism spectrum disorders: Current status and promising directions. *Curr Top Behav Neurosci*, 57, 159-177. https://doi.org/10.1007/7854_2022_334
- van der Crujsen, R., & Boyer, B. E. (2021). Explicit and implicit self-esteem in youth with autism spectrum disorders. *Autism*, 25(2), 349-360. <https://doi.org/10.1177/1362361320961006>
- van Eijk, L., & Zietsch, B. P. (2021). Testing the extreme male brain hypothesis: Is autism spectrum disorder associated with a more male-typical brain? *Autism Res*, 14(8), 1597-1608. <https://doi.org/10.1002/aur.2537>

- Van Ingen, M., Grohmann, S., & Gunnarsson, L. (2020). *Critical realism, feminism, and gender: A reader*. Routledge London.
- Vivanti, G., & Messinger, D. S. (2021). Theories of autism and autism treatment from the DSM III through the present and beyond: Impact on research and practice. *J Autism Dev Disord*, 51(12), 4309-4320. <https://doi.org/10.1007/s10803-021-04887-z>
- Volkmar, F. R. (2021). *Encyclopedia of autism spectrum disorders*. <https://doi.org/10.1007/978-3-319-91280-6>
- Wakefield, A. J., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., Malik, M., Berelowitz, M., Dhillon, A. P., Thomson, M. A., & Harvey, P. (1998). Retracted: Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *The Lancet*, 351(9103), 637-641. <https://www.thelancet.com/journals/lancet/article/PIIS0140673697110960/fulltext?dom=prime&src=syn>
- Wala, M., & Pawlik, S. (2024). It's not that I'm "abnormal". Social and emotional experiences of women with autism spectrum (as) related to the diagnosis in adulthood. *Edukacyjna Analiza Transakcyjna*, 13, 339-350. <https://doi.org/10.16926/eat.2024.13.20>
- Waldren, L. H., Leung, F. Y. N., Hargitai, L. D., Burgoyne, A. P., Licalde, V. R. T., Livingston, L. A., & Shah, P. (2024). Unpacking the overlap between autism and ADHD in adults: A multi-method approach. *Cortex*, 173, 120-137. <https://doi.org/10.1016/j.cortex.2023.12.016>
- Walker, N. (2014). *Neurodiversity: Some basic terms and definitions*. <https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions>
- Walker, N. (2021). *Neuroqueer heresies*. Autonomous Press.
- Waltz, M. (2023). *Autism: A social and medical history*. Springer Nature.
- Wang, R., Liu, Q., & Zhang, W. (2022). Coping, social support, and family quality of life for caregivers of individuals with autism: Meta-analytic structural equation modeling. *Personality and Individual Differences*, 186. <https://doi.org/10.1016/j.paid.2021.111351>
- Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M. C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nat Commun*, 11(1), 3959. <https://doi.org/10.1038/s41467-020-17794-1>
- Watson, L., Hanna, P., & Jones, C. J. (2021). A systematic review of the experience of being a sibling of a child with an autism spectrum disorder. *Clin Child Psychol Psychiatry*, 26(3), 734-749. <https://doi.org/10.1177/13591045211007921>
- Watts, J. (2023). Engendering misunderstanding: Autism and borderline personality disorder. *Int J Psychiatry Clin Pract*, 27(3), 316-317. <https://doi.org/10.1080/13651501.2023.2187843>
- Webster, A. A., & Garvis, S. (2017). The importance of critical life moments: An explorative study of successful women with autism spectrum disorder [Article]. *Autism*, 21(6), 670-677. <https://doi.org/10.1177/1362361316677719>
- Weller, S. (2015). The potentials and pitfalls of using skype for qualitative (longitudinal) interviews.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. Psychology Press.
- Wharmby, P. (2022). *Un-typical: How the world isn't built for autistic people and what we should do about it*. Harper Collins.
- White, L. C. J., Ixqe, K. V., Goodall, K., & Gillespie-Smith, K. (2024). Minority stress, camouflaging, and mental health outcomes in transgender and/or non-binary autistic adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2023.0151>
- White, S., Ayman, G., Bakhai, C., Hillier, T., & Magee, L. (2023). Screening and diagnosis of gestational diabetes. *BMJ*, 381. https://www.bmj.com/content/bmj/381/bmj-2022-071920.full.pdf?casa_token=IAqJeCg6QnsAAAAA:J5XlulUOS3NciL9ajAJmzKrnidWyHt1f49-m7d8ccy1wUevXivdppDnOGCmz3ms_xsQz1ZutZIKXWA
- White, S. J., Gerber, D., Sanchez Hernandez, R. D., Efiannayi, A., Chowdhury, I., Partington, H., & Moss, J. F. (2021). Autistic traits and mental health in women with the fragile-x premutation:

- Maternal status versus genetic risk. *The British journal of psychiatry : the journal of mental science*, 218(1), 28-34. <https://doi.org/https://dx.doi.org/10.1192/bjp.2020.231>
- Whiteley, P., Carr, K., & Shattock, P. (2021). Research, clinical, and sociological aspects of autism. *Front Psychiatry*, 12, 481546. <https://doi.org/10.3389/fpsy.2021.481546>
- Whitlock, A., Fulton, K., Lai, M. C., Pellicano, E., & Mandy, W. (2020). Recognition of girls on the autism spectrum by primary school educators: An experimental study. *Autism Res*, 13(8), 1358-1372. <https://doi.org/10.1002/aur.2316>
- WHO. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. World Health Organization.
- WHO. (2018). *The ICD-11 statistical classification of diseases and related health problems*. World Health Organization.
- Whyte, W. F. (1985). *Learning from the field: A guide from experience*. Sage.
- Wigdor, E. M., Weiner, D. J., Grove, J., Fu, J. M., Thompson, W. K., Carey, C. E., Baya, N., van der Merwe, C., Walters, R. K., Satterstrom, F. K., Palmer, D. S., Rosengren, A., Bybjerg-Grauholm, J., i, P. C., Hougaard, D. M., Mortensen, P. B., Daly, M. J., Talkowski, M. E., Sanders, S. J.,...Robinson, E. B. (2022). The female protective effect against autism spectrum disorder. *Cell Genom*, 2(6), 100134. <https://doi.org/10.1016/j.xgen.2022.100134>
- Wignall, A. (2012). Revolutionary becoming. *Journal of the Motherhood Initiative for Research and Community Involvement*, 3(2). <https://jarm.journals.yorku.ca/index.php/jarm/article/viewFile/36326/33044>
- Wilde, A., & Fish, R. (2025). Gender, feminism and the project of critical disability studies (cdis). *Disability & Society*, 40(3), 533-554. <https://www.tandfonline.com/doi/pdf/10.1080/09687599.2023.2298774>
- Williams, G. L., Wharton, T., & Jagoe, C. (2021). Mutual (mis)understanding: Reframing autistic pragmatic “impairments” using relevance theory [Original Research]. *Frontiers in Psychology*, 12. <https://doi.org/10.3389/fpsyg.2021.616664>
- Williams, K. (2018). *Home educating children with special educational needs - an exploration of how mothers experience this unique learning relationship* University of Essex].
- Williams, Z. J., McKenney, E. E., & Gotham, K. O. (2021). Investigating the structure of trait rumination in autistic adults: A network analysis. *Autism*, 13623613211012855. <https://doi.org/10.1177/13623613211012855>
- Williams, Z. J., Suzman, E., & Woynaroski, T. G. (2021). Prevalence of decreased sound tolerance (hyperacusis) in individuals with autism spectrum disorder: A meta-analysis. *Ear Hear*, 42(5), 1137-1150. <https://doi.org/10.1097/AUD.0000000000001005>
- Williamson, T., Wagstaff, D. L., Goodwin, J., & Smith, N. (2023). Mothering ideology: A qualitative exploration of mothers' perceptions of navigating motherhood pressures and partner relationships. *Sex Roles*, 88(1), 101-117. <https://doi.org/10.1007/s11199-022-01345-7>
- Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education.
- Wilson, A. C. (2024). “Resist, reframe, redo the bullying, the lying, the harassment”: A qualitative investigation of social anxiety and therapy as an autistic person. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0009>
- Wilson, A. C., & Bishop, D. V. M. (2021). "Second guessing yourself all the time about what they really mean...": Cognitive differences between autistic and non-autistic adults in understanding implied meaning. *Autism Res*, 14(1), 93-101. <https://doi.org/10.1002/aur.2345>
- Wilson, J. C., & Andrassy, B. (2022). Breastfeeding experiences of autistic women. *MCN The American Journal of Maternal/Child Nursing*, 47(1), 19-24. <https://doi.org/https://dx.doi.org/10.1097/NMC.0000000000000779>
- Wilson, R. A. (2025). Eugenic thinking in medicine, healthcare, and bioethics. In *Handbook of the philosophy of medicine* (pp. 1-14). Springer.
- Wilson, R. B., Thompson, A. R., Rowse, G., & Freeth, M. (2023). The experience of seeking, receiving, and reflecting upon a diagnosis of autism in the UK: A meta-synthesis of qualitative studies

- conducted with autistic individuals. *Research in Autism Spectrum Disorders*, 103.
<https://doi.org/10.1016/j.rasd.2023.102135>
- Wing, L. (1981). Sex ratios in early childhood autism and related conditions. *Psychiatry Research*, 5(2), 129-137. <https://www.sciencedirect.com/getaccess/pii/S0165178181900433/purchase>
- Wing, L. (1996). Autism spectrum disorders. *BMJ*, 312, 327-328.
<https://doi.org/10.1136/bmj.312.7027.327>
- Winn, B. (2015). WARC's guidelines for interviewing autistic individuals. *WARC, The University of Cardiff*.
- Winnard, R., Roy, M., & Butler-Coyne, H. (2021). Motherhood: Female perspectives and experiences of being a parent with ASC [Article]. *Journal of Autism and Developmental Disorders*.
<https://doi.org/10.1007/s10803-021-05122-5>
- WMA. (2013). *World medical association: Declaration of Helsinki: Ethical principles for medical research involving human subjects* (JAMA, Issue. <https://pdf-it.dev.acw.website/please-and-thank-you?url=https://www.wma.net/policies-post/wma-declaration-of-helsinki/&pdfName=wma-declaration-of-helsinki>)
- Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatr*, 15, 197. <https://doi.org/10.1186/s12887-015-0514-5>
- Wright, B., Spikins, P., & Pearson, H. (2020). Should autism spectrum conditions be characterised in a more positive way in our modern world? *Medicina (Kaunas)*, 56(5).
<https://doi.org/10.3390/medicina56050233>
- Xie, S., Karlsson, H., Dalman, C., Widman, L., Rai, D., Gardner, R. M., Magnusson, C., Sandin, S., Tabb, L. P., Newschaffer, C. J., & Lee, B. K. (2020). The familial risk of autism spectrum disorder with and without intellectual disability. *Autism Res*, 13(12), 2242-2250.
<https://doi.org/10.1002/aur.2417>
- Yeung, T. S., Greene, R. K., Dick, C. C., & Duvall, S. W. (2023). Females evaluated for autism: Characteristics and co-occurring and differential DSM-5 diagnoses. *Clin Neuropsychol*, 1-20.
<https://doi.org/10.1080/13854046.2023.2281709>
- Yu, T., Chang, K. C., & Kuo, P. L. (2022). Paternal and maternal psychiatric disorders associated with offspring autism spectrum disorders: A case-control study. *J Psychiatr Res*, 151, 469-475.
<https://doi.org/10.1016/j.jpsychires.2022.05.009>
- Zajic, M. C., & Gudknecht, J. (2024). Person- and identity-first language in autism research: A systematic analysis of abstracts from 11 autism journals. *Autism*, 13623613241241202.
<https://doi.org/10.1177/13623613241241202>
- Zaks, Z. (2023). Changing the medical model of disability to the normalization model of disability: Clarifying the past to create a new future direction. *Disability & Society*, 39(12), 3233-3260.
<https://doi.org/10.1080/09687599.2023.2255926>
- Zampella, C. J., Parish-Morris, J., Foy, J., Cola, M., Schultz, R. T., & Herrington, J. D. (2025). "You should smile more": Population-level sex differences in smiling also exist in autistic people. *Autism*, 29(5), 1236-1245. <https://doi.org/10.1177/13623613241301113>
- Zeidan, J., Fombonne, E., Scora, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Res*.
<https://doi.org/10.1002/aur.2696>
- Zhuang, S., Tan, D. W., Reddrop, S., Dean, L., Maybery, M., & Magiati, I. (2023). Psychosocial factors associated with camouflaging in autistic people and its relationship with mental health and well-being: A mixed methods systematic review. *Clin Psychol Rev*, 105, 102335.
<https://doi.org/10.1016/j.cpr.2023.102335>