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‘Against the norm’ mothering: A reflexive thematic analysis of autistic motherhood

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Abstract

The *idea* of the autistic mother, and interest in autistic mothering and motherhood, is an emergent area of popular and academic interest which, until very recently, was missing from both autism and motherhood literature. Seeking to improve awareness and understanding of autistic motherhood and to make recommendations to improve our lives, this 'insider' research is underpinned by the disability rights slogan 'nothing about us without us' and the feminist slogan 'the personal is political'. Situating this research within matricentric feminism, alongside its more typical setting within critical autism studies, enables a deeper analysis of the social and cultural expectations of motherhood and their influence on autistic mothers. Asynchronous virtual interviews, conducted using WhatsApp (n=10) and email (n=2), and with a 'friendship as method' approach to generating data, were conducted with 12 autistic mothers of autistic children in the UK. Data were analysed using Reflexive Thematic Analysis, resulting in the development of six themes representing patterns of shared meaning organised conceptually around identity, masking, support, mothering, motherhood and knowledge. My analysis shows how poor awareness, understanding and support of autistic mothers contributes to a perpetuation of mother blame narratives, despite participants demonstrating considerable autism expertise and being highly skilled at meeting the needs of their children. Through seeking to understand how autistic mothers negotiate being autistic, navigate motherhood and how being autistic affects experiences of motherhood, I am able to reveal how autistic mothers are resisting normative ideals of the 'good mother' and how we are in the process of co-constructing our own ideal of the 'good *autistic* mother'.

Aim, objectives and questions

Research aim

To contribute to knowledge about, and to improve the understanding of, autistic mothers of autistic children in the UK.

Research objectives

To understand autistic mothers’ experience of being autistic.

To understand autistic mothers’ experiences of mothering.

To understand how being autistic affects experiences of motherhood.

To make recommendations for policy and practice improvements.

Research questions

How do autistic mothers negotiate being autistic?

How do autistic mothers navigate motherhood?

How does being autistic affect experiences of motherhood?

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List of abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
ASD	Autism Spectrum Disorder
AQ	Autism Spectrum Quotient
AdAS	Adult Autism Subthreshold Spectrum
BAP	Broad Autism Phenotype
BAPQ	Broad Autism Phenotype Questionnaire
BPD	Borderline Personality Disorder
CBT	Cognitive Behavioural Therapy
DISCO	Diagnostic Interview for Social and Communication Disorders
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDS	Ehlers-Danlos Syndrome
EHCP	Education, Health and Care Plan
EMB	Extreme Male Brain
FII	Fabricated or Induced Illness
GP	General Practitioner
ICD	International Classification of Diseases
IEP	Individual Education Plan
INSAR	International Society for Autism Research
IQ	Intelligence Quotient
LA	Local Authority
MA	Master of Arts

MbP	Munchausen Syndrome by Proxy
MH	Mental Health
MP	Member of Parliament
NT	Neurotypical
PA	Personal Assistant
PDA	Pathological Demand Avoidance
PDD	Pervasive Developmental Disorder
PGCE	Postgraduate Certificate in Education
PIP	Personal Independence Payment
PoTS	Postural Tachycardia Syndrome
PPS	Perplexing Presentations
PRU	Pupil Referral Unit
RCPCH	Royal College of Paediatrics and Child Health
RTA	Reflexive Thematic Analysis
SEN/SEND	Special Educational Needs/and Disabilities
SENCo	Special Educational Needs Coordinator
SENDIST	Special Educational Needs and Disability Tribunal
TAC	Team Around the Child

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1. Introduction

Why this and why now?

In March 2016 I stood on a stage at the National Autistic Society's annual professional conference to talk about being an autistic mother of an autistic child. This was the first time I had presented to an audience since narrating a nativity play in infant school, and I was terrified. Having accepted the invitation to speak about a month or so before, I had searched for information and research about autistic mothers of autistic children and found nothing. I knew that I wanted to present more than *just* my story, especially as I would hopefully have an audience full of engaged and interested professionals who encounter autistic mothers in their daily work, so I asked some online friends who were also autistic mothers of autistic children what they would like professionals to know. It was important to me to take full advantage of my time on stage and to make sure the professionals heard from us what they could do better to support us and, as a result, enable us to better support our children. After my 15-minute talk, and answering audience questions, which was all surprisingly exhilarating, somebody suggested to me that "there's a PhD in this", which planted the seed which grew into this thesis.

About six months before standing on that stage I had finally, at the age of 45, been diagnosed as autistic following the diagnosis of my son several years earlier. It seems somewhat ironic that it took being officially recognised as having a social and communication disorder[1] for me to accept an invitation to do public speaking or, in fact, to even attend a conference at all. I had up until that point avoided anything which had required presentations, speaking in public or any situation which might result in unplanned and ad-hoc interaction and communication with strangers, thereby significantly limiting my academic, work and career options and choices. The liberating and empowering nature of self-realisation and the validation of being diagnosed as autistic I experienced was also experienced, to varying degrees, by the autistic mothers who have participated in this research who, like me, were able to understand themselves better and, for some, to use this new understanding to make transformative changes in their lives.

I had graduated from my undergraduate degree as an already mature student some 20 years earlier and had always wanted to do a PhD, but: first, I had far too many interests and could never decide what to pursue; second, I was only the second person in my family to do a degree and I had no idea what a PhD even entailed or how you got to do one, bearing in mind this was before a widespread internet where you could just ‘google it’; and third, I worked full-time, then part-time after my son was born, in a highly stressful job, with all the domestic and financial responsibilities and pressures that brings. Nevertheless, a year after that terrifying and exhilarating conference presentation, a change in circumstances enabled me to be able to give up work and pursue both my long-standing desire to do a PhD and to contribute to filling the, at the time, vast empty space of research concerned with autistic motherhood. Since I first set

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[1] As per diagnostic schedules where autism is framed as a pathological state. See later in this chapter for a discussion on how autism can be conceptualised in different ways.

out, as I will cover in the next chapter, there has been an uptick in research interest in autistic motherhood, and the questions asked in this thesis serve to support, complement and supplement this emergent area of academic work concerned with the experiences of autistic mothers of autistic children. Hence, whilst research about autistic motherhood is still in its infancy, there remain gaps to fill, and before I turn to outline my research aims and questions, I will briefly consider the gaps which need to be filled.

Awareness gaps

The *idea* that mothers of autistic children might also be autistic does not appear to be widely considered. An example which highlights how this can impact our children is how literature and checklists aimed at parents who suspect their child might be autistic assume that the parent informant is a neutral observer. The Social Communication Questionnaire, which is used to capture information from a parent or carer, includes items such as “inappropriate emotions when in conversation”, “makes unusual noises”, “cannot arrange toys properly” and “attachment to unusual objects” (QuestionPro, 2023). These subjective-masquerading-as-objective questionnaire items serve as a means to measure divergence from an expected norm whilst failing to take account of those of us whose children are just like us and where atypical is our ‘normal’. The implied assumption that our children are somehow *other* or *alien* to us results from poor awareness that mothers of autistic children can be, and often are, autistic too. An example here from my own experience illuminates this:

> When my son was about 3, an SEN professional suggested that he was having sensory ‘problems’. I was advised to buy a particular book to help me understand and support him. I bought the book. I read the book. I didn’t recognise him in the

> book at all and gave it to a local charity shop. It was only later, whilst reading accounts by autistic women that the penny dropped, and I realised that I actually had quite significant sensory 'problems', and I hadn't recognised my son in the book because I had used myself as a benchmark for 'normal'. I had to re-buy the book.

In failing to recognise that I was not a neutral benchmark, I failed to fully recognise my son's sensory needs, and without awareness that mothers can be autistic too, our own and our children's needs risk being un-recognised and un-met. As I will demonstrate throughout this thesis, the sharing of stories is an important part of developing understanding of ourselves which, in turn, helps us to better understand and, therefore, care for our children. The stories of my participants, and my interpretation and analysis of those stories, serve to help fill the 'gap' in awareness of autistic motherhood.

Policy gaps

Across the UK, England and the devolved nations each have their own national policy, strategy or code of practice for autism, setting out guidance to improve autistic well-being and outcomes. In England this is "The national strategy for autistic children, young people and adults: 2021-2026" (Department for Education/Department of Health & Social Care, 2021), Northern Ireland has an "Autism interim strategy" (Department of Health, 2021), Scotland has "The Scottish strategy for autism" (Scottish Government, 2011), and Wales has in place a "Code of practice on the delivery of autism services'"(Welsh Government, 2021). Currently, whilst these policy documents are concerned with autism across the lifespan, they appear to fail to consider autism across generations and within families, including the particular needs of autistic mothers (and some fathers and siblings) who are the primary carers and advocates and who are juggling their own needs with the needs of the children (including adult children) who they are responsible for. Whilst policy emerges at different layers of governance, national policy and strategy plays an important part in influencing and guiding regional and local policy and strategy. As this thesis will show, autistic mothers of autistic children face a range of challenges in getting their own and their children's needs met, consequently, national policy commitments which identify and raise awareness of our specific needs have the potential to influence local and professional policy and practice, resulting in improved service and provision, but only if they translate into practice.

Practice gaps

Awareness raising and policy implementation will only matter, therefore, if it results in practice changes and improvements in professional practice with autistic mothers, and this is reliant on professional awareness that autistic mothers exist at all and how best to support and work with us. Some progress is being made, for example, social workers have recently begun to benefit from a practice guide for working with autistic people (BASW, 2023), though I note that a toolkit for GPs is no longer available. However, as I will demonstrate, professional knowledge of autism is often poor or outdated, or reliant on stereotypes, and often lacks the nuance required to understand the experiences of autistic adults, women and mothers in particular. Through highlighting participating autistic mothers' good and bad experiences with professionals, and examining what might be influencing some examples of poor practice, this thesis will provide understanding and knowledge which could inform professional training and practice.

Research aims and questions

The aim of this thesis, therefore, is to contribute to knowledge about, and to improve the understanding of, autistic mothers of autistic children in the UK. Using interview data from 12 participating autistic mothers, this thesis uses reflexive thematic analysis (Braun and Clarke, 2022) to answer the following questions:

- How do autistic mothers negotiate being autistic?
- How do autistic mothers navigate motherhood?
- How does being autistic affect experiences of motherhood?

However, research does not take place within a vacuum, and, like all researchers, I bring my own subjective position, values and social and political perspective into this thesis. To provide transparency about my approach to research and to answering my research questions, I now turn to explain the social and political framework which underpins and informs my positionality and, as a result, this thesis.

Social and political framework

My position as an autistic mother of an autistic child is central to this thesis and my lens of partiality is evident throughout, sometimes in subtle ways, like in the way I interacted with participants during our interviews where I shared information about my own experiences. At other times my position is signalled more blatantly through describing autistic mothers as ‘us’ rather than ‘them’ or where I talk about ‘our’ rather than ‘their’. Alongside, and heavily influenced by my personal position, I draw upon the broad intellectual traditions of feminist and disability studies, and the more focused fields of matricentric feminist and critical autism studies, each providing ways of thinking about and contextualising participant experiences and my interpretation and analysis of those experiences.

The personal is political

Generally attributed to Hanisch (1969), but emerging from the second-wave feminist movement of the 1960s and 1970s, the feminist slogan “the personal is political” is a reminder that women’s personal lives are socially and politically important. As I will show in Chapter 2, the marginalisation in autism research and knowledge of autistic women, and hence autistic mothers too, has only fairly recently started to be redressed through challenging the male bias in autism knowledge and discourse. From a feminist position this reflects centuries old traditions of a male default or male norm in both the production of knowledge and as the subject of knowledge (Code, 2014), as well as in medicine and data collection (Criado Perez, 2019). Despite feminism encompassing a wide range of sometimes conflicting philosophical, theoretical and practical traditions, positions and interests (Leavy and Harris, 2019), at its core is a critique of the unequal and subordinate status of women (Letherby, 2003). In this thesis I am adopting a pluralist approach to feminist research (Stanley and Wise, 2013), enabling me to mix and match from across feminist traditions and positions as I attempt to shed light on autistic motherhood. Whilst the dominant feminist tradition which underpins this thesis is matricentric feminism, which I will briefly outline below, in Chapters 4 to 10 I will also be influenced by and draw upon feminist disability studies, poststructuralist and Black feminists to support my interpretation and analysis.

Matricentric feminism can be described as a “feminism for mothers” (O’Reilly, 2019, p. 13) as it recognises the sub-category of mothers as distinct from the category of women, proposing that mothers face additional and different social, political and economic problems as a result of being mothers. According to O’Reilly (2019), matricentric feminism does not valorise or essentialise mothering or motherhood, that is, it is not saying that all women should be or want to be mothers, or that mothering practice is somehow innate or instinctive or an ideal and aspirational state of womanhood. Rather, it asserts that mothering is skilled work, that mothers matter, that motherhood is culturally and socially situated and, importantly, it seeks to empower mothers to effect social change through maternal practices and activism. My matricentric lens will, therefore, be evident throughout this thesis as I explore participant experiences of autistic motherhood and mothering.

Nothing about us, without us

The disability rights slogan “nothing about us, without us” (Charlton, 1998) highlights the importance of including disabled people in matters about disability. Broadly, in disability studies, disability is presented as a distinct and socially and culturally situated categorisation and system of oppression akin to class, race and gender (Garland-Thomson, 2002; Garland-Thomson, 2005), challenging the idea of disability as inferiority (Garland-Thomson, 2013) in the same way that class, race and feminist theorists have challenged the intersecting ideas that poor people, black and brown people, and female people are inferior to rich, white and male people. As with feminism above, I am adopting a pluralist approach to disability studies, and whilst the dominant strand of disability studies which underpins this thesis is critical autism studies, which I will briefly outline below, in Chapters 4-10 I will also be influenced by and draw more broadly upon feminist disability studies, studies in ableism and the neurodiversity paradigm to support my interpretation and analysis.

Critical autism studies[2] combines an analysis of the power relations evident in the production of autism knowledge, a critique of medical and deficit-based depictions of autism and autistic people, and a commitment to studying the culture as well as the nature of autism (Orsini and Davidson, 2013). In seeking to culturally and socially situate autism (Ryan and Milton, 2023), it provides a means to develop different ways of thinking about autism and enables and encourages autistic activists and autistic and non-autistic academics to work together to enhance understanding and knowledge of autism (O'Dell et al., 2016; Woods et al., 2018). My critical autism studies lens will, therefore, be evident throughout this thesis as I explore participant experiences of autism and being autistic in the intersecting context of autistic motherhood.

What is autism?

Having introduced and discussed autism already in this chapter, it is now time to briefly consider what I mean when I discuss autism, what it might actually be and how it can be conceptualised in different ways, reflecting the various and often heavily contested terrains of autism knowledge (Milton, 2014). These tensions have been helpfully summarised by Kourti (2021) here:

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[2] 'Critical autism studies' was also used by Runswick-Cole et al. (2016), where the validity and usefulness of autism diagnosis was challenged and disputed by non-autistic autism researchers. A useful critique of their framing of 'critical autism studies' is provided by Milton (2016) whose framing informs my own use.

> On the one hand, from its conception, autism has been historically heavily located in the fields of psychiatry, psychology and neuroscience, which often assume access to an "objective," neutral and infallible reality that is external to the research process and is based on the autistic person's biology and behavioural characteristics, which can be scientifically observed and studied. On the other, proponents of the neurodiversity paradigm argue against medicalised and pathologising approaches to autism and toward approaches that consider social constructions of autism and relations of power. (Kourti, 2021, p. 1)

Reflecting these apparently opposing conceptualisations of autism, I will begin my attempt to answer the question "what is autism?" by presenting an overview of the predominant medical/deficit-based definitions of autism, I will then consider how challenges to medical/deficit-based definitions have enhanced our understanding of autism and its classification, before considering the usefulness of a critical realist approach to understanding the nature of autism.

Medical/deficit-based model of autism

Autism in the UK is typically defined and diagnosed according to the classifications provided by two widely used diagnostic schedules: the DSM-5, which is the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013); and the ICD-10, which is the tenth edition of the International Classification of Diseases (World Health Organisation, 2016). Across both, autism is presented as a series of deficits (DSM-5) and abnormalities (ICD-10) and framed as a social and communication disorder with difficulties related to social interaction and communication, and restricted and repetitive behaviours and interests. The influence of such diagnostic definitions is evident across academic and popular writings and representations of autism, including research papers, newspaper and magazine sidebars, and charity websites, where the way that autism is defined and described frequently reflects this medical and deficit-based diagnostic criteria for autism, for example:

In a journal paper investigating the vulnerability of autistic adults:

> Autism spectrum condition … is a neurodevelopmental condition characterised by difficulties in social communication alongside restrictive and repetitive behaviours and interests, as well as a strong need for predictability and sensory hyper-sensitivity. (Griffiths et al., 2019)

As a sidebar providing a "quick guide" to autism in a newspaper article about autistic women's experience of late-diagnosis:

> Autism is a spectrum disorder, which is defined by having difficulties with social communication and restrictive or repetitive behaviours, activities or interests. It is a neurodevelopmental disorder, meaning that those difficulties would have existed since childhood, even if someone is diagnosed as an adult. (Hill, 2021)

On a webpage entitled 'What is autism?', where the National Autistic Society outlines a "list of difficulties which autistic people may share":

> Social communication and social interaction challenges
> Repetitive and restrictive behaviour
> Over- or under-sensitivity to light, sound, taste or touch
> Highly focused interests or hobbies
> Extreme anxiety
> Meltdowns and shutdowns (NAS, 2023b)

Descriptions like these reduce autism, and being autistic, to a checklist of deficits and abnormalities, where being autistic is presented as being deficient and abnormal, a status heavily criticised by many autistic people, including autistic advocates and activists, and scholars of critical autism studies.

The neurodiversity challenge

Thirty years ago, Sinclair's 1993 essay "Don't mourn for us" (Sinclair, 2012) presented a rallying call to parents of autistic children, challenging the tragedy narratives which cast autism as a devastating disease, and clearly asserting that autism is not an appendage, an impenetrable wall, or a death. Sinclair urged parents to stop mourning for the child they had expected to have, to start understanding the child that they had, and to tell themselves:

> This is not my child that I expected and planned for. This is an alien child who landed in my life by accident. I don't know who this child is or what it will become. But I know it's a child, stranded in an alien world, without parents of its own kind to care for it. It needs someone to care for it, to teach it, to interpret and advocate for it. And because this alien child happened to drop into my life, that job is mine if I want it. (Sinclair, 2012, p. 20)

As will be seen later in this thesis, participating mothers very much took on 'that job' and, in most cases, before realising that they shared their child's 'alien' status. Sinclair's essay had grown from networks of autistic adults across the world who made use of the emerging internet through online networks (Milton, 2020), laying the foundations for autistic advocacy, activism and scholarship, and widening and deepening our understanding of autism far beyond the restricted pathologising of the deficits and abnormalities thought to signify and define autism.

The concept of neurodiversity was also born from those same early networks (Singer, 2017) and the neurodiversity paradigm provides a powerful challenge to traditional models of autism, presenting a "deficit-as-difference" (Kapp et al., 2013, p. 66) alternative, where autistic differences are framed in neutral or positive terms, and certainly not something which requires treatment or cure. Within the neurodiversity paradigm, autism is positioned as part of a spectrum of different neurotypes which contribute to a diversity of human life, underpinning critical autism studies by providing a way of thinking about autism which recognises the social and political forces which pathologise and marginalise autistic people (Kapp, 2020). Whilst critical of existing pathologising narratives and criteria, many neurodiversity proponents recognise the need for diagnosis and classification, as diagnosis is often instrumental in accessing "legal protections, social legitimacy, and service provisions" (Kapp and Ne'eman, 2020, p, 168), whilst campaigning for a better and non-pathologising classification and diagnostic system which more accurately represents autistic people. Hence, in rejecting the medical and deficit-based constructions of autism, from within a neurodiversity paradigm autism is instead "positioned … as combinations of disability, difference and identity" (Botha and Cage, 2022, p. 2). This matters because autistic people are not immune to the negative and de-humanising descriptions of autism and being autistic, which contribute to our experiences of stigma and stereotyping, as well as to our sense of self and well-being (Botha, 2021a). As will be shown later in this thesis, overall, participants valued diagnosis for validation and enabling access to support and legal protections but struggled with the often pathologising requirements of assessment and diagnostic processes, especially for their children.

A critical realist approach to autism

Despite having described above different ways to categorise and conceptualise autism, I have so far failed to answer the question "what is autism?". In Chapter 2 I will tell a story of autism, along the way exploring and examining some of the significant attempts to explain autism,[3] and through my thematic analysis and theoretical discussion in Chapters 4 to 10 I will examine the influence of these and other attempts to explain what autism actually is. Diagnostic and classification systems provide us with a set of criteria against which to be measured and categorised, and first-person and insider accounts tell us what it is like to be autistic based on having or exhibiting examples of that criteria, but this is rather circular and does not actually tell us what autism actually **is**. Thus, whilst *objective* and scientific accounts can point to the existence of autism, but cannot tell us what it is, *subjective* and experiential accounts provide understanding of the social and cultural meaning of autism and being autistic, whilst being both reliant upon and somewhat in opposition to the former.

Unsurprisingly, then, autism remains a contested condition (Silverman, 2012), with no singularly identified causal mechanism or universal biomarker (Happé and Frith, 2020), and typically identified or diagnosed through self-, parental- and third-party reports, observation of behaviour and the administration of diagnostic instruments[4] (Hayes et al., 2022). For some, the lack of 'proof' for autism has resulted in arguments to abandon autism diagnosis altogether on the basis that it is founded on "pseudo-scientific claims" (Runswick-Cole et al., 2016, p. 8). For others, and I am including myself here, and as will be explored in Chapter 4, diagnosis provides both a shorthand and a signpost, summarising difficulties and facilitating access and support, as well as contributing to self-awareness and positive well-being and identity. Furthermore, the lack of any incontrovertible scientific 'proof' of autism does not mean that it does not exist or is not

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[3] A comprehensive compilation and analysis of autism theories is provided by Chown, N. (2017) *Understanding and evaluating autism theory*. London: Jessica Kingsley Publishers.

[4] For example, ADOS and DISCO (see list of abbreviations).

real, or should not be treated as real, which brings me to critical realism, a way of thinking about the nature of reality in a manner that enables us to consider things as real even when they are un-provable.

The nature of reality and what counts as real in research will be discussed in Chapter 3, where I will explain why I have adopted a critical realist ontological and epistemological approach to research. Here, I want to briefly prelude that discussion in order to consider the usefulness of a critical realist approach to defining autism. Critical realism offers a wholly different way to consider autism as it provides a means to treat things as real even if we don't observe or experience those things, thus, in relation to autism, "we do not *need* to know about autism for the phenomena we have come to describe as autism themselves to exist. Autism will be autism independent of who is looking into it or who is describing it" (Kourti, 2021, p. 4). Real for critical realists, then, is not the same as fact or truth, and an important tool in the critical realist research toolbox is 'judgemental rationality' (Bhaskar, 2016; Botha, 2021b), a way of assessing and evaluating the available evidence and then using rational judgement to determine the credibility of a claim to knowledge. To draw from legal discourse, this means we can test evidence or a claim to knowledge on the 'balance of probabilities' rather than by requiring evidence to be 'beyond reasonable doubt'. Therefore, on this basis, we can say that autism *appears* to exist, that science has told us that there is a definable and discrete sub-population of people who share a constellation of characteristics which *infers* similarity, and that people who share this pattern of characteristics often feel an *affinity* with both the characteristics and with other people who share those characteristics. We can also say, on the basis of both the 'objective' scientific and the 'subjective' experiential evidence available, that this population is quantitatively and qualitatively distinct from the wider population. Perhaps most importantly, from within a critical realist framework, we can say that autism is a useful way to describe particular and meaningful patterns of characteristics, whether it exists as a provable fact or not.

A brief note on autistic and autism language

Throughout the thesis, I will describe autistic people as 'autistic people', not as 'people with autism'. This reflects personal, participant and broader autistic community preferences (Botha et al., 2023; Bottema-Beutel et al., 2021; Kenny et al., 2015). I am aware that at times I will use language which some autistic people might find jarring or objectionable because it is rooted in medical and deficit-based models of autism, for example, the descriptor *special* interests[5] or describing non-autistic people, development or characteristics as typical (Bottema-Beutel et al., 2021). On the whole, however, the language choices I make are driven by a combination of pragmatism and enabling clarity as well as respecting and reflecting the language choices of my participants.

Thesis outline

This thesis comprises 11 chapters. This introductory chapter has introduced the personal and theoretical background and foundations for this research, in particular, the underpinning ethics and values-base of the feminist slogan "the personal is political" (Hanisch, 1969) and the disability rights slogan "nothing about us, without us" (Charlton,

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[5] The use of the term 'special interests' to describe autistic people's hobbies and interests will, however, be discussed in sub-theme 6.3: '*I have a need to know exactly what something is about'*.

1998) which have informed this research from start to finish. I have also provided a consideration of different models of autism and made a case for a critical realist approach to understanding autism, acknowledging the lack of 'scientific proof' that autism exists as a discrete 'thing', whilst also recognising the usefulness of autism as a way to provide understanding and connection for people who are considered to be, or consider themselves to be, autistic. This chapter has also introduced my research questions and identified the gaps which I intend to attempt to fill, at least in part, through conducting this research, and which I will return to in Chapter 11 when I conclude this thesis and outline my contribution to knowledge about autistic motherhood.

Chapter 2 will present my review of the literature. I have chosen to conduct a narrative review (Greenhalgh et al. 2005; Greenhalgh et al., 2018) as a way to highlight how historical knowledge influences current knowledge, and to present a storyline across time to understand why the existence and experiences of autistic mothers of autistic children was absent from autism research and knowledge for so long. Essentially, I asked the literature "what took you so long?" and, as will be demonstrated, the clues to the existence of autistic mothers were there from the earliest iterations of autism knowledge. Importantly, research literature is finally catching up, and I am able to include new and original research exploring autistic motherhood, including research conducted by, or in collaboration with, autistic mothers.

Chapter 3 explores and justifies my methodological and method choices. I begin with an appraisal of the 'ologies', ontology, epistemology and axiology, as I interrogate and clarify the importance of showing my workings as I consider the nature of reality, knowledge and ethics and how they influence and undergird this thesis and inform my critical realist approach to research methodology. After introducing the procedural, situational and relational domains of research ethics the chapter will consider the ethical benefits of participatory research, autoethnography and friendship as method. I will then move on to the more practical and pragmatic elements of research, to explore sampling, recruitment, and my interviewing process, including the benefits of using WhatsApp for its flexibility and accessibility. The chapter will end with my justification for using reflexive thematic analysis (Braun and Clarke, 2022) as a method of data analysis, where I will provide a step-by-step walk-through of my analytical process and theme development.

The findings and discussion of my data analysis will be presented thematically in Chapters 4-9. Drawing on participant contributions to this thesis, I will present six themes which explore experiences of autistic motherhood, as I situate participant experiences and my analysis of those experiences within existing empirical and theoretical literature. Theme 1: 'Knowing I'm autistic helps me to understand myself' considers the benefits for participating autistic mothers in discovering they were autistic and of diagnosis through the sub-themes 1.1: 'It was like a lightbulb', 1.2: 'Affirmation of my autistic identity has been helpful' and 1.3: 'I didn't recognise the red flags'. Theme 2: 'Masking is a real double-edge sword' explores the tensions expressed by participants around the costs and benefits of masking their autism, and the impact of a double masking burden where mothers mask for both themselves and their children, through the sub-themes 2.1: 'There's a lot of pressure of mothers to "fit in"' and 2.2: 'I'm the queen of camouflaging'. Theme 3: 'Women like me "fall through the gaps" of support' examines participant experiences of accessing, and attempting to access, support and the ways that participating mothers have created and developed solutions to ameliorate the dearth of formal supports available through the sub-themes 3.1: ‘It’s hard to get support from anyone who understands my kind of autism’ and 3.2: ‘I’ve had to make my own support network for myself’. Theme 4: ‘A good mum wants the best for her children’ demonstrates some of the particular challenges and strengths of autistic mothering through the sub-themes 4.1: ‘You have to squash down your own needs’, 4.2: ‘Being an autistic mother feels like having insider information’ and 4.3: ‘”Against the norm” mothering’. Theme 5: ‘Autistic mothers are judged and problematised by the same forces that police gender roles in society’ examines participant experiences of being the default parent and of mother blame, in the context of the social roles and expectations of mothers and motherhood, through the sub-themes 5.1 ‘Mum is the one who keeps things in place’ and 5.2: ‘We get blamed a lot for our kids’. Theme 6: ‘If you’re autistic it’s presumed that you don’t know anything about anything’ illuminates the high levels of knowledge and expertise evidenced by participants and how this expertise is frequently under-recognised and under-valued, through the sub-themes 6.1: ‘All sorts of myths float around to make up for outdated knowledge’, 6.2: ‘They just see us as mum, who knows nothing’ and 6.3: ‘I have a need to know exactly what something is about’.

Chapter 10 provides a broader discussion in the form of a meta-analysis of cross-theme patterns, supported and informed by empirical and theoretical literature, and organised around my research questions. Where Chapters 4-9 present my thematic analysis as discrete yet interconnected themes, in Chapter 10 I step back and look at the bigger picture to consider in more depth, the different ways autistic motherhood can be understood through the application of different conceptual and theoretical approaches. In answering the question "How do autistic mothers negotiate being autistic?" I adopt a neurodiversity lens to explore participant experiences of creating a supportive "homeplace" (hooks, 2015, p. 43) for themselves and their children; I examine the ways that participants used masking in their mothering practice; and I consider the difficulty of finding time for themselves and the challenges presented by autistic inertia (Buckle et al., 2021) and monotropism (Murray et al., 2005). In answering the question "How do autistic mothers navigate motherhood?" I adopt a matricentric lens to examine the particular social role of mothers, as distinct from fathers and parents (Dash et al., 2023), to highlight the importance of mother-centred research and understanding; I consider how autistic mothers are faced with many of the same responsibilities and challenges experienced by all mothers, yet often with added layers of complexity and additional demands; and I explore the impact of representations of the 'good mother' and how some participants have developed and engaged in virtual community mothering as a means to share and develop knowledge and support. In answering the question "How does being autistic affect experiences of motherhood?" I begin by illuminating the ableism and disablism inherent in 'good mother' narratives and how ableism contributes to participant masking, whilst recognising the ways that autistic mothers resist normative expectations and go 'against the norm'; I present an argument which frames participating mothers' advocacy and support for their children as both culturework (Longman et al., 2013; Frederick et al., 2019) and maternal activism (Mendoza, 2023); and I consider the idea of an autistic mother advantage as a way to recognise the insider knowledge gained through sharing a neurotype, and the authoritative knowledge

(Landsman, 1998), intimate expertise (Lilley, 2011) and unorthodox knowing (MacGregor, 2021) demonstrated throughout by participating autistic mothers.

Chapter 11 will conclude this thesis, beginning with a summary of the research and a re-cap of my answers to the research questions. Then, through a consideration of my original contribution to knowledge I will consider my contributions to awareness raising and knowledge of autistic motherhood, and also how my methodological and method choices have contributed to originality. This will be followed by an examination of the implications and recommendations which arise from this research, before presenting a discussion of its limitations. Finally, I will bring the thesis to an end with my final reflections.

Overall, this thesis presents an in-depth exploration and analysis of autistic motherhood, through the experiences of the 12 participating autistic mothers of autistic children. The use of asynchronous virtual interviews contributed to detailed, focused and extensive contributions from participants, enabling the breadth and depth of experiences showcased in this thesis.

2. Literature review

Introduction

Having introduced the thesis, this chapter will situate my research in the literature, and I will do this by telling the story of my investigation and interrogation of autism literature by asking the question "what took you so long?", as the clues to the existence of autistic mothers were evident in the earliest writings on autism yet we remained largely absent from that body of literature until very recently. This is important, as will be demonstrated later when I explore participant experiences and present my analysis, for the autism knowledge of the past exerts a heavy presence in the present. I will begin this chapter by reporting what was known and not known about the experiences of autistic mothers when I set out to design my research project, then I will briefly describe my justification for conducting a narrative review, before presenting the literature which both underpins and acts as a springboard for analysis and further theorising later in this thesis.

The meaning we attach to a concept such as autism is shaped by academic and popular knowledge, as well as by our own experiences. Autism has been through a series of iterations since it was first conceptualised as a unique condition in the 1940s, and despite even the earliest research acknowledging the existence of autism in both sexes, autism became known as a largely male condition (Lai et al., 2015). As a result, autism is often missed in girls and women (Ratto et al., 2018) who tend to be diagnosed later than boys and men (Lai et al., 2015; Russell et al., 2022) with a male: female ratio of approximately 3:1 (Loomes et al., 2017). When I started this research project, there were indications that increasing numbers of women were being diagnosed as autistic following the diagnosis of their children (Hill, 2017), yet there was a dearth of published academic research focused on autistic mothers. Some insight had been provided by Lawson's autobiographical writings (2000), and later, Prince's (2010) autoethnographic narrative of autistic motherhood and Grant's (2015) book, which explored pregnancy, birth and early motherhood, and autistic women were starting to write about their experiences of motherhood (for example, James, 2017; Lloyd-Williams, 2018). Fletcher-Randle's (2022) thematic analysis of online autistic parenting accounts provides a useful overview of the time, highlighting both the scarcity of content related to autistic parenting, particularly when compared to content about autism parenting,[6] and the emerging first-person autistic accounts and sympathetic non-autistic accounts of autistic parenting. In 2017 an article in Spectrum outlined unpublished research[7] showing that autistic mothers "often feel isolated, unsupported and judged negatively. For example, teachers or social workers may interpret a child's challenging behaviour as resulting from poor parenting, leaving the mother vulnerable to unreasonable scrutiny from child welfare services" (Baron-Cohen and Hampton, 2017, para. 6). This reflected a report for the United Nations by Autism Women Matter (Blakemore, 2015) which presented a series of case studies highlighting how professionals misinterpret autistic mothers' behaviours and interactions with their autistic children, resulting in discrimination and interference in family life, including removal of their children. These reports of

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[6] As per Fletcher-Randle (2022), I distinguish between autistic mothers/parents and autism mothers/parents. The former are autistic themselves whilst the latter are typically non-autistic mothers/parents of autistic children.

[7] Later published by Hampton et al. (2022a; 2022b; 2022c; 2022d; 2022e)

misunderstanding, judgement and lack of support, alongside the paucity of research exploring the experiences of autistic mothers, influenced my research questions:

- How do autistic mothers negotiate being autistic?
- How do autistic mothers navigate motherhood?
- How does being autistic affect experiences of motherhood?

As I discussed in the previous chapter, I had conducted cursory, and unsuccessful, searches for research on autistic motherhood before even considering doing a PHD, but I had hoped that this time it would be different, especially as I now had academic access to journals and databases. I, optimistically, began by conducting a literature search across various databases using the specific terms "autistic mother" and "mother with autism", which produced no relevant results. I then searched for academic articles using the search term "(autis* OR asperger*) AND (mother* OR parent*)" across a range of search engines and databases, producing tens of thousands of results to sift through. The overwhelming focus of the search results centred on maternal/parental stress, the parenting and treatment of autistic children, familial traits, and the broader autism phenotype. Only two studies were found which were explicitly about autistic parenting, one suggesting that autistic parents of autistic children were less satisfied than parents of non-autistic children (Lau and Peterson, 2011) and the other finding that autistic mothers scored more highly on parental efficacy measures than fathers, and similar to parents from non-autistic families (Lau et al., 2016). Neither of these studies provided the experiential focus that I believed needed to be explored. Some research had looked at autistic women’s experiences of pregnancy, birth, and the immediate post-natal period, highlighting issues such as sensory difficulties, communication problems and poor understanding by midwives and other healthcare professionals (for example, Gardner et al., 2016; Rogers et al., 2017) all issues which would be reflected in later research, including this thesis. The experiences of mothers with intellectual disabilities have also been studied, often with a focus on parenting capacity (for example, Aunos and Pacheco, 2020), removal of children (for example, Gould and Dodd, 2014) and the need for improved support and understanding to address stigma and assumed incompetence (for example, Franklin et al., 2022; Theodore et al., 2018), however, these studies do not explicitly include autistic mothers and are, therefore, beyond the scope of this review. Therefore, with my interest being focused specifically on autistic mothers of autistic children, there remained a clear gap in research. Furthermore, whilst my initial searches provided clear evidence for the lack of research into autistic motherhood at the time, it was not an effective way to source material that would situate my research in the literature. As a result, I decided to conduct a narrative review.

Narrative reviews rely on the researcher identifying material which provides “clarification and insight” (Greenhalgh et al., 2018, p. 2) and enables the reviewer to search and identify useful material among a mass of sources. A narrative approach recognises the importance of historical knowledge and how it shapes and influences current knowledge, creating storylines across time (Greenhalgh et al., 2005). I wanted to be able to demonstrate the importance and influence of historic autism knowledge on the understanding and experiences of autistic mothers today, and to do that I sourced literature through keyword searching of academic search engines, following up references and citations, and locating key texts and papers within the field of autism research. My storyline of autism literature is presented in this chapter as a series of key phases and concepts which, whilst not strictly chronological, help tell the story of how we have come to know what we think we know about autism and autistic mothering. As this literature review will show, the idea that some mothers of autistic children might be autistic was suggested in some of the earliest and foundational writings on autism, yet it took until the 2020s for academia to catch up and take interest.

Autism as a childhood condition

The history of autism has been well documented (Donvan and Zucker, 2016; Evans, 2017; Feinstein, 2010; Grinker, 2008; McGuire, 2016; Silberman, 2015; Silverman, 2012; Waltz, 2013) reflecting both academic and popular interest in autism. These historical accounts are informed by, and part of, the mass of literature recording, informing and driving changes in understanding, scientific developments and diagnostic categories. My aim here is to highlight the lack of research on autistic mothers and examine how the dominant knowledge, theories and concepts may have contributed to, and continue to contribute to, our awareness and understanding of autistic mothers today. The vast majority of this review focuses on autism from its first conception in the 1940s, to the end of the twentieth century, and how research from that period continues to shape understanding. This was a period which predominantly presented autism as a condition of childhood, mostly present in boys, and with a focus on causes and treatments. However, this period also saw the emergence of first-person autistic writings which would come to showcase and highlight the experiences and lives of autistic adults and lay the groundwork for studies such as this.

Autism was initially considered to be a childhood disorder or disease, its earliest iterations described as "early infantile autism" (Kanner, 1944, p. 211) and "autistic psychopathy in childhood" (Asperger, 1944, p. 37). It was often considered to be, and codified as, a form of childhood psychosis (Creak, 1951; Remschmidt, 1994; Wing and Wing, 1982), which was reflected it its inclusion in the 1952 DSM-I and 1968 DSM-II as a form of childhood schizophrenia (Roth, 2010). In 1980 the DSM-III recorded "infantile autism" as a distinct category, though "infantile" was removed in 1987 (Roth, 2010, p. 37) and, until the UK fully ratifies the use of the ICD-11, expected to be in 2026 (NHS, 2023b), the currently used edition of the ICD-10, first published in 1994, maintains the category of "childhood autism" (WHO, 2016). It is noteworthy that Donnellan's (1985) anthology of "Classic readings in autism" was entirely concerned with autism in childhood, and as recently as the turn of the century, a chapter on "adults with autism" in an edited collection reported only ten known published studies on autistic adults at that time (Gillberg and Coleman, 2000). Moreover, and despite the emergence of first-person autistic accounts of autistic lives (for example, Blackman,1999; Grandin, 1986; Holliday Willey, 1999; Lawson, 2000; Williams, 1992), researchers largely ignored both the existence and perspective of autistic adults. Furthermore, autism in adults continues to be a marginalised area of research, representing only 7% of total UK autism research spending (Autistica, 2019).

Nevertheless, even the earliest autism literature alludes to the presence of autism in adults and, more importantly, in family members, including mothers, who are often described in ways which will be familiar to those used to reading descriptions of autistic children. In Kanner's (1943) original study, he noted particular behaviours in the mothers of the children, including “obsessive preoccupation with details” (p. 12), “obsessive and excitable” (p. 22), “hypomanic” (p. 27), and “self-controlled, placid, logical person” (p. 30) and in his discussion he noted that the children in his case studies “all come from highly intelligent families″ (p.40). Kanner notes a high degree of obsessiveness in the families, a lack of warm-heartedness, and goes on to describe the marriages as cold and heartless, describing the families as “emotional refrigerators” (1949, p 58) which would form the foundation for the concept of the ‘refrigerator mother’. Yet he also suggests that the parents themselves might be “successfully autistic adults” (Kanner, 1954, p. 75), noting the resemblance between children and parents.

Asperger (1944) also identified traits in mothers, describing one mother, Frau V, as:

> ...very similar to the boy. This similarity was particularly striking given that she was a woman, since, in general, one would expect a higher degree of intuitive social adaptation in women, more emotion than intellect… [she] knew her son through and through and understood his difficulties very well. She tried to find similar traits in herself and in her relations and talked about this eloquently’ (Asperger, 1944, p. 41).

This was the first recognition that a mother of an autistic child might herself be autistic (see Limburg, 2021 for a chapter dedicated to Frau V). Asperger (1944) considered autism to be a “natural entity” (p. 67) and of 200 cases of autism seen by his clinic, he reported traits in the parents or relatives in every case where families were assessed (p. 84). He also commented that while he had not met any girls with what he described as “the fully fledged picture of autism” (p. 85), he had encountered several mothers with obvious traits, leading him to suggest that perhaps autism might not be apparent in girls until post puberty. This delayed appearance of ‘symptoms’ would not be recognised in a diagnostic manual until the release of the DSM5 (APA, 2013).

Despite the importance of both Kanner’s and Asperger’s works to the study of autism, it is interesting that whilst both recognised at least the possibility of autistic mothers, future research would largely ignore us. Until the recognition of autistic people without apparent intellectual disabilities, in large part due to Wing’s English language description of Asperger Syndrome (1981b) which entered the ICD-10 and DSM-IV in 1994, it was almost inconceivable for autism researchers to consider autistic adults forming stable relationships and becoming parents. This lack of recognition may have contributed to the academic and popular support for ‘refrigerator mother’ and maternal deprivation theories of autism.

Refrigerator mothers and mother blame

The idea that autism in children was caused by maternal failings was heavily and widely popularised by Bettelheim’s best-seller “The Empty Fortress” (1967), which compared autistic children to victims of concentration camps, and mothers to camp guards. Building on psychoanalytic Freudian principles which analysed mothers’ relationships with their autistic children, alongside theories of attachment and maternal deprivation (in particular, Bowlby, 1951; and see also, Segal, 1971), psychogenic theories of autism considered childhood psychiatric conditions to be the result of inadequate and ambivalent mothering. Kanner (1949) himself had suggested that:

> Most of the patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only. They were the objects of observation and experiment conducted with an eye on fractional performance rather than with genuine warmth and enjoyment. They were kept neatly in refrigerators which did not defrost. Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude. (Kanner, 1949, p. 61)

Kanner based this statement on a study of 55 families where there were many siblings who had not withdrawn and were not considered autistic, and he was unable to adequately explain this inconsistency, later backtracking and suggesting that this was not enough to explain the etiology of autism (Kanner, 1956).

Despite challenge, the ‘refrigerator mother’ theory of autism endured, and psychogenic theories long remained dominant in countries such as France and South Korea (Golding and Stacey, 2018; Grinker, 2008), and the popularity of its legacy remaining both in reality and memory. The 2003 documentary film “Refrigerator Mothers” featured mothers of autistic children diagnosed between the 1950s and 1970s in North America, where Bettelheim and others like him practised. In the film the mothers speak about their experiences with psychiatrists, psychologists and social workers who believed them to be responsible for causing their children’s autism. The mothers recall being described as psychotic, with disordered personalities, accused of not caring for or wanting their children, and presenting with “fanatical” bonding with their child, even resulting in a diagnosis of “symbiotic parasitic infantile psychosis” in one case. Treatment typically involved psychoanalysis for the mother and removal of the child, described as “parentectomy” (Schopler and Reichler 1971, p. 212). Parents of autistic children faced specific problems as a result of the invisibility and poor understanding of autism, as

Furneaux (1969, p. 171) pointed out, “[t]he pity and sympathy extended to a blind or crippled child is not evoked in the same way by the autistic child” and this may have contributed to parental acquiescence to clinical advice. One mother was told by a school principal that families were the worst place for children to grow up and she was separated from her child for two years. Bettelheim features in the film and describes excluding parents from his residential school to prevent them intruding on the new life of the children, and he describes a large outdoor figure of a woman which the children are encouraged to run over and kick. The film-maker suggests that Bettelheim manipulated outcomes to ensure continued funding (for example, one contributor informs us that Bettelheim re-framed the accidental death of his brother, who was an in-patient returning home on a visit, as death by suicide resulting from a ‘villainous’ mother’s rejection of the child) and was able to reject evidence which contradicted his approach more easily due to his popularity and high visibility (Refrigerator Mothers, 2003).

Challenges to parental and mother blame theories largely came from those who believed autism to be innate (as both Kanner and Asperger had originally suggested), and many supporters later backtracked, admitting that they had “overstate[d] their case” (Rimland, 2015, p. 70). Rimland, writing in 1964, a psychologist and parent of an autistic child, refers to those who were not at all convinced by psychogenic theories, and criticises heavily the unscientific nature of the psychogenic hypothesis. He describes the hostility of child psychiatrists towards parents, suggesting that “[t]o add a heavy burden of shame and guilt to the distress of people whose hopes, social life, finances, well-being, and feelings of worth have been all but destroyed seems heartless and inconsiderate in the extreme.” (Rimland, 2015, p. 86). Of note, in his forward to Rimland’s book, Kanner refutes the ‘refrigerator mother’ hypothesis.

Notions of mother blame were becoming increasingly challenged, with research offering alternative explanations. Research began to show how parents of autistic children were more varied than originally thought, and the presence of non-autistic siblings undermined theories which had been built on the premise of harmful family dynamics causing autism (Koupernik, 1971). Schopler and Reichler (1971) suggest that psychogenic theory was a way to fill a gap in knowledge and to cover up for the lack of evidence. Critics of psychogenic theories highlighted the confirmation bias in autism parenting research, demonstrating how standard testing of parents was conducted in the context of parental, and especially maternal, blame and guilt. Yet when parents were tested in a positive context, as paid and valued informants, the “impairment scores” were closer to those of parents of non-autistic children (Schopler and Reichler, 1971, pp. 212-213). Parents, and especially mothers, however, were (and still are, as will be explored later in Chapter 8) exposed to clinicians who framed them as the problem from the outset, often considered ineffectual and failing to reinforce desired behaviours. This contributed to the promotion, use and acceptance of interventions influenced by operant conditioning training (Skinner, 1963), including applied behaviour analysis (Lovaas et al., 1974) which aimed to ameliorate and extinguish observable autistic behaviours.[8]

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[8] Applied behaviour analysis (ABA) has been heavily criticised within the autistic and neurodiversity community, and whilst a full appraisal of the ethics of ABA are beyond the scope of this thesis, see Milton (2018) for an overview.

The lack of evidence for a psychogenic theory of autism (Rutter, 1985) did not stop the scapegoating of parents (Schopler, 1985), however, there was a shift in focus among some autism researchers. Rather than viewing parental behaviours as the reason for a child's autism, there was increasing evidence that previously pathologised parental behaviours could actually be the *result* of the difficulties of raising an autistic child, not the *cause*. Schopler (1985) describes how parents' "emotional and intellectual confusion" (p. 236), "perplexed and disaffected reactions" (p. 241) and obsessive seeking of knowledge, made it easy to scapegoat the parents, who were often isolated and struggling with guilt, confusion and embarrassment. Blaming and stigmatising parents, especially mothers, then, had provided a way for clinicians to cover up the lack of knowledge about autism. Others came to welcome the input of mothers, recognising mothers as "the best source of information for the clinician required to make an assessment of the child with a possible neuropsychiatric disorder." (Gillberg, 1995, p. 30) and observing how "[n]either parents nor child are helped when a child's inborn, that is, constitutional, difficulties are attributed to family pathology" (Wolff, 1995, p. 13). However, as the twentieth century came to an end there was greater recognition (though not yet universal rejection) that unusual behaviour identified in mothers was more likely either the result of having an autistic child, or perhaps the "mark of a broader genetic phenotype" (Jordan 1999, p. 7).

Broad autism phenotype

Whilst research building on the 'refrigerator mother' hypothesis continued, other researchers started to shine a light on genetic and hereditary causes for autism. The earliest indication of a genetic link came from Folstein and Rutter's (1977) twin study which evidenced a high concordance rate of autism in identical twins compared to non-identical twins, and which found evidence of a broader cognitive disorder in some identical twins that was considered to be possibly related to autism. As the authors described being unable to explain how autism was inherited "since autistic children rarely reproduce" (p. 728), it was suggested that the answer might be found in the children of the twins affected with the broader cognitive disorder. When the study was followed up (Bailey et al., 1995), over 90% of the non-autistic identical twins showed signs of cognitive and social difficulties, including three meeting the criteria for Pervasive Development Disorder (PDD).

This recognition of a broader but more subtle presentation of autistic-like behaviours in siblings, parents and other family members, also recognised by both Kanner and Asperger as previously discussed, would become known as the "Broad Autism Phenotype" (BAP) (Gerdts and Bernier, 2011; Sucksmith et al., 2011). The first comprehensive review of a broader phenotype of autism (Bailey et al., 1998) reviewed a number of previous studies and described "genetically related milder phenotypes" (p. 369) of autism, highlighting increased rates of PDDs, language disorders, social and communication difficulties and psychiatric and personality disorders among family members of autistic children. Research into BAP and familial traits has identified that parents of autistic children are more likely to struggle with pragmatic language (Landa et al., 1992), executive functioning tasks (Wong et al., 2006), processing facial expression (Adolphs et al., 2008), weak central coherence (Happé et al., 2001), cognitive and emotional empathy, (Grove et al. 2014), sensory sensitivities and intolerance of uncertainty (Uljarević et al., 2014; Uljarević et al., 2016a), and may present more restricted and repetitive behaviours than controls (Uljarević et al., 2016b).

Attempts to formulate a comprehensive psychometric measure, taking account of the multiplicity of autism traits identified as making up BAP, and preventing the need to administer multiple time-consuming separate psychometric tests (as described by Losh et al., 2008), include using the Autism Spectrum Quotient (AQ), and the development of specific BAP measures including the Broad Autism Phenotype Questionnaire (BAPQ) and the Adult Autism Subthreshold Spectrum (AdAS). The AQ consists of 50 questions and was developed as a self-scored measure of autistic traits against autism diagnostic criteria (Baron-Cohen et al., 2001). Parents of autistic children were shown to consistently score higher than controls when using the AQ (Bishop et al., 2004; Wheelwright et al., 2010). The BAPQ, consisting of 36 questions, was developed specifically to measure what the authors identified as key features of BAP, aloof and rigid personality traits as well as pragmatic language, and was considered by its developers to be an effective and reliable measure of BAP (Hurley et al., 2007). The AdAS comprises 160 questions across seven domains, and draws on the DSM5 autism criteria (Dell'Osso et al., 2017). Other measures have included the Family History Interview, the Social Responsiveness Scale and the Broader Phenotype Autism Symptom Scale (Dawson et al., 2007; Bernier et al., 2012).

BAP research is primarily affiliated with large-scale genetics studies, and whilst the specific BAP scaling tools have not been developed as diagnostic schedules, they do demonstrate the extent of autism and autism-like traits within families and across generations (Sasson et al., 2013a; Sasson et al., 2013b). Further, it is of note that the AdAS claims to be effective at recognising the more subtle and camouflaged presentations of autism often seen in women and girls. Considering how what were previously considered sub-clinical thresholds now fall within diagnostic criteria, and how many women remain undiagnosed or have been misdiagnosed (Gould and Ashton-Smith, 2011), and that BAP studies do not screen for undiagnosed autism, it is possible to speculate that a significant number of those who have been identified as BAP are indeed autistic.

Occurring simultaneously with research into BAP was the identification and development of diagnostic criteria for Asperger Syndrome. Gillberg's (1991) study of six families of children and adults diagnosed under his own criteria for Asperger Syndrome is of particular importance as it demonstrated the likelihood of genetic links between (what was described at the time as) classical autism, Asperger Syndrome and Asperger-type traits. It also highlighted the presence of Asperger-type traits in sisters, mothers and grandmothers, and recognised that symptoms in girls may be less obvious. It would however be some time before the extent of autism in women and girls, alongside recognition of less stereotyped presentations, would be recognised (and there is still much more to do). The introduction of the Asperger Syndrome criteria would also prove to be a double-edged sword for autistic women and girls as, despite recognising autism in children and adults without apparent intellectual disabilities, it also exaggerated the sex differences and sex ratios.

Sex differences and male bias

Epidemiological and other studies have consistently shown that boys and men are more likely to be diagnosed with autism than girls and women (Loomes et al., 2017). The first such study, of the entire population of Middlesex, showed a male:female ratio of 2.6:1, whilst estimating there to be approximately 3000 autistic children in England and Wales (Wing et al., 1967), and finding an elevated level of “affective disturbances” (p. 390) in parents. A decade later, a similar study, carried out in Camberwell, found the same overall ratio, but also identified a stark contrast depending on IQ, where among those with an IQ above 50 the sex ratio was 14.2:1 (Wing, 1981b). Sex comparisons typically showed girls presenting with lower IQs (Lord et al., 1982; and later, Pilowsky et al., 1998). This was reflected in a meta-analysis of epidemiological studies, which also found higher sex ratios in studies including a higher IQ range (Wing, 1993; and later tentatively supported by Loomes et al., 2017). A recent population-based study of UK GP records from 1998-2018 found that approximately one in four people with an autism diagnosis are female, with an increase in female autism diagnosis over the period studied (Russell et al., 2022).

Yet, despite autism being as prevalent in adults as in children (Brugha et al., 2011), it is still often unrecognised, especially among women (Brugha et al., 2016), and the male bias may not be as significant as once thought (Lai, et al., 2015). Sex ratios are typically based on diagnosis rates, and stereotypes of autism may contribute to under-diagnosis of women and girls (Evans-Williams and Williams, 2016), as diagnostic tools are mostly biased towards a stereotyped male phenotype (Haney, 2016; Kreiser and White, 2013). Whilst some studies have attempted to ensure equal sample sizes (Kirkovski et al., 2013), brain scan studies over-represent males by as much as 15:1 (Lai, 2018) despite the current suggested ratio of 3:1. Clinical and diagnostic tools are based on research studies which typically include only those with clinical diagnoses, resulting in a cycle of male bias creating a self-fulfilling prophecy which permeates popular, clinical and diagnostic discourse and practice.

The idea of autism as a particularly male condition has been promoted by the extreme male brain (EMB) hypothesis (Baron-Cohen and Hammer, 1997; Baron-Cohen, 2003) which locates male and female humans along a continuum to represent an extreme female brain-type at one end and an extreme male brain-type at the other. Female brains are associated with empathy and male brains with systemising. Focusing in particular on the high sex ratios present in those diagnosed with Asperger Syndrome, Baron-Cohen suggests that autism is analogous to extreme male behaviours and brain-types, presenting "an exaggeration of typical sex differences" (Knickmeyer and Baron-Cohen, 2006, p.825) which is speculatively considered to be related to foetal testosterone exposure in the womb. Whilst Baron-Cohen and collaborators recognise that other factors, such as diagnostic overshadowing, masking and bias in diagnostic tools and procedures, may account for the disparity, they remain convinced that male bias is more likely the result of biological factors which become expressed psychologically (Baron-Cohen et al*.,* 2011).

EMB theory supporters have provided further evidence, for example, autistic women have been found to have elevated testosterone and display fewer feminine characteristics (Bejerot et al., 2012), boys showed greater systemising (Mandy et al., 2012), and a brain scan study suggests that autistic brains present the possibility of different biological bases of male and female autism (Lai et al., 2013). Others found no significant or substantial differences in either social behaviour (Grove et al., 2017) or psychiatric symptoms such as challenging behaviours (Worley and Matson, 2011). Despite claims by EMB proponents that genetic and hormonal causes are key to understanding sex differences (Werling and Geschwind, 2013) other studies have suggested that social and cultural factors may have a greater impact on our brains than perhaps previously thought, for example:

> [T]he psyche is ... not a discrete entity packed in the brain. Rather, it is a structure of psychological processes that are shaped by and thus closely attuned to the culture that surrounds them ... the mind cannot be understood without reference to the sociocultural environment to which it is accustomed and attuned. (Kitayama and Cohen, 2007, cited in Fine, 2008, p. 71).

It is possible then, that it is not sex, but gender (here meaning the socially and culturally ascribed pervasive norms and stereotypes associated with each sex, see Fine, 2005, for example), which may offer a “protective factor” in autistic women and girls (Cheslack-Postava and Jordan-Young, 2012, p. 1673). Goldman (2013, p. 677) suggests that gendered socialisation is often ignored “to the point where, despite the same social deficit, a girl may be perceived as shy and a boy as unresponsive”. Krahn and Fenton (2012, p. 97) speculate that female socialisation (to be empathetic, socially engaged and so on) “smacks of ‘early intervention’, effectively providing a means for them to be reciprocally engaged with others and in ways that are markedly less conspicuous than their male counter-parts”. Failing to understand the context of cognitive processes is highlighted by research into “stereotype threat” (Fine, 2010, p. 30) which explores how stereotypes impact performance and brain activity. In one study, participating women were given negative, positive and neutral stereotypes of women's abilities before undertaking a task. Results showed women in the negative stereotype group performing poorest, with increased brain activity in areas linked to emotions, and better performance by the positive stereotype group, showing increased brain activity in areas linked to visual processing and working memory (Wraga et al., 2006). Rippon's (2019) work similarly suggests that our brains generate predictions and guide behaviour based on experiences, creating rules from patterns, and that stereotypes become part of this "guidance system" (p. xv).

Ultimately, EMB theory fails to account for these contextual, social and cultural experiences and expectations, and appears to reify sex-role stereotypes. Fine has suggested that internalised stereotypes support "neurosexism" (2008, p. 369). Her review of functional neuroimaging studies indicates that brain science has a history of sexism and "unjustified claims ... for traditional gender stereotypes" (Fine, 2013, p. 397). Whilst EMB essentialises brain types by behaviour (Rippon, 2019), it ignores brain plasticity, and in particular how early hormonal effects on the brain are not permanent, and how social and cultural experiences affect biological factors, for example, a reduction in testosterone among fathers who do more caring for children, and through the experience dependent plasticity seen in the brains of taxi drivers and musicians (Fine, 2013). This makes it harder to separate out what is sex and what is gender when we look at brain types (Kaiser, 2012).

Presenting a combination of autistic neurotype and female sex-role socialisation and stereotypes, ignoring or essentialising these external influences on the brain results in a perpetuation of the male bias in recognition and diagnosis. To understand how autism presents and is experienced by women and girls we must look beyond the observable behaviour, cognitive and psychological processes which result from our gendered experiences.

Autistic women and girls

Temple Grandin's 1986 autobiography "Emergence" presented one of the earliest first-person accounts of being autistic. The 1990s saw a steady growth in autistic accounts of autism, diagnosed both as children and in adulthood and often authored by women (for example, Blackman, 1999; Holliday Willey, 1999; Lawson, 2000; Williams, 1992), challenging the orthodoxy of autism knowledge. Williams describes how stereotypes of autism, such as lack of humour or empathy, hinder recognition and become circular, hence, if all you see is stereotypes "the stereotypes become self-fulfilling prophecies" (Williams, 1996, p. 13). Stereotypes of autism have had a significant impact on the invisibility of autistic mothers, who are not children, or male, or lacking in the empathy required to form relationships or nurture children. In fact, the very existence of the autistic mother presents a considerable challenge to the many stereotypical representations of autism.

Autistic mothers are autistic women who were once autistic girls. The lack of recognition of autistic mothers is inextricably linked to the lack of recognition of autism in girls and women, who remain under-diagnosed, through missed-diagnosis and misdiagnosis

(Gould and Ashton-Smith 2011; Gesi et al., 2021). Theories relating to foetal testosterone exposure and extreme male brains, alongside diagnostic criteria and practices based on observed autistic male behaviours, have perpetuated an imbalance between the sexes. However, as more girls and women have been recognised and diagnosed as autistic (Russell et al., 2022), research and clinical practice has considered the impact of sex-role socialisation and stereotyping on female autistics (Kelly et al., 2022), highlighting the intersection between autism and gendered social expectations (Ratto et al., 2018). The interaction between our physiology, neurology and experience is complex, for "[s]ocialization is not a pattern of interferences, which obscures the underlying design of the infant: it is an essential part of the process whereby the phenotype is completed." (Levy, 2004, cited in Krahn and Fenton, 2012, p.96). It is crucial to acknowledge that girls and women are subject to different social and cultural forces than boys and men and to recognise the complex interplay of autism and female socialisation. One significant area of research highlights how women and girls are more likely to mask or camouflage our autism.

Masking and camouflaging

The notion of masking or camouflaging[9] has its roots in work on stigma and impression management (Goffman, 1990a; Goffman, 1990b; Schneid and Raz, 2020), and the myriad of ways that people perform roles as a way to blend in or fit in. As a conceptual tool to aid in the understanding of masked and camouflaged presentations of autism, work on masking and camouflaging was initially developed in first person accounts (for example,

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[9] Masking and camouflaging are sometimes used interchangeably, sometimes to represent different phenomena. Within this thesis I have mostly used them interchangeably whilst endeavouring to respect researcher and participant preferences.

the aptly titled “Pretending to be normal” by Holliday Willey, 1999), and is a common theme in mainstream media accounts of late diagnosis in women (Brady, 2023; Braithwaite 2018; James, 2017; Mandavilli, 2015; McGuiness, 2023; Pinto, 2017; Russo, 2018; Szalavitz, 2016). Both male and female autistic children and adults use masking and camouflaging strategies as a way to assimilate and connect with other people (Hull et al., 2017), though women typically use camouflaging strategies more often (Lai et al., 2017). It can be both conscious (based on observation and study of other people) and unconscious (mimicry without realising) and is often exhausting, having a deleterious effect on identity (Bargiela et al., 2016; Miller et al., 2021) and mental health (Cage and Troxell-Whitman, 2019). Camouflaging may be a factor in poor diagnosis rates for women and girls, meaning that understanding how autistic women mask could help with addressing the sex-bias in diagnostic tools and processes (Hull et al., 2019).

Masking often begins in childhood, though it does not appear to increase with age, rather it ebbs and flows across the lifespan (Lai et al., 2017). Autistic girls are typically considered more socially motivated than boys and men (Sedgewick et al., 2016) and present with better non-verbal communication skills (Rynkiewicz, 2016) which may support masking and camouflaging. A playground study noted that autistic girls appear to be more socially typical as they tend to stay close to other girls and look to be part of the other girls’ activities, whereas autistic boys are more noticeably apart and separate from the other boys (Dean et al., 2017). In Baldwin and Costley’s (2016) research, using data from 82 autistic women who were part of a larger study, which enabled comparison with data from autistic men, it is suggested that masking might be the reason why autistic girls are offered less support than autistic boys at school, and they also highlight the poor recognition of the support needs of autistic women. These gendered differences appear to continue into adulthood with women being more likely to use camouflaging behaviours at university and work (Cage and Troxell-Whitman, 2019).

Research into masking and camouflaging in women has looked at both possible causes and potential outcomes of these behaviours. Autistic women and men have been found to show different cognitive profiles, and whilst late-diagnosed men tend to demonstrate better verbal skills, late-diagnosed women tend to present better executive functioning and information processing skills which may support successful camouflaging (Lehnhardt et al., 2016). Women and girls appear to be subject to greater social demands (Hull et al., 2017), particularly around gendered social roles and the expectations of being female, specifically the pressure to *"the wife, the mother, the girlfriend"* (Bargiela et al., 2016 p. 3290). Kourti and MacLeod's (2018) study explored this with 21 autistic women who took part in an online focus group exploring gender. Participants highlighted struggling with the expectations of socially constructed gender roles, particularly when younger, but also described using them as a way to mask, reminding us that autism is socially situated and experienced.

The complex and multi-layered nature of masking behaviours supports the need for a dimensional approach to diagnosing autism (Gould, 2017), which takes account of this social and cultural context. As Hull et al. (2017) point out, it has been argued that successful camouflaging negates the need for a diagnosis, but this fails to take account of the exhaustion and mental toll of masking our autism. Furthermore, research has identified camouflaging as a specific and unique risk factor for suicide in autistic people, and that for “autistic adults, non-suicidal self-injury, camouflaging, and number of unmet support needs significantly predicted suicidality.” (Cassidy et al., 2018, p. 1). Moreover, the same research reminds us that autistic people are considerably more likely to attempt or die from suicide compared to both the general population and other clinical groups.

Building on both academic and clinical knowledge, Zener (2019) describes how autistic women are at greater risk of mental health problems, trauma, substance misuse, poor quality of life, bullying and sexual abuse, and that women often seek a diagnosis after a mental health crisis, as well as following the diagnosis of a family member and through hearing accounts of autistic women. When women and girls are diagnosed, they often present more severe difficulties than boys and men (Holtmann et al., 2007; Ratto et al., 2018), particularly as adults (Lai et al., 2011), and are more likely to pass thresholds for psychiatric disorders (Kreiser and White, 2015). Furthermore, unrecognised autism can mimic psychiatric disorders such as borderline personality disorder (Watts, 2023) when undiagnosed autism co-occurs with anxiety and depression (Trubanova et al., 2014). Getting the right diagnosis is, therefore, vitally important as early diagnosis can have a significant positive effect on quality of life (Atherton et al., 2021) and enable a better understanding of the cause of any mental health difficulties (Kelly et al., 2022). For autistic mothers of autistic children, the additional expectations of motherhood add a further dimension and set of pressures.

Mothers of autistic children

As the ‘refrigerator mother’ hypothesis started to fall out of fashion in the 1970s, there was a shift from looking at personal and psychological variables in family members, especially mothers, to social and cultural experiences and support needs. Read’s (1991) study of mothers of severely disabled children suggested that whilst there was less emphasis on blame and more on what might help, services for families often created more work for mothers of disabled children, who were often judged in areas of life other mothers were not, resulting in feelings of vulnerability and powerlessness. Whilst a child’s clinical diagnosis could “provide moral reprieve from judgments” (Davis and Manago, 2015, p.79), mothers of disabled children continued to experience blame (Blum, 2007; Mitra, 2022).

As a challenge to the blame narrative, stories such as those told in an anthology by mothers of autistic children (Golding and Stacey, 2018), highlight how some mothers have challenged this narrative by becoming fierce advocates and therapists for their children. Describing themselves in terms such as “part lawyer, doctor, advocate and fundraiser” (p64) and “investigative forensic journalist, a ferreting researcher and an innovative home therapist” (p129), these mothers highlight a move from being blamed for causing their child’s autism, to being responsible for curing their child’s autism (Sousa, 2011). Douglas (2013) tracks the rise of the ‘feminine warrior autism mother’ as a neoliberal construct, the ultimate consumer, seeking not just enhancements for herself but for her child through therapies, treatments and interventions, such that “she must consume her autistic child into being as non-autistic” (p.177). Reflecting this shift from mother *blame* to mother *cure*, the role of the ‘autism warrior mother’ has essentially replaced the ‘refrigerator mother’. However, mother blame is not extinct, and is now often about what a mother does not do rather than what she did do. Unfortunately, the expectations placed on mothers of autistic children today are potentially just as harmful as those from the past, with mothers still struggling with guilt, isolation and poor health (Courcy and des Rivieres, 2017).

Maternal well-being and stress are common themes in the literature about parents of autistic children (for recent examples, see Kütük et al., 2021 and Papadopoulos, 2021), producing a mass of literature, which is largely beyond the scope of this review. Mothers of autistic children have been found to suffer from greater stress than mothers of children with other disabilities or no disabilities (Estes et al., 2009; Estes et al., 2013; Seymour et al., 2013). Autistic children’s behaviour difficulties appear to be a common cause of increased stress and depression in mothers but this may have less impact on fathers (Hastings et al., 2005), who appear to experience less stress than mothers (Davis and Carter, 2008), though fathers are also less likely to participate in research studies (Johnson and Simpson, 2013). Seymour et al. (2013) explored the relationship between child behaviour difficulties, stress, coping and fatigue, finding that maternal fatigue might be the mediating factor between parenting challenges and parenting stress. Maternal exhaustion and stress can also make it harder to access community support, with the factors that increase stress, such as behavioural problems, also making it harder to access support (Boyd, 2002). Mothers of undiagnosed (but likely) autistic children have been found to experience poorer quality of life and higher stress than mothers of diagnosed autistic children (McKechanie et al., 2017), highlighting perhaps the importance of prompt diagnosis for family well-being and a need for support prediagnosis. Vasilopoulou and Nisbet's (2016) systematic review of studies concerned with quality of life for parents of autistic children supports prior research, finding that mothers suffer demonstrably lower quality of life than fathers, which, at least in part, correlates to mothers being more likely to be the primary caregivers. As reflected in the choice of literature included here, there has been an enduring interest in stress and quality of life measures for mothers of autistic children, painting an often highly bleak picture of mothering an autistic child.

Bias, then, is a potential problem with the maternal stress research, and like earlier studies which found bias in parenting research (see previously discussed Schopler and Reichler, 1971), it is possible that by looking for problems, problems are found. In contrast to research into stress, Markoulakis et al., (2012) looked at the benefits of mothering an autistic child, with a small qualitative study of eight mothers from local support organisations. Findings highlighted the importance of financial support so that parents could support their children better; of social benefits like making new friends; of taking more care of their health; how parenting and advocacy experience led to new types of employment; a strengthening of marital relationships; and of their other children benefiting from better quality interactions; to the extent that "all of the women saw themselves as having become better people" (Markoulakis et al., 2012, p. 53). Another as yet unexplored criticism of maternal stress research is a lack of recognition that some of those mothers might be autistic, and how this interacts with the other factors. Using an online questionnaire, Pruitt et al., (2018) looked at links between BAP and depression in mothers with autistic children, finding that higher BAP scores related to poorer relationship satisfaction and greater depression. Interestingly, in light of previous research into maternal stress, BAP was more significant than child behaviour problems as a predictor for depressive symptoms, and the researchers acknowledge that mothers with social difficulties (represented by their BAP scores) might struggle to access support. There is no indication in the study that participants were asked if they were or suspected to be autistic themselves.

Ryan and Runswick-Cole (2008) explored the portrayal of mothers of disabled children in disability and other literature, describing a "position of liminality; we are neither disabled or non-disabled" (p.199). As they explain, even the search for a diagnosis can be considered controversial, with mothers blamed for pathologising our children, despite the frequent need for a diagnosis to access most support. Autistic mothers might find this particularly problematic, needing to make choices for pragmatic reasons for their children, whilst risking censure for being seen as complicit in perpetuating a medical and deficit-based model of autism and disability. I would suggest that autistic mothers of autistic children occupy a similar, but different, liminal space, where we are both autistic and mother of autistic.

Autistic mothers

Despite littered hints throughout the body of literature, the autistic mother was a largely invisible figure in the research, until the early twentieth century. Research into autistic motherhood initially tended to focus on pregnancy, childbirth, and early motherhood which McDonnell and DeLucia (2021, p. 100), in their systematic review of autistic pregnancy and parenthood, identified as "*key transition periods in adult development*." Infant feeding among autistic mothers has also garnered interest, as Grant et al. (2022)

demonstrate in their systematic review of qualitative research and grey (i.e., non-academic) literature, which highlights poor support for postnatal autistic mothers, particularly around breastfeeding which can pose significant sensory difficulties for some autistic women (Wilson and Andrassy, 2022). In a similar vein, Hampton et al.'s work (2022a; 2022b; 2022c; 2022d; 2022e) presents the results of mixed methods research into the pregnancy, childbirth, and postnatal experiences of autistic and non-autistic women, highlighting increased stress, anxiety and sensory problems among autistic participants and the need for better understanding and communication adjustments by professionals. Donovan et al. (2023) focused on post- birth and early bonding experiences, highlighting, like other similar studies, the need for an awareness of differences in communication and sensory needs of autistic mothers, and suggesting that autistic mothers are given privacy and more time to recover after birth.

The first published comprehensive study of autistic mothers was provided by Pohl et al.'s (2020) research comparing the pregnancy and motherhood experiences of both autistic and non-autistic mothers. Data collected from 355 autistic survey participants provided an important insight into autistic motherhood, contributing to findings which shed light on this previously marginalised sector of autistic people. The study reported autistic mothers' difficulties with multi-tasking, communicating with professionals, isolation, judgement, and lack of support as well as highlighting how, overall, participating autistic mothers had no difficulties with prioritising their children's needs and enjoyed being a mother. Since the publication of the results of Pohl et al.'s study, there has been a flurry of research published exploring the experiences of autistic mothers. Adams et al. (2021) conducted a statistical analysis to compare the family outcomes and parental stress of

20 autistic and 20 non-autistic mothers of autistic children, finding no significant differences between the two groups. As they point out, the nature of their approach perhaps lacks some of the nuance of Pohl et al.'s research and that qualitative analysis could enhance understanding of the experiences of autistic mothers. Describing itself as "the first study to investigate in detail the experience of motherhood in autistic women", Dugdale et al.'s (2021, p. 1981) qualitative research approach presents an in-depth exploration of autistic motherhood. Four themes explore how being autistic affects parenting, the struggles of accessing support, self-awareness, and insight, and the good and bad of parenting, resulting in recommendations for improving awareness of autism in adults among healthcare professionals. Concerned with poor understanding of autistic parents in social work practice, Hwang and Heslop (2023) conducted a focus group study with seven autistic parents (4 mothers), highlighting the misunderstanding of autistic parents and negative attitudes by social care professionals, despite evidence of good parenting practice, and promoting a strengths-based approach to parenting assessments. Significantly, these studies present evidence of autistic women as capable and competent mothers, despite some often-significant challenges, particularly in accessing health and social care support.

Balancing the challenges of autistic parenting with the responsibilities of parenting autistic children is a common thread running through the autistic motherhood literature. Marriott et al. (2021) recruited eight parents (seven mothers) who suspected they were autistic, and who all had autistic children, to explore the parent's lived experiences. Parents with significant autistic traits were found to struggle with mental health and professional interactions, described how sharing an autistic identity with their children could be both useful and challenging, and how the safe and accepting nature of home provides respite from the challenges of the world outside. Winnard et al. (2022) interviewed eight autistic women (four mothers) to explore perspectives and experiences of autistic parenting, with themes developed around support, routine and structure, social and sensory challenges, and the advantage of having a "unique insight" (p. 2319) as an autistic parent of an autistic child. This unique insight was central to Crane et al's (2021b) mixed methods research which explored how autistic parents talk to their autistic children about autism. Responses from 34 autistic parents (30 mothers) to an online survey resulted in themes which highlighted the benefits of being open and honest about being autistic as a parent, being able to use their own experiences when talking about autism, being able to support their children's differences positively, and to adapt their communication to enhance understanding. Importantly, participating parents "felt well equipped to support their children using their own knowledge and experiences" (Crane et al., 2021b, p. 1166), again demonstrating the competence of autistic mothers.

Returning to the notion of unique insight are the qualitative studies which are sole- or lead-authored by autistic mothers of autistic children. Whilst some of the aforementioned autistic motherhood and parenting studies included autistic co-authors or had some form of autistic input into study design, across the broad span of this literature review there is often a sense, as an autistic woman and mother, of what Tyler (2020, p. 229) calls "being the anthropological object" when "caught in the gaze of another" (p. 331). In short, and this will be discussed in the next chapter, it is the difference between research about *us* and research about *them*. Developing greater understanding of the sensory experiences of autistic mothers was the focus of Talcer at al.'s (2021) study, with participants reporting increased sensory sensitivity after their babies were born, particularly relating to noise and touch, which contributed to increased stress as mothers were unable to withdraw from the source of this sensory discomfort. Coming from an autistic parent's perspective, Murphy's (2021) qualitative study explores the pros and cons of autistic parenting through interviews with six parents (five mothers). In line with other studies, difficulties with organisation, sensory needs, stress, and professional interactions, alongside the benefits of empathy, acceptance and positive relationships with their children, present key themes for participants. Smit and Hooper (2023) conducted a study with nine parents (eight mothers), which as well as highlighting the competence of autistic parents, also supported other studies which report on the added stress of professional interactions and the importance of support from other autistic parents. An interesting perspective is provided in Gore et al.'s (2023) recent study which explored the experiences of 10 Australian autistic working mothers, which highlighted financial, social and well-being advantages of employment, whilst recognising the challenge of accessing accommodations, masking and burnout. Heyworth et al. (2022) conducted the largest qualitative study included here, including 35 Australian autistic parents (33 mothers) participants, with the lead-author identified as an autistic parent of autistic children and two co-authors also identified as autistic. This research focused on parenting experiences during the early stages of the COVID-19 pandemic, presenting a particularly interesting insight into life under lockdown. Their study participants described initially experiencing relief and respite from the usual demands of everyday life for themselves and their children but also how, over time, the demands and restrictions of lockdown created "new pressures" (p. 6), such as the need for new routines and the intensity of constant proximity in the home. Yet, despite being unable to access informal and formal supports, contributing to worsening stress and deteriorating mental health and well-being, autistic parents continued to prioritise and support their children’s needs “often driven by a deep devotion to their children and families” (p. 9).

However, despite these studies demonstrating that autistic women are often highly attuned and capable mothers, with a good understanding of our children’s needs and how to support them, autistic mothers of autistic children are potentially four times more likely to have their parenting abilities questioned by professionals (Griffiths et al., 2019). Benson (2023), herself an autistic mother, undertook a qualitative study exploring the experiences of ten autistic mothers who had been subject to social work interventions. Weaving her own experience into her analysis, her findings consider how autistic mothers are judged against standards of “compulsory neuro-normativity” (p.15), i.e., how a ‘normal’ mother should present, for how they mother their “perplexing” (p. 15), i.e., autistic, children. She highlights how autistic behaviours are framed as “perplexing presentations” (p. 9), in the assessments, reports and recommendations of social workers through the application of a normative lens which ignores or dismisses neurodivergence and, too often, results in mother blame when normative parenting practices fail. Normalising autistic motherhood and mothering practices is, therefore, key to countering mother blame narratives built on poor and often outdated understanding of autism, not only for social workers and other professionals, but also in order for autistic mothers to understand their own mothering experiences and to reject judgement founded on normative notions of good mothering. Since the publication of

Grant's book on autistic pregnancy, birth and early motherhood in 2015, others have followed, providing a range of accessible resources for autistic mothers and mothers-to-be, for example, Jurkevythz et al. (2020) present their own autistic mothering stories alongside advice for autistic mothers of autistic children, whilst Quinn (2021) provides a highly practical guide to becoming an autistic mother, providing essential reading for autistic women contemplating motherhood and the health and social care practitioners who support them. A different approach is taken by Ashburn and Edwards (2023) who explore some of the tensions around parenting autistic children from their positions as autistic and non-autistic mothers (a topic too big to address here) and present an informative guide to supporting and advocating for autistic children.

As can be seen from the publication dates of the literature in this section, interest in autistic motherhood is very recent, for too long we were assumed not to exist or were ignored and marginalised. Indeed, many of us didn't know we were autistic mothers until we discovered our children to be autistic.

Summary and conclusion

This literature review set out to ask the question 'what took you so long?' as I wanted to understand and explain why it took decades before there was acknowledgement and recognition in the field of autism research that autistic mothers, like me, like my participants, and like all autistic mothers, existed and were worthy of research. As I have demonstrated, the marginalisation of autistic girls, autistic women, and autistic mothers, arose from early literature which focused on autistic boys, and which perpetuated and continues to perpetuate myths and stereotypes about who is autistic and what being autistic is like. The recent emergence of a growing body of literature concerned with autistic girls and women has been vitally important in broadening our understanding of the heterogeneity of autism, where research into masking has been crucial in recognising and understanding the often more subtle presentation of autism, particularly in girls and women. Without this literature it is unlikely that many of us autistic mothers would have considered that we might be, or be recognised as, autistic ourselves. The even more recent emergence of literature concerned with autistic mothers represents an important shift in the research, and as I have shown and will show further, challenging many enduring assumptions about autism. I am particularly pleased to be able to introduce and draw upon research about autistic motherhood conducted by autistic mothers and look forward to contributing to this emergent field of study and interest.

Having presented my review of the literature, the next chapter will tell the behind-the-scenes story of this thesis, as I present the philosophical, ethical, and practical considerations, decisions and actions taken in the course of conducting the research which forms this thesis.

3. Methodology

Introduction

As demonstrated in the previous chapter, where I presented my review of the literature, autism research has largely focused on causes, treatment, childhood, and males, and with autistic people as phenomena to be studied rather than as active participants, contributors, or researchers. The dominant paradigm of autism research has been positivist and quantitative, embedded in an individualistic or medical model of disability, which sees disability situated within the individual person. Autistic and other scholars have challenged this and have proposed a participatory model for research, which centres the autistic voice and focuses on autistic well-being (for example, Milton and Bracher, 2013), built on a social model of disability (Oliver, 2013) where disability emanates from societal barriers, alongside the neurodiversity paradigm (Kapp, 2020) where the diversity of neurotypes is valued as an essential part of human diversity. The challenge posed by participatory research to the ontological and epistemological orthodoxies of autism research reflects criticism levelled at ‘traditional’ research paradigms by feminist scholars who sought to centre women’s voices and improve the lives of women (for example, Oakley, 1981), highlighting further the situating of this research within the research traditions of feminist and disability studies.

As a result, by adopting a critical realist ontology, and working within a qualitative research framework, I draw upon participatory and feminist epistemologies to produce research centred on the lives, perspectives and well-being of autistic mothers and our experiences, whilst also taking account of the impact of social and structural forces. The emphasis of this project on experience, amplifying marginalised voices, and supporting social and structural changes and improvements, results in a methodological approach which aims to be ethical, respectful and empowering.

The goal of this research, then, is to explore these questions:

- How do autistic mothers negotiate being autistic?
- How do autistic mothers navigate motherhood?
- How does being autistic affect experiences of motherhood?

This chapter is where I ‘show my workings’, laying out the building blocks of my research process and highlighting the important and necessary thinking, analysis and practices which underpin this thesis. I will start with laying the foundations by examining the nature of values, reality and knowledge, and move on to demonstrate the usefulness of critical realism as a paradigm. Critical realism was introduced in my first chapter as a way to contextualise autism, and here it is used to provide a philosophical scaffold which enables me to conduct cohesive research and to answer my research questions. I will then move on to discuss some specific ethical considerations, before exploring how participatory and feminist research, autoethnography, and friendship as method have influenced this research project. This chapter then turns to more practical matters, explaining how I approached sampling and recruitment, followed by an examination of my interviewing process. Throughout the chapter, my position as a critical insider and my personal and academic values can be seen to influence my choices and approach, sometimes explicitly and sometimes tacitly. This will be further reflected in the final part of this chapter where I introduce reflexive thematic analysis (Braun and Clarke, 2022) as the method I have chosen to analyse my interview data. The chapter will conclude with a walk-through explaining how I conducted my analysis.

The Ologies

A researcher's choices cannot be fully understood without first exploring and explaining the philosophical and theoretical basis for methodological decisions made in the research process:

> To ignore questions of methodology is to assume that knowledge comes from nowhere allowing knowledge makers to abdicate responsibility for their productions and representations. To side-step methodology means that the mechanisms we utilise in producing knowledge are hidden, relations of privilege are masked and knowers are not seen to be located [Methodology] is a theory of methods which informs a range of issues from who to study, how to study, which institutional practices to adopt (such as interpretative practices), how to write and which knowledge to use. (Skeggs, 1997, p. 17)

Research methodology includes axiological, ontological and epistemological considerations, and whilst it is possible to do social research without explicit analysis and explanation of why and how they influence and underpin our work, I believe that reflexive and ethical research requires "epistemic responsibility" (Code, 2014, p. 10). This means recognising my own position and prior knowledge as well as a responsibility towards my participants and their contributions to the production of knowledge within this thesis. My responsibilities, to my participants, and autistic mothers more broadly, are fundamentally driven by my values.

Axiology is the philosophical study of value, and within research is often considered either to include or to be synonymous with ethics (Kara, 2018). Whilst early social scientists attempted to remove values from social research, it is now widely accepted that value-free social research is not achievable and may, indeed, not even be desirable (Bryman, 2016). Our values, which inform our ethical position and the decisions we make, are apparent in the research process from the moment we formulate a research topic, through to our choosing of theories, methodology and methods, to the collection and analysis of data, and the eventual presentation, dissemination and use of our research (Edwards and Mauthner, 2002). My values are interwoven throughout this chapter and, as introduced in Chapter 1, are broadly represented by the disability rights slogan "nothing about us, without us" (Charlton, 1998), meaning that disabled people must be included in matters about disability, and the feminist slogan "the personal is political" (Hanisch, 1969), meaning that women's personal lives are of social and political importance. Before I explore the ethical considerations of this research, I will outline the ontological and epistemological considerations I undertook to develop my methodology and, in turn, the methods used for conducting this research.

Ontology is the philosophical study of the nature of reality and is often exemplified in the binary ontological positions of realism and relativism (Braun and Clarke, 2013). Put simply, what this means for social research is whether we think reality is something that exists independently and is just waiting to be discovered (realism), or that reality comes in many different forms and is constructed by individuals and groups through interaction, language and shared meaning (relativism).

If we take these ontological positions in turn, we can consider how useful they are to this research. A realist take on autistic mothers might ignore subjective experiences and interpretations of reality, and a relativist take might ignore the material and structural conditions of reality. In essence, at their extremes, they both fail to take account of the interplay between human experience and perception and the structural and material world. One attempt to reconcile this ontological problem has been the development of critical realism which recognises the existence of a real world, encompassing material reality and real social structures, whilst acknowledging that it is experienced and viewed through the lens of our social and cultural influences (Braun and Clarke, 2013). Before considering the usefulness of critical realism to this research, I will explore epistemology.

Epistemology is the philosophical study of the nature of knowledge. Two influential and contrasting epistemologies in social research are positivism and constructivism. Positivism is a realist epistemology which values objective, empirical data as a way to produce knowledge that aims to discover the truth or laws about reality (May, 2001). It is typically deductive, that is, it often starts with and is guided by a theory or hypothesis (Bryman, 2016). Constructivism is a relativist epistemology and suggests that knowledge is constructed, or produced, as a result of our interactions with other people and the world around us, and is shaped by experience, prior knowledge, culture and history (Creswell and Cresswell, 2018; Lincoln, Lynham and Guba, 2018). Constructivism is often, though not always, inductive, seeking to generate theory from the data (Bryman, 2016).

As I did with ontology above, it is worth briefly considering how these epistemological positions might, or might not, be useful to this particular research. A positivist epistemology of autistic motherhood might use a survey to ask autistic mothers about their lives to discover specific facts about survey respondents which could be compared to demographic characteristics such as race, age and educational attainment. A constructivist epistemology of autistic motherhood might explore how autistic mothers describe their experiences to demonstrate the multiple ways they understand their lives. The knowledge produced by the positivist might produce a vast amount of data about what autistic mothers do and think, though only within the confines of the questions asked, but would be unlikely to provide any deep insight into motivations, experiences and interpretations. The knowledge produced by the constructivist could result in multiple and rich descriptions of “autism”, “mother” and “autistic mother”, which might be very interesting, but equally might not be useful for achieving the aims of this research which includes making recommendations to improve interactions with clinicians and professionals.

In practice, few social researchers work at the extreme ends of any of these ontological or epistemological positions, and most social research will include at least a nod to the other side of the objective/subjective divide (Crotty, 1998). My own position is that there is an objectively real world, and that there are things about it that we don’t yet know, but that we view and interpret this world through a filter of our own subjective position and experiences. As mentioned above, this is a perspective shared by critical realists, and the methodology for this research will draw upon some of its central principles.

Critical realism

Critical realism includes ontological realism, epistemological relativity, and judgemental rationality, described by its founder, Roy Bhaskar, as the “holy trinity” of critical realism (Bhaskar, 2016, p.25). Firstly, ontological realism allows for there to be a real world that existed before us and which will exist when we are gone. Our thoughts about the world are important and our individual and social discourses become part of the world around us, but the world is still the world (Bhaskar, 2016; Pilgrim, 2020). Secondly, epistemological relativism describes how we develop our own interpretations of the world which are subject to change. There are things which exist independently of us, but our interpretation and knowledge about them is not fixed, thus, for critical realists “knowledge is socially contingent but truth remains independent” (Pilgrim, 2020, p. 4). Like constructivists there is a belief that “our knowledge of reality always is filtered through language and concepts that are changing over time and social contexts” (Danermark, Ekström and Karlsson, 2019, p. 35). Finally, judgemental rationality refers to people’s ability to have and use a sort of rational logic, meaning the ability to weigh up the likely truth and plausibility of a claim to knowledge (Bhaskar, 2016). Drawing upon the ontology-epistemology of critical realism provides some useful concepts and considerations for this research, which I will now outline.

Generative mechanisms

Critical realism claims that there are three ontological domains which help us to understand why things happen. These are the *empirical* events we experience, *actual* events that happen, and *real* things which cause events (Fryer, 2021). To understand why things happen we need to identify a causal relationship. Whilst positivists look for causes in the actual realm and constructivists focus on experience and interpretation rather than causation, critical realists are interested in identifying “causal mechanisms and how they act as tendencies to influence the world we observe” (Fryer, 2021, p. 24). These “generative mechanisms” (Bhaskar, 2016, p. 3) exist as structures which we cannot directly observe but which have an observable effect, even if we are unaware of them, for they “operate whether or not they are acknowledged to exist.” (Dy, Martin and Marlow, 2020, p. 152). Generative mechanisms will be considered in my analysis, particularly when I explore how being autistic affects experiences of motherhood.

When looking at the broader experiences of autistic mothers of autistic children, two generative mechanisms I had in mind were sexism and ableism. Sexism can be described as “the branch of patriarchal ideology that justifies and rationalizes a patriarchal social order” (Manne, 2018), “the belief that the members of one sex are less intelligent, able, skilful etc. than the members of the other sex, especially that women are less able than men” (Cambridge Dictionary, 2021) and is defined by the Council of Europe (2021) as “any expression (act, word, image, gesture) based on the idea that some persons, most often women, are inferior because of their sex”. Ableism “privileges a non-disabled perspective and promotes the inferior and unequal treatment of disabled people” (Nario-Redmond, 2020, p.5) and can be described as a:

> system of causal relations about the order of life that produces processes and systems of entitlement and exclusion. This causality fosters conditions of microaggression, internalized ableism and, in their jostling, notions of (un)encumbrance. A system of dividing practices, ableism institutes the reification and classification of populations. Ableist systems involve the differentiation, ranking, negation, notification and prioritization of sentient life. (Campbell, 2017, pp. 287-288)

What we see in these descriptions is how both sexism and ableism can be described by both the effect they have on individuals and as the causal or generative mechanisms which have an effect. A critical realist ontology-epistemology enables us to reject the universal laws of positivism and the pure subjectivity of constructivism and provides a means to understand how socially constructed entities, like sexism and ableism, can act as generative mechanisms, even when they are unacknowledged by those affected. This makes it possible for the researcher to explore and explain social tendencies and to use judgemental rationality to identify causes and develop theories using retroductive reasoning.

Retroductive reasoning

For critical realists all knowledge is important, both subjective and objective, and all knowledge is treated as being fallible (Fletcher, 2017). Retroductive reasoning is an important part of the research process for critical realists and provides an opportunity to generate knowledge by “making an inference about the causal mechanism that lies behind and is responsible for regularities that are observed in the social world” (Bryman, 2016, p. 25). Retroduction “incorporates the Latin *retro* (“going backward”) and *ducere* (to lead)” (Sage, 2019, p. 8) enabling the researcher to create new knowledge by applying and adapting existing theories and knowledge, sometimes speculatively, when attempting to make sense of an account or phenomenon (Pilgrim, 2020; Sage, 2019). Glynos and Howarth, writing from a poststructuralist position, describe a ‘retroductive cycle’ of social research, and explain how “as we move from one ‘moment’ to the next, and back again, revising aspects of our account in light of adjustments made in other moments, we never return to the same spot.” (Glynos and Howarth, 2018, p. 9). As I will demonstrate later in this chapter, I have chosen a method of data analysis, reflexive thematic analysis, which supports such a back-and-forth retroductive approach.

Retroductive reasoning, then, alongside judgemental rationality, allows us to revisit and revise our data and findings to develop and adapt theories as we go, acknowledging that knowledge and theories are dynamic, contextual and provisional. It enables social researchers to provide a ‘best guess’ explanation for a problem or phenomenon without the need for reliance on universal laws or essentialist accounts of social phenomena (Glynos and Howarth, 2018). As this research concerns a scarcely researched social group, I was conscious when developing an interview guide and considering potential questions that I cannot know what is possible to know about autistic mothers, therefore, my approach needed to be flexible and adaptable. A retroductive approach can help to address some such problems encountered in researching ‘new’ populations, for example, after my pilot interview I made some changes to my interview schedule and returned to ask her if she wanted to respond to the new questions and topics. It also undergirds the discussion of Chapter 10, where I will consider different ways to conceptualise and theorise autistic motherhood.

Commitment to social change

According to Bhaskar (1989), critical realism is committed to social understanding as a foundation for social change:

> We will only be able to understand – and so change – the social world if we identify the structures at work that generate those events and discourses... These structures are not spontaneously apparent in the observable pattern of events; they can only be identified through the practical and theoretical work of the social sciences. (Bhaskar, 1989, p. 2)

For critical realists, structures and cultures develop from human interaction (Brönnimann, 2021) whilst simultaneously existing "independently of actions, but ... these structures enable and constrain actions, which in turn reproduce and transform social structures" (Stutchbury, 2021, p. 3). Awareness of structures affects and potentially shapes individual decisions and actions (Archer, 2017) but it does not determine them (Booker, 2021). It is this relationship between structure, culture and agency that forms what we think of as the social world, where culture emerges from the interaction between structure and agency (Stutchbury, 2021). Both social and cultural structures are more than the sum of their parts, existing beyond the individual (Gorski, 2013) yet reproduced by multiple individuals (Manicas, 1998), and this means that they are open to change through individual and collective action. Recognising that "changes in activity do change society ... suggests that social sciences is potentially liberating" (Manicas, 1998, p. 321), and, as Gorski (2013, p. 669) writes, "[t]he social sciences are not 'value-neutral'. They presuppose an axiological commitment to human well-being." My motivation for undertaking this research is to improve the lives of autistic mothers, to effect social change for the better. Thus, in a retroductive step, we have returned to axiology, and this chapter will now consider in more detail how my values as a researcher drive my ethical and methodological choices.

Ethical considerations

Before applying for ethical approval, I read several ethical guidelines for conducting social research, including the LSBU Ethics Code of Practice for research involving human participants (2020), the British Sociological Association Statement of Ethical Practice (2017), the University of Manchester Guidelines for conducting research with the autism community (Gowen et al., 2020) and the Shaping Autism Participatory autism research starter pack (2020). The autism specific ethical guides were useful reminders of practices to consider when working with autistic participants, for example, ensuring full information is given on what to expect, providing information about me and the location for in-person interviews, and offering different ways to conduct interviews depending on communication needs and preferences. I provided a detailed participant information pack (Appendix A), including a list of support organisations (Appendix B), and all participants consented (Appendix C) to participate freely and eagerly, were asked to provide pseudonyms to enable the anonymity of their contributions, and were assured of confidentiality, data security and their right to withdraw from the study.

However, whilst ethical guidance and approvals ensure that researchers consider a range of ethical issues that might arise in the research process, they are only part of the range of ethical considerations which concern us. For the purposes of this research I am concerned with three domains of ethics: procedural, situational and relational (Ellis, 2007). Procedural ethics, submitting to an ethics board or committee to evidence compliance with ethical guidelines, as outlined above, cannot account for all of the ethical issues which might arise during the research process. Situational ethics refers to risks that arise while the research is being conducted, thus it is contextual and dependent on the researcher's ability to recognise and ameliorate potential ethical tensions as they arise. Whilst procedural ethics are rooted in duty, situational ethics are founded on principles (Hammersely and Traianou, 2012), for example, the feminist research ethic goes beyond the duty of "not doing harm" and instead implores that we commit to "doing good" (Kingston, 2020, p. 533). Relational ethics stem from an ethic of care or caring (Gilligan, 1982; Hill Collins, 2022), prioritising interconnections, relationships, emotion and empathy, and the ethic of friendship (Ellis, 2007, p. 735) which underpins friendship as method which will be discussed later in this chapter.

Participatory research

Participatory autism research, where autistic people are fully engaged as active participants in the research process, has the potential to improve the quality and ethics of autism research (Pellicano et al., 2022). As I will explore later in theme 6: 'If you're autistic it's presumed that you don't know anything about anything', autistic expertise on autism is often under-recognised and under-valued by the clinicians and professionals we encounter. Autistic expertise is also often ignored or side-lined in research, and this was highlighted when a large-scale study, Spectrum 10k, which aimed to collect DNA samples and survey responses from 10,000 autistic people, was paused shortly after launch.

The pause of Spectrum 10k followed considerable criticism from autistic people and advocates (Pring, 2021), who were concerned about future misuse of autistic DNA data (Chapman, 2021), and highlighted the importance of researcher engagement with individuals and communities being researched. Whilst the research team had assembled a panel which included autistic people to advise on ethical matters (Chapman, 2021) it became clear that this was not enough, and new plans were developed to introduce a more comprehensive and co-designed consultation process (Spectrum 10k, December 2021, personal correspondence, 1 December). In the projects team's apology and update which announced the pause the problem is presented as one of poor communication of the research aims and the need for further consultation (Baron-Cohen, 2021). In terms of community engagement and participation, this presents like someone closing the stable door after the horse has bolted, and perhaps the community response would have been more positive if autistic people, including autistic researchers, had been more involved from the outset as genuine collaborators and contributors.

The use of advisory panels of autistic and allied stakeholders, for example, the AIMS-2-TRIALS project's A-Reps steering committee (AIMS-2-TRIALS, 2018) and the INSAR Autistic Researchers Committee (INSAR, 2020), has certainly been a step in the right direction. However, like Spectrum 10k, none of these examples offer genuine partnership, rather, they tend towards tokenism. Arnstein's (1969) ladder of citizen participation (below) locates informing, consulting and placating in the realm of tokenism and thus not as genuine participation, for "[m]uch of what passes as 'participatory' research goes no further than contracting people into projects which are entirely scientist-led, designed and managed.” (Cornwall and Jewkes, 1995, p. 1669).

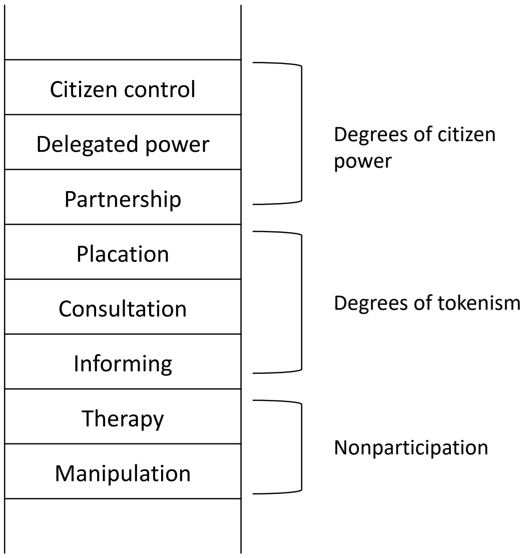


Figure 1: Arnstein's ladder of citizen participation (1969)

Genuine participation, therefore, would require autistic people to be involved and integrated at every stage of the research process (Milton, 2019), and whilst Milton (2019) suggests that participatory research “should be conceived of as an ethos or ideal” (para. 6), others have attempted to develop guidance for conducting participatory research (Chown et al., 2017; Fletcher-Watson et al., 2019; Gowen et al., 2020; Nicolaidis et al., 2019). These how-to guides are aimed primarily at non-autistic researchers conducting autism research and encourage researchers to “incorporat[e] the views of autistic people and their allies about what research gets done, how it is done and how it is implemented.” (Fletcher-Watson et al., 2019, p. 943). Whilst participatory research can often be hard work and undervalued (Pickard et al., 2022), involving autistic researchers can improve participation and engagement (Pellicano et al., 2021), for example, Jenny, one of my participants told me that “it has helped speaking to a researcher who is autistic, a mother and who uses a feminist approach.”

For the purposes of this research, I choose to work within an ethical framework of participatory principles, ideals and values, reflecting both Milton’s (2019, para. 6) “ethos or ideal” framing of participatory research and my own longstanding personal and academic interest in feminist research ethics and methods. Feminist research methods provide a “moral and ethical framework” (Preissle, 2007, p. 515), by valuing the experiences of women (Hughes, 2002), by validating those experiences through knowledge production (Parr, 2020), and by “suggest[ing] ways forward to a better world in which critical scholarship plays an active role in inspiring and enabling social change” (Leavy and Harris, 2019, p. v). However, combining participatory and feminist research methodology and method is not new. For example, feminist participatory action research (Gatenby and Humphries, 2000) seeks to include and empower women as part of a wholly collaborative research process (Johnson and Flynn, 2020) and feminist standpoint theory (Harding, 1986; Hartsock, 1983) uses the “situated knowledges” (Haraway, 1988, p. 581) of women to illuminate and challenge hegemonic social and structural hierarchies and what we think we know about them (Gurung, 2020; Sprague, 2018). Whilst this research is not a truly collaborative project it was, as I described in the first chapter, developed out of discussions with other autistic mothers who felt poorly represented in autism research and who believed, like me, that telling and broadcasting our stories and improving awareness and understanding about us and our experiences has the potential to make our lives better. Furthermore, telling our stories also provides a means to greater understanding of ourselves, as explained by Lydia:

> I would say that the biggest takeaway I have from this experience has been justifying the way I am as a mother, which is in a conscious way with empathy and compassion. Even if it isn't a mainstream way. If this is because I am autistic, then it is one reason I am grateful to be so.

Story-telling is an important thread running through this thesis and, from a participatory and feminist standpoint, it enables me to centre and empower the voices of my participants, and to conduct an analysis which is faithful to their stories. This will be explored further when I discuss my analysis later in this chapter.

Autoethnography

Story-telling as a way to improve understanding is key to ethnographic and autoethnographic approaches to research. Ethnography has its roots in anthropology and the study of 'other' cultures and societies (Hammersely and Atkinson, 2007), providing insight into the lives and worlds of 'them'. Autoethnography, in contrast, invites us to learn about the worlds of 'us', and attempts to present 'other' as less alien and more human. Thus, in Bochner's 'mini-manifesto for autoethnography' (2017, p. 69) he describes producing research which is "'an experience of our experience' that would make it possible for readers/audiences to see Others in themselves or themselves in Others." Subjectivity and reflexivity are considered key to autoethnographic research, which aims to challenge dominant narratives and outsider knowledge, to create insider knowledge, to capture knowledge that can't be captured another way, and to create accessible texts (Adams et al., 2017). It "seeks to describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno)" (Ellis et al., 2011, para. 1) and has been used by autistic scholars to showcase the autistic voice through aut- or autie-ethnography (Milton, 2017; Rourke, 2019; Yergau, 2013), which artfully entwines experience, reflection and analysis to create engaging and evocative works which enhance understanding of autism from an autistic insider standpoint.

However, autoethnography's reliance on the researcher being "deeply immersed in self-experience while observing, writing, journaling and reflecting" (Edwards, 2021, p. 1) presents an ethical challenge, for none of us live in isolation and our individual stories include reference to other people, who may not want us to include them. Telling our stories of motherhood requires us to also tell the stories of our children, and whilst I can use pseudonyms and protect participants' and their children's anonymity, as a doctoral researcher I cannot be anonymous, nor grant anonymity to my child. I need to be able to research 'us' without necessarily researching 'me'. This quandary led me to an earlier iteration of autoethnography, described as the "ethnographies of their 'own people'" (Hayano, 1979, p. 99), which reflected the shift away from colonial anthropology towards research by members of cultural and social groups, communities and sub-cultures. In this tradition, I draw upon analytic autoethnography (Anderson, 2006) which requires the researcher to be a visible member of the group being researched and also to "use empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves" (Anderson, 2006, p. 387). Whilst I take heed of Ellis and Bochner's (2006, p.436) critique of analytic autoethnography which they describe as "aloof autoethnography", I will demonstrate throughout this chapter and as I present my findings, that my approach is far from aloof. In essence, and returning to my use of a critical realist ontology, I seek to combine my unique insider position with my "sociological imagination" (Mills, 1959, p. 5) to "reconstitute the women's experiences through sociological conceptualisation and theorising" (Parr, 2020, p. 272).

Friendship as method

As will be discussed later in this chapter, my original plans for recruiting through charities and gatekeepers, and for offering in-person interviews, were stymied by both Covid lockdowns and university restrictions on conducting in-person research. Furthermore, when I started this research, I had expected that my participants would all be strangers, misguidedly as it turned out, believing that it would be unwise or unethical to invite friends to participate. Whilst I had only met three of my participants in real life, including one directly as a result of her interest in this research, I had prior virtual friendships of varying intimacies with seven of the women who took part. Several of the participants were part of the original group who provided ideas, opinions, support and encouragement back in 2016 when the seeds of this research were planted during my preparation for a presentation at a large autism conference (as discussed in Chapter 1). Then, as I started to recruit and conduct interviews for this project, I was reminded how invested these friends were in this research, and it felt unethical *not* to offer the chance to contribute and participate. I googled "using friends as research participants" and was delighted to discover a body of work on 'friendship as method' and, in particular, this summary:

> Researching with the practices of friendship means that although we employ traditional forms of data gathering (e.g., participant observation, systematic note taking, and informal and formal interviews), our primary procedures are those we use to build and sustain friendship: conversation, everyday involvement, compassion, giving, and vulnerability. (Tillman-Healy, 2003, p. 734)

Reflecting my earlier discussion on autoethnography, Tillman-Healy (2003, p. 735) goes on to write that “friendship as method demands radical reciprocity, a move from studying ‘them’ to studying us” as she describes researching at a “natural pace” (p. 734) and with an “ethic of friendship” (p. 735). The ethic of friendship is embodied within Ellis’s (2007) description of relational ethics, adding a third domain to the procedural ethics (e.g., ethics committees) and situational ethics (e.g., responding to risks that arise during the research process) which typically concern researchers. Relational ethics is dynamic and reflexive, demanding that we ask ourselves “[h]ow can we act in a humane, nonexploitative way, while being mindful of our role as researchers?” (Ellis, 2007, p. 5). Keeping this question in mind has been crucial throughout this research. I was very aware that interested friends might feel obligated to volunteer, therefore I was careful to use a light touch when inviting and encouraging participation. I was also concerned that as both friend and researcher there might be “role conflict” or “over disclosure” (McConnell-Henry et al., 2010, pp. 3-4), and I considered this as I conducted my interviews, which I will discuss later in this chapter.

Sampling and recruitment

Sampling and selection of participants in qualitative research typically relies on some form of purposeful sampling (Shaheen et al., 2019), a process of choosing participants deliberately because they present as “theoretically interesting” (Gadd and Farrall, 2004, p132) but also as a means of “identifying and selecting cases that will use the limited research resources effectively” (Campbell et al., 2020, p. 654).

Identifying and recruiting participants for this study presented a challenge. I knew that there was interest in this topic, and that I would not struggle to find participants if I cast a wide net. However, I was keen to encourage and invite participation from autistic mothers who may be under-represented in autism research and/or who do not typically volunteer to participate in research. This might include lesbian women, women from ethnic and other minority communities, and women with co-occurring conditions, as well as women who do not engage in autistic community activity or who do not share or disclose their autism to others. I was particularly keen to avoid concerns about poor representation of women from minority communities and from lower socio-economic groups (Maye et al., 2021) and those raised by Pickard et al. (2022, p.84) "regarding a perceived lack of diversity among the autistic people who contributed to research, noting that a 'core group' of people were consistently involved." I hoped to be able to represent autistic mothers both in breadth and depth, representing a range of experiences of autistic motherhood in rich detail. A significant factor in choosing interviews as a method, rather than perhaps focus groups, was that it would provide participants, who I suspected in many cases would be tied to their home or locality, with the most flexibility, supporting my aim to include women who are more isolated.

In the early stages of recruitment and following introductions, I contacted three small autism or related charities and one large special school, explaining my research and my search for autistic mothers who might be under-represented in autism research. I was disappointed that these contacts did not result in any referrals or recruitment of participants. However, I suspect that had I been able to go and meet in-person, I may have been more successful, but pandemic restrictions prevented this at the point where it would have been useful. I also placed a flyer in a local autistic/autism group but again received no interest. I had more success in smaller online groups where I was already known and had prior relationships with the other members, and with women who I already considered friends and who had expressed an interest in this research. I also directly contacted women who I knew had stories to tell but who had not volunteered, as a way to encourage participation from women who would not usually volunteer to take part in research. Unfortunately, attempts to recruit from ethnic minority communities were not successful, however, like me, one participant was a second-generation immigrant, and we discussed the impact of this in our interview. Participants did, however, represent a range of backgrounds in relation to disability and health conditions, sexual orientation, class, educational attainment, income, and family set-up. Three women who showed strong interest in taking part withdrew before either consenting or interviewing due to personal and health demands and pressures, however, one woman who withdrew later participated in a truncated interview. I stopped recruiting once I had completed 11 full interviews and the one part-interview, in part due to slightly exceeding my planned deadline for completing data collection, but also due to sensing that I had amassed a sufficient wealth of incredibly rich and detailed interview data full of "thick description" (Geertz, 1973, p. 3). Whilst recruiting more participants might have provided an even broader range of experiences, the richness and density of the interview data I collected, as will be shown across the thematic analysis in Chapters 4-9, provided plentiful material to meet the aims of this research.

Interviewing

Interviews are commonly used by researchers interested in hearing the stories and experiences of our participants, and whilst there are many different ways to conduct interviews, qualitative researchers typically "use conversation to elicit data from research participants" (Leavy and Harris, 2019, p. 138). We aim to build rapport and to ask meaningful questions which act as triggers (Willig, 2013) to generate data. Moreover, framing interviews as a means to *generate* data rather than as a process of data *collection* enables us to recognise the interactive and dynamic nature of interviewing where "[t]he relationship between interviewer and interviewee is fluid and changing, but it is always jointly constructed" (Collins, 1998, para. 3.1). This interactional nature of research interviews was powerfully articulated by Oakley (1981) who asserted that there could be "no intimacy without reciprocity" (p. 49), making an important feminist challenge to mainstream social research which demanded objectivity and a clear delineation between the roles of researcher and 'subject'. My aim was to conduct interviews underpinned by feminist research ethics which value empowerment, reflexivity and reciprocity (Kingston, 2020).

When I set out to do this research, my intention was always to offer a range of options for interviews, including in-person and virtual. I had many years' of experience conducting interviews in a professional capacity and was looking forward to building on those skills in a research setting, by meeting and interacting with participants in-person. I was particularly aware that some of the autistic women I hoped to interview might have never met another autistic woman, and that this itself could be significant and powerful. It was extremely unfortunate that soon after being granted ethical approval, we entered the first Covid lockdown. As in-person interviews were no longer possible, and a lack of privacy in my home meant that I could not guarantee confidentiality for phone or video interviews, I opted to conduct text-based interviews. In my ethics application I proposed using WhatsApp or email for virtual interviews. WhatsApp was my preferred choice for text-based interviews due to its simplicity, functionality and inbuilt end-to-end encryption. The use of WhatsApp by researchers is a new and growing phenomenon, in part spurred on by the limitations on in-person contact as a result of the Covid pandemic (for example, Kok et al., 2021), to access hard-to-reach communities (for example, Heywood, Ivey and Meuter, 2022), and as a way of enhancing ecological validity (for example, Colom, 2022) by enabling participants to take part from their own space and to engage at their own pace. Participants were asked if they would be happy to be interviewed over WhatsApp and offered email as an alternative. Of the 12 participants, 10 were interviewed using WhatsApp and two using email.

I opted to conduct an initial pilot interview over WhatsApp, which helped me to work out the logistics of how best to format and post questions and to test whether my questions worked to generate the detailed responses I was hoping for. The pilot interview took place over three weeks and enabled the participant to dip in and out of the interview, providing time for thinking and reflecting for both of us. My use of asynchronous virtual interviews suited my busy participants, providing flexibility around how and when we interacted, and whilst I used the same standard interview schedule (Appendix D) for all interviews, every participant responded and interacted differently. The semi-structured interview schedule included five main sections, which broadly reflect the aims of this research, covering demographic information, being autistic, being a mother, social expectations, and interactions with professionals and clinicians.

For each interview, I provided very clear information on what to expect at the start of each interview and interviews typically included fixed questions interspersed with follow-up questions and general chatting about our experiences. I was keen for questions to be very clear and straightforward but also with enough scope for participants to contribute what was important for each of them. Responses varied from fairly direct answering of the questions to broad responses reflecting the topic area of the questions, generally with a mix of both, which suggests that the interview schedule worked well. Follow-up questions were a mix of asking for more detail and using "iterative conversation" (Fraser and Taylor, 2020), a useful technique for interviewing members of hard-to-reach groups where there might be topics which are considered controversial or where there is fear of being judged. Raising issues from my own experiences or as reported in previous interviews was one way to achieve this. Without exception, participants were keen to tell their stories, and provide opinions, with remarkable candour. As raised in my earlier discussion of friendship as method, I was concerned that including friends as participants might cause role conflict or tend towards over-disclosure, or even a reticence to disclose, but I could find no evidence of patterns to support this in the interview transcripts. It is possible that using WhatsApp helped ameliorate some of these potential risks as participants were able to edit as they went, providing enhanced control of their contributions.

Interviews each took between a few days to a few months to complete, which resulted in the period spent interviewing exceeding plans but was necessary to avoid needing to focus on multiple interviews at once. Having a prior friendship or connection with most participants made it easier to engage during the interviews and removed or reduced most of the need for rapport-building, resulting in what felt like authentic and reciprocal interaction. Participants who commented on the interview process were positive and grateful to have the opportunity to tell their stories and be heard in the hope that something positive would be achieved. It is quite hard to express my gratitude to all the participants for their contributions. They have provided me with what Limerick et al. (1996, p. 450) call "the gift", "conclud[ing] that material collected from interviews needs to be accepted by the researcher as a gift from those who have participated in the research project because it is our story of their story that forms the written report". Following interviews, I transferred the text from WhatsApp (or email) to protected documents and deleted my copy of the WhatsApp (or email) interview, leaving participants free to choose to keep or delete their copy of the interview. All participants were offered copies of their interview transcript to read or amend, but only two requests were received, and no changes were requested.

Reflexive thematic analysis

My choice of reflexive thematic analysis (Braun and Clarke, 2022) as the method used to analyse my data is influenced by the ontological, epistemological and ethical positions outlined in this chapter, and my need for a method which provides a flexible, reflexive and transparent process of data analysis. Reflexive thematic analysis (RTA) is a methodologically flexible method which provides a means to develop themes from qualitative data, where a theme is defined as “a pattern of shared meaning organised around a central concept” (Braun and Clarke, 2022, p. 77). A flexible approach was necessary in practical ways to enable me to be creative in working within my autistic disposition, as well as in theoretical ways where it enables the researcher to perform “a continual bending back on oneself – questioning and querying the assumptions we are making in interpreting and coding the data” (Braun and Clarke, 2019, p. 594), echoing the retroductive approach of critical realism discussed earlier in this chapter. Reflexivity matters as it reminds us that “methods of data analysis are not simply neutral techniques because they carry the epistemological, ontological and theoretical assumptions of the researcher who developed them” (Mauthner and Doucet, 2003, p. 415), enabling me to be transparent about *how* and *why* I did what I did. My engagement with the data, the stories of the women who have taken part in this research, and how I choose to include, interpret and present those stories, rests on my standpoint, position and values. By choosing RTA I reject positivist diktats demanding replicability and statistical generalisability, and instead I embrace my subjective and socially located position by telling my story of their story (Limerick et al., 1996).

Reflexive thematic analysis involves a six-phase process which starts with familiarisation with the data (phase 1), and continues through coding (Phase 2), generating initial themes (Phase 3), developing and reviewing themes (Phase 4), refining, defining and naming themes (Phase 5), and writing up (phase 6) (Braun and Clarke, 2022, pp. 35-36). I kept a reflexive journal throughout this process both to note reflections as I worked through the transcripts, and also to enable me to accurately record my process. This was my first time analysing qualitative data of this scale, and I was keen to work through the phases without rushing and by allowing myself time to think about and reflect upon the data and my thoughts about the data. So far, this chapter has spent a lot of time explaining *why*, and now it is time to turn to *how*.

Phase 1: Familiarisation

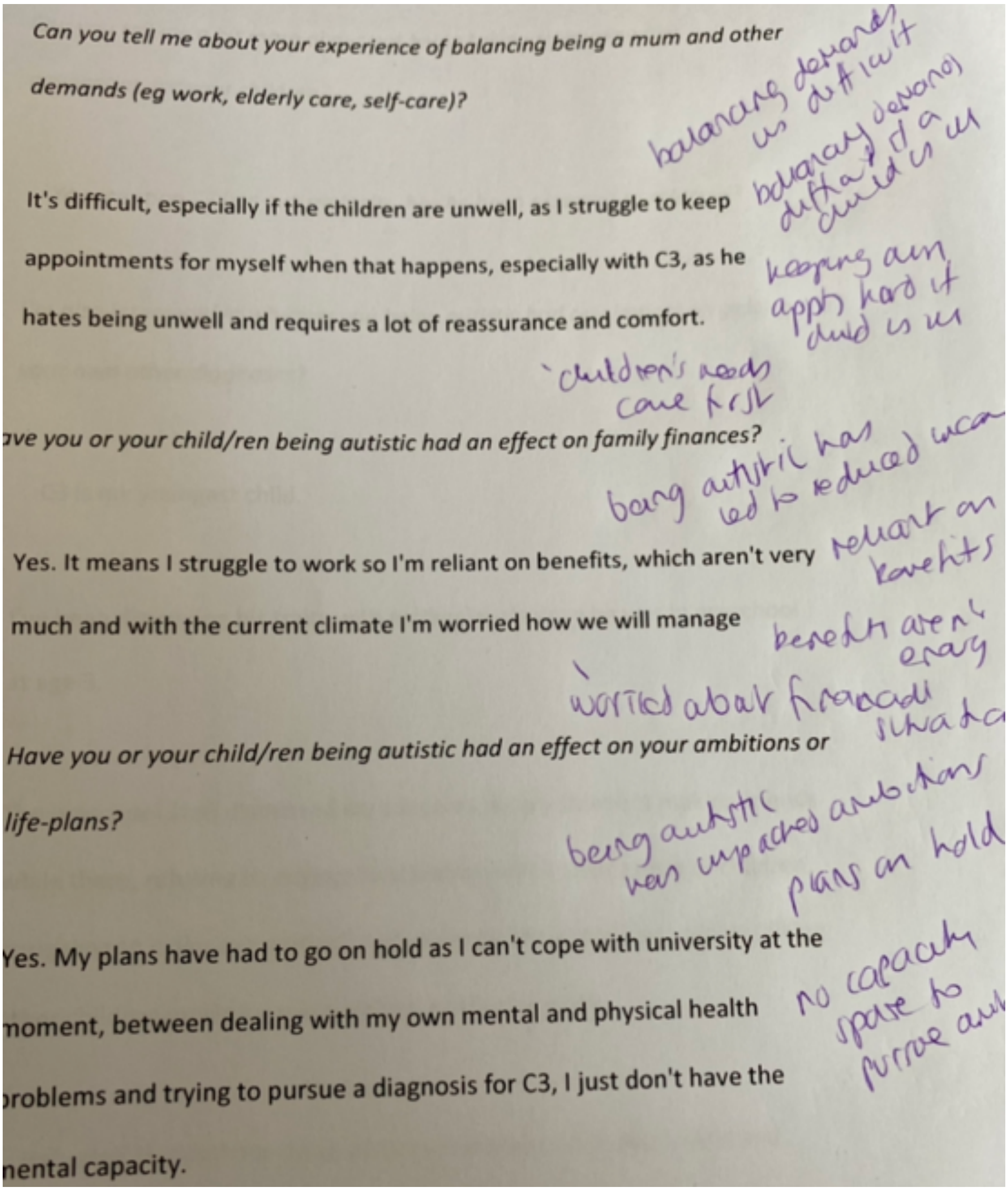
The 12 interviews generated nearly 110,000 words of transcripts to analyse. The density of this data should not be underestimated, as described in this reflective account of using WhatsApp for interviews:

> *[I]t became evident to me that the data from [WhatsApp] were much more dense than that obtained through my face-to-face interviews. In the transcripts of face-to-face interviews, I often had to trawl through reams of transcript to salvage one or two rich insights. In contrast, with the digital interviews, each response from a participant seemed to be rich with meaning. (Gibson, 2020, p. 13)*

Despite having conducted the interviews myself, and scan-reading the interview scripts as I turned them into useable transcripts, I was not prepared for such generous, thoughtful, detailed and rich contributions to this project. I read through the transcripts twice, thinking about what had been said and what was implied, trying hard not to fix my thinking on any specific areas or potential themes. As I reflected on the transcripts, I couldn’t avoid starting to spot patterns and I made notes as I went, for example, some participants talked about mothering differently in public and private, which reminded me of Rich’s (1986, p. 195) account of outlaw mothering, the intuitive and uninhibited mothering we do when we feel free to mother without judgement. I also spotted an interesting disparity between the knowledge that participants claimed to need or have, and the level of knowledge demonstrated by participants throughout the interviews. I tried, however, to not become too attached to these early patterns, and approached the next phase, coding, with an open mind.

Phase 2: Coding

Coding transcripts is a way to reduce a vast dataset into a series of smaller building blocks (codes) which can later be clustered and developed into themes (Braun and Clarke, 2022). As I had never coded before I dove straight in, working with printouts and coloured pens, and worked through all the transcripts, mostly relying on semantic codes to capture points of interest (Figure 2). Semantic codes tend to be explicit, capturing words and ideas expressed by participants. Later refining of my coding resulted in more latent codes, where I captured implied meaning, and started to apply my own interpretation more confidently. Every interesting, relevant or illuminating part of a transcript was given a code label, a succinct summary or analytic observation which could stand alone and still infer meaning even when removed from the data extracts.



Can you tell me about your experience of balancing being a mum and other demands (eg work, elderly care, self-care)?

balancing demands is difficult

It's difficult, especially if the children are unwell, as I struggle to keep appointments for myself when that happens, especially with C3, as he hates being unwell and requires a lot of reassurance and comfort.

balancing demands difficult if a child is ill

keeping own apps hard if child is ill

children's needs come first

ave you or your child/ren being autistic had an effect on family finances?

being autistic has led to reduced inco

Yes. It means I struggle to work so I'm reliant on benefits, which aren't very much and with the current climate I'm worried how we will manage

reliant on benefits

benefits aren't enough

worried about financial situatio

Have you or your child/ren being autistic had an effect on your ambitions or life-plans?

being autistic has impacted ambitions

plans on hold

Yes. My plans have had to go on hold as I can't cope with university at the noment, between dealing with my own mental and physical health roblems and trying to pursue a diagnosis for C3, I just don't have the nental capacity.

no capacity spare to pursue am

Figure 2: Early coding example

My first round of coding produced over two thousand codes and, whilst some may have been duplicates, this was clearly an unmanageable number! I decided to type up code labels and to combine and refine them as I went, creating a master code list, and referring back to the transcripts and my first-round coding to ensure these code labels worked. I then conducted a second-round of coding using my master codes, which again resulted in more changes as I became more efficient and proficient at identifying meaningful segments in the dataset. Slowly, through spending time with the transcripts and the code labels, and a lot of thinking and consideration of how well the participant experiences were represented in the codes, I reduced the number to 73. As I worked through coding, I couldn't help but start to consider patterns, for example, the code 'implied mother blame' seemed closely linked to the codes for 'refrigerator mother', 'fabricated and induced illness (FII)' and 'judged for how I mother'. With 73 codes and a sense that I was beginning to identify some bigger patterns, it was time to start considering how the codes relate to each other and to start considering some provisional clustering of codes that could be developed into themes.

Phase 3: Generating initial themes

In RTA a theme is, as mentioned previously, a "pattern of shared meaning organised around a central concept" (Braun and Clarke, 2022, p. 77) and generating initial themes is where I started to focus my thinking on how patterns of meaning cluster together. I needed to see all the themes together to get a sense of the whole of the coded dataset and used post-it notes on a whiteboard. Seeing the code labels all together for the first time really demonstrated the depth and complexity of my participants' contributions to this project (Figure 3).

Figure 3: Completed coding

Using post-it notes meant that I could move and re-position the code labels to explore different ways to cluster the codes. Initially, I did this on sheets of paper tacked to a wall (Figure 4).

Figure 4: Early attempt at clustering codes

My early clustering resulted in themes which lacked conceptual depth, for example, my notes at this stage mention masking, challenges, mothering, stereotypes, and coping mechanisms. These are all important factors, but they err towards being what Braun and Clarke (2022, p. 231) call “topic summaries”, where a theme includes everything said about each topic, but lacks the analytical approach to themes in RTA which “captures the patterning of meaning across the data” (2022, p.76). With this in mind, I played around with different combinations. I started to get a sense of how I might develop themes, for example, I developed a cluster which reflected one of my earlier notes (Figure 5) which represents the seeds of Theme 6: ‘If you’re autistic it’s presumed that you don’t know anything about anything’:

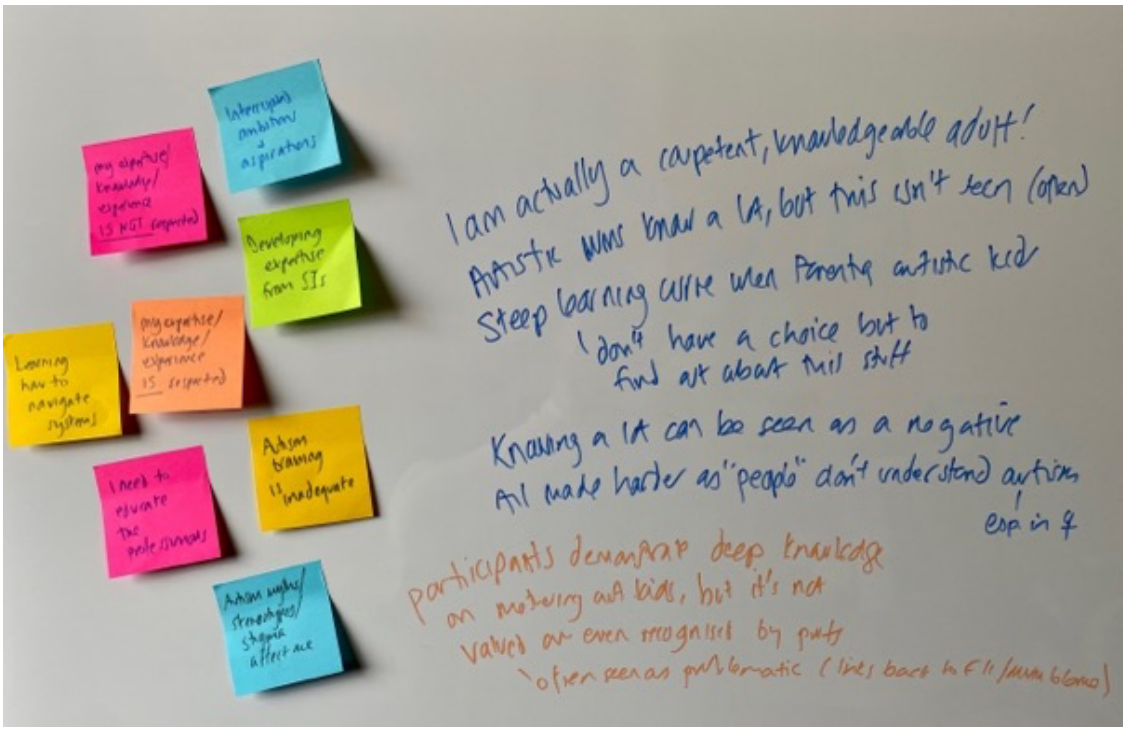


Figure 5: Refined code clustering

Phase 4: Developing and reviewing themes

The nature of RTA as a recursive or retroductive process became apparent at around this stage, where I began to go back and forth between phases 3, 4 and 5, moving my post-it code labels around and returning to the full transcripts and coded extracts to ensure that my developing themes represented both participant stories and my interpretations. I entered phase 4 with a set of 9 potential themes (Figure 6).

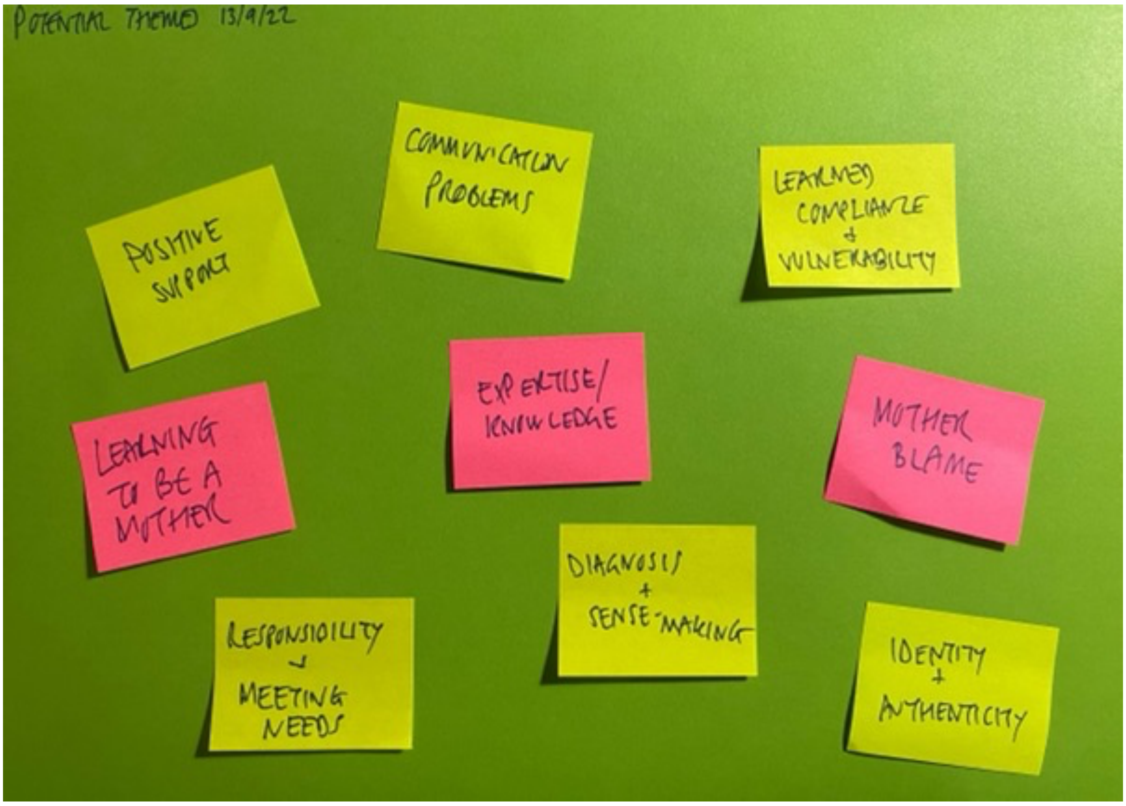


Figure 6: Early theme development

Braun and Clarke (2022) suggest using thematic mapping to help with the process of theme development, but I found this didn't work for me, and both my brain and my post-its ended up in a tangled spaghetti mess. Having already familiarised myself with all the phases of RTA and knowing that I do my best analytical thinking through writing, I felt comfortable proceeding without a thematic map. Whilst at this stage I was unable to articulate how the potential themes would work together, I was reasonably confident I would be able to express this later when writing up.

I used these potential themes to start organising codes and coded extracts (Figure 7), resulting in a series of code-clustered themes that appeared to represent patterns of shared meaning.

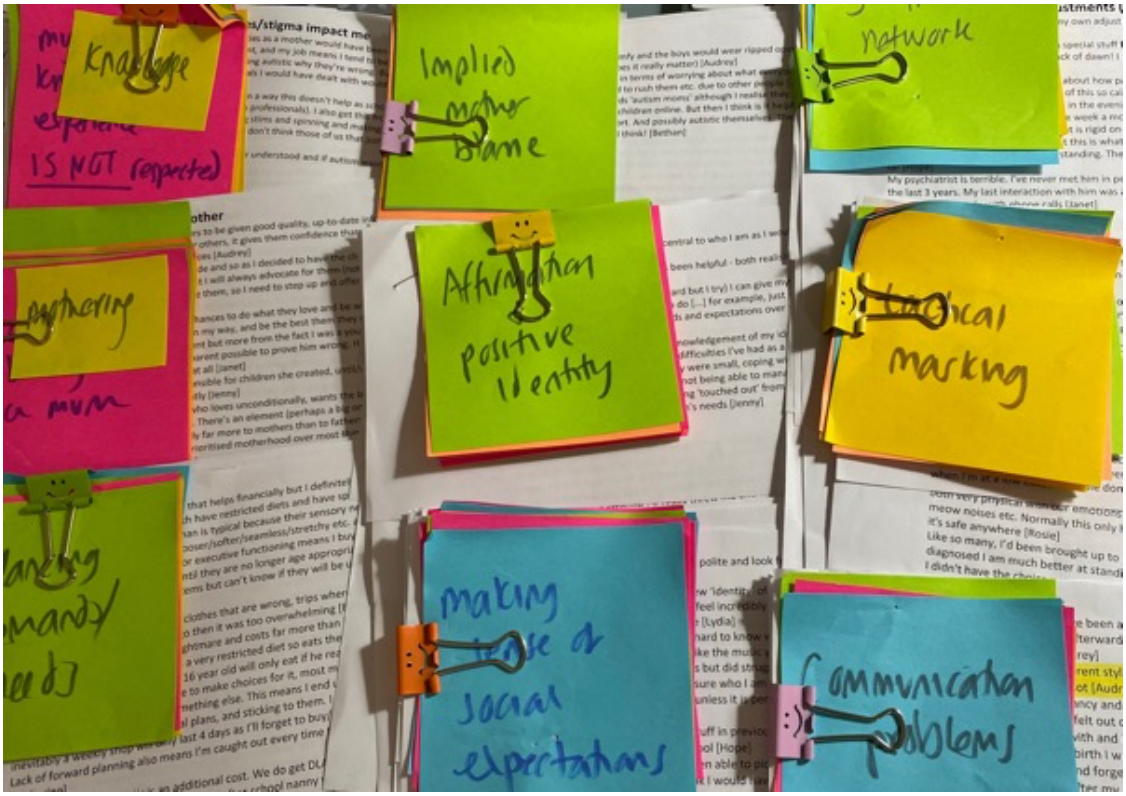


Figure 7: Refining theme development using coded data extracts

Phase 5: Refining, defining and naming themes

By this point, I felt reasonably happy with my theme development, meaning that it was time for naming my themes. Reading back through my journal I found a couple of notes with participant quotes which seemed to reflect some of the bigger conceptual ideas which formed the basis of my themes, prompting me to re-visit the coded extracts to see what I could find. It felt important to use participant ideas and words wherever possible, to demonstrate a connection between participants and analysis, and I found I was able to use participant quotes verbatim, or minimally edited for clarity, to name the developing themes. These early names would later go through a series of iterations as I refined the themes and the theme names, but they provided a useful starting point for writing my analysis.

Following Braun and Clarke's (2022) advice, I decided at this stage to prepare short descriptive abstracts for each theme, providing me with an opportunity to test what they describe as the "themeyness" (p. 108) of my themes. For example, this is the original theme abstract for theme 3: 'Women like me 'fall through the gaps' of support':

> This theme considers the benefits of good support, through an exploration of experiences of support and, as articulated across the dataset, a frequent dearth of quality support. Participant stories describe experiences of inadequate support and how, alongside poor understanding of autism, this often gives rise to disengagement and distrust. However, participants also provide examples of good practice which could improve support for autistic mothers and their autistic children, and describe the significance of encountering professionals, employers, and service providers who 'get it'. Participants also share experiences of finding and developing their own informal support networks to fill some of the gaps.

Writing theme abstracts helped me to check for clarity within and between themes and formed the foundation for writing up.

Phase 6: Writing up

Braun and Clarke (2022, p. 118) suggest that "writing is embedded in the analytic process", meaning that the iterative and analytical process of developing themes in RTA continues throughout writing up. Looking back at my journal from the earlier stages of writing up highlights the backwards and forwards nature of my analytical thinking as I continually played around with themes until I was happy. The retroductive nature of critical realist research became evident as I flitted between the transcripts and coded data, my interpretive notes and reflections, and wider literature, concepts and theory. Sometimes my data and interpretations would lead me to explore existing research, and other times I speculatively approached my data through a conceptual or theoretical lens. I considered *generative mechanisms*, i.e., the possible underlying causes for participant experiences, and used *retroductive reasoning* to interpret and infer from the data. In writing up my themes, I opted to integrate my results and discussion, enabling a deeper connection between the development of participant stories and my interpretation (my story of their story), and through the use of prior research and theory. Later, I realised that an additional broader discussion chapter would be necessary to explore conceptual and theoretical ideas across themes, and to demonstrate more explicitly how my thematic analysis answered my research questions, which I will present in Chapter 10.

Importantly, my ethical and values driven approach continued to influence my work as I made choices about how to use participants' data in my write-up. Throughout the process I was conscious that "in essence the job of a researcher is to tattle, i.e., tell tales, on their participants" (van den Scott, 2020, p. 773) and that in doing this I had a responsibility to tell my participants' stories respectfully and honestly. A benefit of my choice of interviewing method was that it accorded participants considerable flexibility in how they responded to interview questions, often resulting in long-form responses which provided extensive detail and analysis. In essence I was dealing with a “double hermeneutic” (Smith et al., 2009, p. 3) as I attempted to make sense of participants’ own sense-making narratives. Some of these deep and highly illuminating long-form responses are included: to provide necessary examples to support my analysis; to highlight the extensive knowledge and insight of participants; and to reflect and respect participants’ contribution to this research. Importantly, I was keen to ensure that all participants were represented in the write-up, and this was particularly important in reflecting Anna's chosen contribution which focused on her experience of domestic abuse. Excerpts from Anna’s interview, therefore, only appear in sub-theme 1.3 ‘I didn’t recognise the red flags’ where her experiences present an illuminating and important insight. Furthermore, I was equally conscious that I had a responsibility to protect participants’ anonymity, and whilst some participants would have chosen to participate openly, the children they spoke of were unable to consent. Therefore, preserving the anonymity of participants was an important consideration when selecting data excerpts to support my analysis, particularly bearing in mind the risk of jigsaw identification where pieces of information can be put together to re-identify people (Medical Research Council, 2019). In practice, this meant choosing less-identifying excerpts, where this was an option, as well as editing excerpts to remove any obvious identifying detail, including, but not limited to, people and place names. Spelling and grammar errors in excerpts were corrected where necessary to aid clarity and readability.

Table 1: Themes and sub-themes

Theme	Sub-theme
1. Knowing I'm autistic helps me to understand myself.	*1.1. It was like a lightbulb!* *1.2. Affirmation of my autistic identity has been helpful.* *1.3. I didn't recognise the red flags.*
2. Masking is a real double-edged sword.	*2.1. There's a lot of pressure on mothers to 'fit in'.* *2.2. I'm the queen of camouflaging.*
3. Women like me 'fall through the gaps' of support.	*3.1. It's hard to get support from anyone who understands my kind of autism.* *3.2. I've had to make my own support network for myself.*
4. A good mum wants the best for her children.	*4.1. You have to squash down your own needs.* *4.2. Being an autistic mother feels like having insider information.* *4.3. 'Against the norm' mothering.*
5. Autistic mothers are judged and problematised by the same forces that police gender roles in society.	*5.1. Mum is the one who keeps things in place.* *5.2. We get blamed a lot for our kids.*
6. If you're autistic it's presumed that you don't know anything about anything.	*6.1. All sorts of myths float around to make up for outdated knowledge.* *6.2. They just see us as mum, who knows nothing.* *6.3. I have a need to know exactly what something is about.*

Summary and conclusion

This chapter has outlined the philosophical, ethical and practical foundations of this thesis. Through my engagement with ontological, epistemological and axiological debates and considerations, I have presented a case for adopting a critical realist ontology/epistemology and for conducting ethical and values-driven research which is underpinned by “nothing about us, without us” and “the personal is political”. I have described the processes and methods of recruitment, data generation and analysis which inform the following six chapters where I present the themes developed through my reflexive thematic analysis of participant experiences of autistic motherhood (Table 1).

As previously discussed, developing the themes was a highly iterative process, which continued throughout the writing up of the thematic and discussion chapters. Even now, as I am introducing the already written up themes and discussion, I know that I could do it differently and, indeed, I probably would if I started over again from the beginning. But that would be a different thematic journey, and here I am reporting on the one already taken, with a set of themes which present my story of my participants’ stories. Participant stories are told through extracts from their interviews, and mine is told through commentary, interpretation, and by situating these stories in ‘the literature’.

Introducing the participants

Finally, it is time to introduce the participating autistic mothers who participated in this research:

Anna is in her 60s and has four adult children. She realised she was autistic after three of her children were diagnosed. She is a former social worker and academic.

Audrey is in her 30s and suspected she was autistic after her children were diagnosed. She lives with her husband and two sons and works as an autism professional in the third sector.

Bethan is in her 40s and recognised herself as autistic after her son was diagnosed as a small child, she also has a young daughter who she suspects is autistic. She is self-employed and lives with her husband and two children.

Clare is in her 40s and was diagnosed after two of her sons were diagnosed. She lives with her husband and four teenage and adult children and works for a third sector organisation.

Emily is in her 50s and was diagnosed following her partner and two children being diagnosed. She works as an artist and educator, and lives with her adult daughter and teenage son.

Hope is in her 50s and is a former teacher who lives with her two autistic children. She realised she was autistic when reading about autism in girls while her daughter was being assessed.

Janet is in her 30s and was diagnosed after having children, but before recognising autism in her youngest child. She lives with her three children and previously worked as a childcare professional.

Jenny is in her 40s and first suspected she was autistic in her late teens, though not diagnosed until after having her three children, who she suspects are all autistic. She lives with her partner and two of her children and is an academic.

Katharine is in her 40s and was diagnosed after her middle son received a diagnosis. Of her four children, her adult daughter is awaiting assessment and her youngest son has been acknowledged to be on the autism spectrum. She has a postgraduate autism qualification and is not currently working.

Lydia is in her 40s and was diagnosed after her older daughter, and her younger daughter is also awaiting assessment. She is not currently working and lives with her husband and two daughters.

Rosie suspected she was autistic before having her first son. Learning about autism and then her own diagnosis resulted in her recognising traits and presentations in her older son. She is in her 30s, lives with her two sons, and is self-employed.

Victoria is in her 40s and was diagnosed before having her daughter, who has also now been diagnosed. She is self-employed and lives with her partner and daughter.

4. Theme 1: Knowing I'm autistic helps me to understand myself

Introduction

This theme will consider the ways that participating autistic mothers began to "think autism" (Hacking, 2009, p. 1467) and of their finding ways to describe, contextualise and make sense of their experiences through realising that they were autistic. Here, I explore the importance, reflected throughout the dataset, of affirmation, validation and understanding of oneself as an autistic person, woman, and mother. Participating mothers described the impact of realising that they were autistic and some of the ways that it helped with making sense of their lives. These moments of realisation, represented in the first sub-theme 'It was like a lightbulb!", presented important early opportunities for participants to start the process of making sense of their lives and coming to terms with being autistic. Whilst participants often started the process of autistic self-awareness and identity-forming long before seeking assessment, diagnosis was typically seen to confer validation and legitimacy, and this is explored in the second sub-theme 'Affirmation of my autistic identity has been helpful'. The final sub-theme 'I didn't recognise the red flags' describes participant experiences of vulnerability and victimisation, and how participants attempted to make sense of these experiences as autistic women and mothers.

Sub-theme 1.2: It was like a lightbulb!

Structured around participant experiences of realising that they are autistic, this sub-theme explores the lightbulb moment of realisation and how it resulted in the beginnings of sense-making for participants. Participants suspected or realised they were autistic in different ways. Some participants made accidental discoveries whilst reading about autism, for others family members suggested that they might be autistic, and for some it was the result of a gradual realisation whilst researching autism following their children's assessment and diagnosis.

Increased public awareness of autism (Dillenburger et al., 2013; Kelly et al., 2022) alongside media coverage of the misdiagnosis and under-diagnosis of autistic girls and women (for example, Hill, 2017; McGuiness, 2023), autistic women bloggers (for example, Kim, 2014a; Kim, 2014b) and autobiographies by late-diagnosed autistic women (for example, May, 2018) have contributed to raising awareness generally and, in the case of some participants, introducing the idea of autism as a potential explanation for their own differences and difficulties. This was an illuminating and positive experience in general, indeed, Rosie described feeling euphoric when she first read about autistic women:

> In about 2006 I read an article in a Sunday supplement in a Dr's waiting room about women on the spectrum, how they present differently to men, and how many are often misdiagnosed with BPD. It called the women 'little philosophers' as opposed to the male 'little professor'. It was like reading about myself I felt euphoric! It was all I could think about for days afterwards, and I alternated between feeling like I had the 'answer' to all my difficulties in life and feeling foolish and that I had misunderstood the article and/or myself.

Rosie’s wavering continued until she had her first son two years later and her “reaction to becoming a parent” left her even more certain that she was autistic, at which point she sought assessment. Janet remembered researching autism in the course of her work with children in a nursery, “reading about the ways girls presented differently to boys” and thinking “ah, that explains a lot”. Jenny also came across articles by chance, and here she describes how she started to think she might be autistic after taking online tests:

> I read articles about autism in The Guardian when I lived in Germany, was pregnant, and didn't have much else to do but read news articles online ... I scored very high for systemising and very low for empathising (I realise this is flawed but it seemed important at the time), and it gave me a sense I might be autistic.

These accounts highlight the importance of positive representations of autistic women in popular media. Women are perhaps less likely to recognise themselves in Sheldon or Rainman but might see themselves in Hannah Gadsby or Christine McGuinness, hence, popular and cultural representations of autistic women are potentially a key source of information for women seeking explanations for their experiences.

However, some participants, despite often having undertaken extensive research to help with supporting their autistic children, missed their own autism or, like Rosie, were wavering, and were alerted to the possibility by family and friends. Bethan had started to suspect she might be autistic after her son was diagnosed and was told by her husband and friends “oh yeah we always thought you might be.” For Victoria, the possibility of autism had been raised both in childhood by her mum, and again in young adulthood by a college nurse, and she then spent many years “dithering over whether it would be useful to even approach anybody and whether I was ‘autistic enough’.” Autism is fairly common in Audrey's extended family, but she hadn't considered it as a possibility for herself until her husband and parents suggested she might be autistic:

> Eventually, my parents and [my husband] asked me if I realised I was autistic too. It was like a lightbulb! I had known I felt a lot of empathy for autistic people but didn't think my sensory differences and social differences etc. were 'extreme' enough for me to be considered actually autistic. Having other people say they thought I was (especially my sister, who was actually diagnosed) was weird but very validating.

Likewise, Lydia's husband suggested that autism might provide an explanation for some of her difficulties:

> My husband suggested I might be autistic about a year after my eldest daughter was diagnosed (I would have been about 34). I had never really thought of myself as autistic before that, it wasn't on my radar as I hadn't even suspected my daughter's various difficulties might be autism. We were very similar, especially in what my parents had recounted to me as 'sensitivities' when I was a child. I had a lot of routines and rituals, that hadn't really become apparent until I cohabited with my husband.

These accounts indicate that the suggestion of autism wasn't a complete surprise, as participants were able to quickly make connections between their experiences and what they knew about autism.

In contrast to having autism suggested, some participants described a more gradual sense of realisation that they might be autistic. Those participants described increasing awareness and understanding of autism as they researched autism to help support their autistic children, and how this prompted self-reflection about their own lives and introduced the idea that they too could be autistic. For both Hope and Emily, who each have an autistic son and an autistic daughter, it was specifically reading and learning about autism in relation to their daughters that prompted them to consider that they might be autistic themselves:

> I think it wasn't really until my daughter really fell off the plane at age 11. I think I wasn't as aware of female autism. My son was showing more 'normal' signs, such as having problems transitioning between tasks, so it was just about on my radar, but a friend whose son is ASD suggested PDA [Pathological Demand Avoidance] for [my daughter] and as she went through diagnosis the realisation gradually dawned. (Emily)

> Reading through the Tania Marshall [see Marshall, 2021] list when looking at the possibility that [my daughter] was autistic, there was a big Ohhhh moment. It took a long while to do anything about it though and only when butting up against professionals that do not understand my method of communication did I start the process of getting a diagnosis. (Hope)

Clare's gradual realisation was shared by her mum, as they discussed what they were learning about autism while Clare's son went through the assessment process:

> When my son was going through the 'discovery' phase - when we were trying to find out what was wrong […] things started to resonate with me. My mum and I discussed it and for us it was a bit of a lightbulb, things from my childhood made sense and it explained how difficult life had been. It was a gradual process but toward the end it was just very obvious that it fitted with my life experience and current feelings.

Clare eventually felt that "it was very obvious" and this certainty is reflected in most participant accounts, typically following extensive information gathering, research and reflection. Katharine initially "thought the criteria were ridiculous as everyone was like that" until she learned more about autism and was able to recognise her own differences, concluding that she "met the criteria as well." Like Clare, Katharine spent a long time researching and re-appraising her experiences, until she felt confident in her assertion that she met the criteria for an autism diagnosis.

Overall, participants described discovering that they are autistic in positive terms especially in relation to sense-making. When talking about their lightbulb moment, participants commonly described a backdrop of having never really understood themselves, and of now having greater insight and self-awareness. Bethan explained that it has “been a relief to be honest. A lot of things make sense, especially my eating issues when I was younger. Still have a few but I'm a lot better. I just look back and it explains a lot.” A sense of relief was also expressed by Janet, “I felt relief. Glad that I wasn't going crazy and how I felt had been justified.” A particularly positive outcome for several participants was of being able to reframe past difficulties as the result of being autistic rather than as personal failures and inadequacies. This process of “biographical disruption” (Bury, 1982, p. 169) is more commonly recognised post-diagnosis (Kelly et al., 2022; Stagg and Belcher, 2019; Wilson et al., 2022), however, the findings here, which support Sandland’s (2021) doctoral research, indicate that this process begins at the lightbulb moment and may be well developed by the time diagnosis is sought.

Sub-theme 1.2: Affirmation of my autistic identity has been helpful

Whilst I did not set out to exclude participation from autistic mothers without a diagnosis, only one participant was undiagnosed, as Bethan explained, “I don't have a diagnosis and I might try to get one although I'm not sure how it would help me at the moment other than confirming things?”. The confirming and validating nature of diagnosis is reflected in this sub-theme, where an autism diagnosis is presented as a significant sense-making experience for autistic mothers, providing a "positive turning point" (Kelly et al., 2022, p. 23) in their lives. Building on the previous sub-theme, participant accounts here explore why they sought diagnosis and how it has helped with validation as well as enhancing understanding and making sense of their experiences, and also often regret that they weren't diagnosed earlier.

Participants typically sought an autism assessment at a point in their lives when they perceived having a diagnosis as something useful, for example, both Jenny and Lydia were struggling in the workplace and pursued diagnosis as a way to legitimise requests for reasonable adjustments (as per Equality Act, 2010) and to access support at work. As Jenny recalled, "I was disciplined for fairly nebulous things and the final warning letter looked like a list of autistic characteristics (from a fairly stigmatising perspective). I felt at the time that a diagnosis might help me avoid similar situations." Audrey was initially unsure about diagnosis for herself and, like many autistic mothers, was busy focusing on her children's needs but, as she explains here, learning more about autism changed her mind:

> Initially I didn't see the point in getting assessed, partly as I was still battling to get the boys diagnosed and that was more important. I also wasn't sure what benefit there would be to getting an autism diagnosis as an adult. As I learned more about autism, I realised there were benefits to a diagnosis as an adult (self-validation, having it on medical records for eventualities when I can't self-advocate, easier access to reasonable adjustments etc.) so I started to look into that possibility.

Like Audrey, most participants sought diagnosis after their children were diagnosed, and for a variety of reasons, which is consistent with Crane et al.'s (2018) research which found that adults “reported accessing a diagnosis via a range of routes (e.g., following a crisis; following many years of experiencing difficulties without understanding the reasons behind these; following their children receiving an autism diagnosis).” (p. 3764).

When talking about diagnosis, participants often described how it helped to re-frame negative past experiences in a new light, as Katharine explained here:

> In a more personal way, receiving my diagnosis meant I could pick apart so many past issues and reframe them with autism in mind, with the executive functioning, anxiety and obsessions clarifying so many things which had been seen as me being lazy, stupid, useless.

For Katharine, the combination of her diagnosis and increased autism awareness enabled her to re-assess both her own and other people’s perceptions of herself, providing a framework and discourse – “executive functioning, anxiety and obsessions” – to better explain and articulate her difficulties. Clare described a similar re-framing, commenting that diagnosis “probably saved my life [to be honest]. It gave me an explanation that wasn’t just ‘you’re inadequate’ and it gave me the right to feel sorry for myself rather than beating myself up all the time.” Likewise, Jenny has found the affirmation of diagnosis helpful in understanding why she struggles with some things that others don’t, “I can give myself less of a hard time for not doing the things other people are able/inclined to do.” These accounts support claims that diagnosis provokes “discoveries and new explorations of self” (Stagg and Belcher, 2019, p. 354) whilst “providing a logical, scientific explanation for their experiences” (Atherton et al., 2021, p. 9), and contributed to greater self-compassion (Wilson et al., 2022), highlighting the impact diagnosis has on sense of self as participants shifted away from feeling as if they had failed to a position of greater self-awareness and increased self-worth.

Overall, participants wished they had known they were autistic or had been diagnosed earlier in life, often evoking a sense of grief, “I feel a lot of grief over my diagnosis, I think it’s related to difficulties I had throughout my life that could be explained or understood differently through an autistic lens” (Lydia). Alongside re-appraisal, some participants also expressed regret at past choices and missed opportunities, bemoaning the lack of support which might have improved their quality of life. Here, Janet reflects on her past, exposing her vulnerability and sense of failure and her belief that had she been diagnosed autistic, her life would be better now:

> Once I'd been diagnosed, I reflected on my life and the choices I made. I truly believe I'd have had an entirely different life […] it made things harder, not being diagnosed as there was no support in place for if I failed, like I failed at school, I failed at work, I failed choosing a life partner. I didn’t do very good at all when I think about it. Had I been diagnosed earlier, in my teens for example life would definitely have been easier as I would have had better support to attend school and work towards my GCSEs and I wouldn't have been trying to juggle motherhood, an abusive relationship, studying and working full time, often in toxic conditions due to bullying from other staff members.

The idea of a “different life” if she had known she was autistic earlier was also expressed by Clare, “I could have made choices” and Katharine, “I think I would have had more belief in myself”, reflecting the sense of grief expressed by Lydia. This “expression of grief” is reported by Leedham et al. (2020, p. 143) as “related to the intense pain for all they had previously endured, leading to a ‘loss’ of a life where they were understood by themselves and others.” Yet, whilst receiving an autism diagnosis in adulthood is recognised to be “emotionally impactful” and which “necessitates accommodating changes into one’s self concept” (Corden, Brewer and Cage, 2021, p. 1) there is little support available (Crane et al., 2018; Stagg and Belcher, 2019) to process the potentially “life-changing” (Katharine) implications of a late diagnosis, which can result in additional struggles with well-being and identity as newly diagnosed women are frequently left without support (Harmens et al., 2022).

However, some participants were offered post-diagnosis support, including individual and group sessions, though those who chose to attend had mixed feelings about the experience. Katharine attended “2 face to face appointments with the diagnosing psychologist. She recommended some books, talked about how to overcome common difficulties, discussed PIP in case I wanted to claim”, Rosie was offered either individual or group sessions and chose “group sessions because I wanted to meet other people like me. It turns out we were all very different!”, and Hope attended a group which also included people recently diagnosed with ADHD where she “had a meltdown as one lovely girl talked very fast, and I could not process it all in time”. Jenny was reluctant to attend mixed-sex group therapy with people, “especially men”, that she didn’t know. Whilst participants who received post-diagnosis support found it broadly useful, and were grateful for the opportunity, there is a sense that it could be targeted better, and that groups for mixed-diagnoses and mixed-sex might exclude some newly diagnosed women.

Post-diagnosis support, typically provided shortly after diagnosis, also fails to take account of the often-lengthy reflection and sense-making process experienced by the late-diagnosed. As Lydia points out, diagnosis can result in mixed feelings:

> I feel very torn about my diagnosis, it has made sense of a lot of things, but I don't feel in a way that is meaningful enough to improve my material existence. I still feel 'not autistic enough' but too autistic to be around normies.

It takes time and requires space to reflect in order to process and make sense of being diagnosed autistic. Katharine, diagnosed a number of years ago, told me that "it took a good 2 years to work through my past and be able to accept myself", whilst relatively newly diagnosed Hope explained how "I was undiagnosed for half a century, one year is not long enough to unpick it". Moreover, as late-diagnosed autistic mothers are likely to be processing their own diagnosis alongside supporting their children with their own diagnoses and support needs, it would be beneficial to provide supportive space and time for mothers to explore the implications of diagnosis.

Sub-theme 1.3: I didn't recognise the red flags

A significant part of the sense-making process for some participants involved reflecting on experiences of vulnerability and abuse because, as Anna suggested, "many autistic people, no matter the intellectual ability, are easily manipulated". Upon self-realisation or diagnosis, participants often began to re-frame their victimisation experiences using their knowledge of autism, for example, as Jenny explained, "I have no doubt that my life as an autistic woman and an autistic mother has been far more fraught with vulnerability, sexual violence, domestic abuse, legal difficulties, anxieties and immense struggles in comparison to the average woman." This sub-theme, therefore, focuses on the ways that participants make sense of these vulnerabilities through recollections of exploitation and victimisation, and also draws attention to the added risks faced by autistic girls, women, and mothers.

When discussing their experiences of vulnerability, participants sometimes framed this within a context of trying to make friends and develop social networks. Whilst a broader analysis of 'fitting in' will be explored within the next theme, within this sub-theme it helps aid understanding of the ways participants frame their vulnerabilities (as per Gibbs and Pellicano, 2023). Here Clare describes the "massive advantage taking" she experienced when trying to make new 'mum friends' which resulted in her being used for before and after school care for two of her son's school friends:

> I can't tell the subtlety of friendship, acquaintance etc. and I [rely] on what I've learned through observation or experience. So, for example, my house was convenient for three kids to walk to school for secondary. Two were dropped here and the third was mine. Within a week I was providing biscuits and PlayStation time to kids whose parents collected them later and later. One started leaving kit here while he went to a club up the road and then collecting it afterwards - so he stayed 'til 5, went to the club and mum would collect his kit at 7. Massively inconvenient.

In Clare's account there is a recognition that struggling to understand other, non-autistic, people's motivations is difficult for autistic people (Gibbs and Pellicano, 2023; Pearson et al., 2022), which aligns with the double empathy problem (Milton, 2012a), but even once Clare had recognised that she was being used, she found it hard to extricate herself from this escalating responsibility. This accords with Sedgewick et al.'s (2019) research which found that autistic women "were often much more vulnerable to exploitation due to difficulties with interpreting others' intentions" and "found it more difficult to manage social conflicts and challenges" (para. 42) but importantly, that this became easier as they aged, demonstrating that there is scope for learning how to navigate challenging friendship issues.

There were many concerning accounts of vulnerability and victimisation provided by participants who had experienced sexual abuse and exploitation, echoing the findings in Bargiela et al.'s 2016 research where they found a "shockingly high incidence … of sexual abuse" (p. 3288) in their sample of autistic young women, and a recent French study which found that nearly nine out of ten autistic women had been victims of sexual violence (Cazalis et al., 2022). Janet talked about her teen years and trying to 'fit in' with the "cool kids", feeling pressured to use cannabis and how "when I was 14, I honestly believed the 19-year-old I was seeing was in love with me and not just after sex with a gullible young girl". Several participants talked about 'missing signs' of abusive or potentially abusive behaviour, the eponymous 'red flags' of this sub-theme, and how this increased their vulnerability. Hope told me that she is "worried about predatory men. If you don't pick up the signs, you are going to get in a whole heap of trouble. I have had a run in with some predatory men. I worry about [my daughter]." Bethan described being "too trusting":

> I also think I've been taken advantage of in the past by men. I've had some horrible exes and now I can look back and see I've been too trusting and I just completely miss signs. I expect that's a lot of neurotypicals experience too, but I do seem particularly bad at spotting these people so I'm very careful since.

What is evident in these accounts is that autistic women, in missing signs that might be more apparent to non-autistic women, appear to have an added disadvantage in determining other people's motivations. It is important to note that participants quoted in this sub-theme often blame themselves for missing signs and failing to assert boundaries. This does not mean that their victimisation was their fault, and I agree with Cazalis et al. (2022) who state that:

> Suggesting to a victim that she should have learned how to better state her personal limits is not fundamentally different than telling her that her skirt was too short. Be it in a more benevolent and well-intended way, it is as hurtful and unfair. (Cazalis et al., 2022, p. 16)

Whilst widescale social change is necessary to eliminate sexual violence, the stories told here provide an opportunity to reflect upon the particular vulnerabilities of autistic girls, women, and mothers, and how improved awareness of risks and vulnerabilities by family, caregivers and professionals might reduce victimisation (Cazalis et al., 2022; Gibbs et al., 2022). This is especially important as autistic people are at greater risk of violence than non-autistic people (Gibbs et al., 2022), are more likely to have experienced domestic abuse (Griffiths et al., 2019), and autistic women are at greater risk of violence than other disabled and non-disabled women (Cooke et al., 2022).

Furthermore, it is widely accepted that predators are often highly skilled at identifying vulnerable women and girls, and that "most offenders are smart predators, who are very aware of what they are doing" (Cazalis et al., 2022, p. 16). An added risk, highlighted here by Victoria, is that the signs, the non-verbal cues and body language, that we project might be mis-read:

> Other people assuming me to be NT ended with me in difficult situations particularly sexual situations where I hadn't read the signals correctly. Either the other person had assumed I was NT and was responding to their unspoken communication, or they knew I wasn't and recognised me as vulnerable. I try not to dwell on the likelihood of the latter.

Victoria's experiences demonstrate the two-way nature of the double empathy problem (Milton, 2012a). It isn't just that we autistic people struggle to fully understand non-autistic people, but that non-autistic people also struggle to understand us and, as a result, might mis-read our intentions and, indeed, our discomfort or distress. This reflects Bargiela et al.'s (2016, p. 3290) finding that "some women believed that a tendency to mimic others and prioritise fitting in above their own needs had led them to be manipulated and abused by others: and had caused others not to notice their needs for help." An implication of this struggle to articulate our distress is that it might be misinterpreted as consent.

As well as sexual abuse, some participants shared their experiences of domestic abuse. Janet, who had experienced sexual abuse as a child and was a victim of domestic violence as an adult, reflected on how learning she was autistic and recognising her social difficulties enabled her to identify abusive behaviours in her relationship with her children's father:

> I don't think I'd have ended up with the children's dad had I realised and had support, as it was only after I was able to see he'd spent all those years abusing my difficulties with social interaction and my taking things at face value.

Janet's experience of repeat victimisation is not uncommon among autistic people (Cooke et al., 2022). Her belief that support might have prevented victimisation is also supported by Cazalis et al. (2022) who state the importance of "[e]ducating families and professionals about the risk of sexual victimization of girls on the autism spectrum" (p.17). The difficulty with this, of course, is that many girls are not recognised or diagnosed as autistic until later in life, missing a vital opportunity for pro-active support.

In general, participants worked it out for themselves that they had been or were being exploited or victimised, extricating themselves from abusive situations with little or minimal professional support. Anna told me that it took her daughter making a report to the police for her to fully recognise her own experience of domestic abuse because she "didn't recognise the signs, the so-called red flags that allistic[10] people seem to pick up." She provided a useful insight into how autistic girls are socialised into accepting abusive and exploitative relationships:

> Some of this starts at a young age and is not thought about in schools, Jane Eyre is not a romance and it by no means feminist, but that is not what's taught. Wtaf, Rochester destroys his wife, locks her up commits bigamy 'for love' of the governess he has employed to teach his bastard child (to demonstrate some morals) and she goes back to him ... Bella in Twilight accepts Edward climbing in her bedroom window and watching her sleep. Heathcliff a violent thug. Here is where we need to look, at how many autistic women spent their break time at school reading, and this is what we are given to read because the librarian sees girls.

In drawing attention to this, Anna explained how girls and young women are set up to accept abusive behaviours as normal:

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[10] Non-autistic.

> We stay because we are not aware that we are being abused, it was my daughter that initially reported it. We stay because we don't know we have options … The simple answer to staying is for the sake of the children, but in a situation whereby the majority of the household is autistic it is far more complicated.

In making sense of her experience, Anna highlights the added complexity for autistic mothers of autistic children living with an abusive partner, a vulnerability which can continue even after separation, as Jenny who explained, "having children meant my ex could keep controlling me and my parenting decisions were under a lot of scrutiny … I think having children made me very vulnerable. The implications of the participant experiences explored within this sub-theme are that not only does being autistic and female increase vulnerability and victimisation, but that the combination of being autistic and a mother presents further vulnerabilities and opportunities for victimisation.

Summary and conclusion

This theme has explored how participating autistic mothers learned to 'think autism', that is, to re-consider and re-interpret their lives and experiences in the context of being autistic, of knowing themselves to be autistic, and how this resulted in better understanding of themselves. Participants recalled the lightbulb moments which prompted them to consider that they might be autistic and how this resulted in a sense-making process as they came to terms with the possibility or likelihood of actually being autistic. For some participants the lightbulb moment was a sudden realisation and for others it came after careful consideration, generally occurring after their children were recognised or diagnosed as autistic. Positive representations of autistic women in the media were highlighted as important sources of information for women who might be unaware of or considering they might be autistic. Moreover, realising they were autistic typically resulted in a sense of relief for participants, providing a positive ‘turning point’.

Following the lightbulb moment, most participants pursued a clinical diagnosis of autism. Participants discussed their reasons for pursuing a formal diagnosis and, on the whole, diagnosis was sought at a point of convergence between being confident that they were autistic and believing that a diagnosis would be a useful thing to have. Diagnosis was typically sought for personal validation and affirmation and/or to enable access to adjustments and accommodations in the workplace or when accessing healthcare and other services. Importantly, diagnosis often prompted further sense-making as participating mothers learned more about being autistic as they continued to examine and interpret their experiences through an autism lens. These reflections sometimes resulted in regret at the loss of a different life had they known earlier, and participants highlighted the lack of support to help process their diagnoses and the associated thoughts and feelings. For some participants, re-appraisal of their experiences of victimisation was a significant part of the sense-making process, where accounts of exploitation within friendships, sexual abuse and domestic abuse, highlighted the additional vulnerabilities of autistic women and autistic mothers.

My analysis in this theme has illuminated the multiple ways in which recognising themselves to be autistic, which is often aided by the legitimisation and validation of a clinical diagnosis, was both disruptive and sense-making as participants learned how to think of themselves as autistic. In the next theme, I will build on this through an exploration of masking and how participants come to terms with being autistic.

5. Theme 2: Masking is a real double-edged sword

Introduction

Building on the previous theme which considered how participants began to see themselves as autistic, the impact this had on their identity and the subsequent sense-making this prompted, this theme considers participant accounts of being autistic, through an exploration of masking, camouflaging and other compensatory behaviours and the ways in which these interact with motherhood. Across the dataset, participating autistic mothers reflected on their experiences of masking and camouflaging and the impact on their lives and experiences as autistic women and mothers. In the first sub-theme 'There's a lot of pressure on mothers to 'fit in'' participants with a strong history of masking describe their attempts to un-learn conforming and camouflaging behaviours and the impact on their sense of self and identity. Building on this is a consideration of the double burden of masking to fit in faced by autistic mothers who mask both for themselves and for their children. The second sub-theme 'I'm the queen of camouflaging' explores the utilisation of strategic masking by participants as a form of impression management and how, whilst the idea that masking is detrimental is reflected across the dataset, participants also consciously and strategically use masking behaviours when prudent, typically to benefit their children.

Sub-theme 2.1: There's a lot of pressure on mothers to 'fit in'

This sub-theme considers experiences of masking, camouflaging and other compensatory behaviours, how these have been used by participants to help 'fit in', and how this impacts their experiences as mothers. Participants told me how they had a lifetime’s experience of masking, supporting Miller et al.’s (2021, p. 336) finding that “masking often began in childhood”. Furthermore, they were often unaware of the extent of their masking, as Janet explained, “masking is something I did so often I didn't even realise I was doing it anymore.” Participants reflected on their attempts to, as Hope said, “fit in and be normal”, to avoid being seen as difficult, weird, or rude, highlighting the stigmatised and negative connotations of observable autistic behaviours. This was elaborated upon by Victoria who “used to think [masking] was a good thing, that it enabled me to "fit in" and "act normal" which was important to me after years of being told I was a weirdo, a saddo, needed to get a life, etc.” Whilst learning they were autistic helped participants to make sense of their lives (see previous theme) and contributes to a positive identity (Botha et al., 2022), it is clear that masking compensates for the stigma of being different as much as it compensates for the stigma of being autistic.

Stigma can be defined as “a special kind of relationship between attribute and stereotype” (Goffman, 1990b, p. 14) which is “socially discrediting to the individual” (Milton, 2013, para. 19) and is an important consideration here as it is strongly linked to masking (Perry et al., 2022). Moreover, learning that you are autistic and, therefore, belong to a stigmatised group later in life, can be particularly disrupting for, as Goffman (1990b, p. 48) points out “such an individual has thoroughly learned about the normal and the stigmatised long before he must see himself as deficient.” It is unsurprising, then, that masking, and participant awareness of masking, has resulted in confusion around identity and sense of self. As Audrey explains:

> [Masking] affects my sense of identity. It's hard to know who you are when you're constantly being a you that you think others will accept. Do you really like the music you like? Do you really like the clothes you wear? I have a much better sense of myself these days but did struggle for a long time.

The idea of not knowing who you are was also expressed by Emily, “at times it means I’m not really sure who I am or what I really think” and Hope, “I am not really sure of who I am”, with Victoria worrying, “that under the mask there isn't much of 'me' left”. This can be quite destabilising, as Lydia explains:

> I have been in therapy for almost a year, and I am starting to learn that many of my behaviours are so ingrained I was unaware of them. Masking leads to so much anxiety for me, I have recently realised a lot of the bad feelings I get are actually from masking, and not being my authentic self.

Not being her “authentic self” is clearly a source of great distress for Lydia as she comes to terms with her autistic self. As Cage and Troxell-Whitman (2019) found, the sense of disconnection resulting from camouflaging, either all of the time or some of the time, results in increased levels of stress, and this is apparent here.

For most participants, trying to fit in started in childhood, and learning about masking has resulted in some participants re-evaluating their past efforts to fit in, for example, Claire, who described herself as “always disliked”, struggled with friendship difficulties and bullying at university:

> I kept trying to be friends with the popular crowd ... I just didn’t know what I was doing wrong or how I wasn’t the same as them … I just didn’t understand why I couldn’t make friends and fit in and I kept trying and trying to mould myself to fit in.

Clare’s use of camouflaging and masking to fit in and avoid bullying and social exclusion is common among autistic people (Cage and Troxell-Whitman, 2019), who also use mimicry as a way to fit in (Bargiela et al., 2016) and to pretend to be ‘normal’ (Holliday Willey, 1999). Janet described her strategy of copying the “cool kids”:

> I would adjust my behaviour and copy those I thought were doing the right things, so I'd fit in better ... I thought everyone copied other people, so I copied who I thought were the cool kids because I wanted to be cool and popular and have friends. It backfired. They realised I was just mimicking their behaviour.

Despite her careful studying and attempts to imitate the behaviours of the popular kids, Janet was unable to emulate their social success, thereby drawing attention to her difference, and resulting in further social exclusion and increased isolation. In contrast, Victoria explained how she uses mimicry as a means to improve her own communication skills, “I don't know how to assert boundaries so I borrow / mimic words and stance from those who do. It's a work in progress so one day I hope to be able to do it without the masking!”. The mimicking behaviours described here reflect a distinction between *social* imitation, copying as a way to improve social integration, and *instrumental* imitation, copying as a way to learn skills (Over, 2020), with motherhood presenting new pressures to socially integrate and develop new skills to facilitate social acceptance and avoid stigma.

One area of particular pressure for participants to fit in was in relation to their children. Participating mothers talked about not wanting to stand out, and wanting to be accepted so their children wouldn’t be isolated or miss out on opportunities. As Victoria explained, “there is pressure from other adults to be 'normal,' but also from children towards our children, and that triggers an urge to protect them by not being too weird" acknowledging the stigma around being autistic. Most participants experienced similar motivations to try and fit in at the school gate, as a way to support their children fitting in and to ensure their children's social needs were met. An important factor in trying to fit in relates to networking among other mums which, as Jenny explained, is key to gaining useful information and support:

> I also found it hard to integrate within school-gate social groups etc. and this does cause difficulty with support network, information-sharing, parties etc. Mums would invite me for one cup of coffee and that would be it ... I felt I never had a tribe.

Likewise, Clare described the isolation she experienced as a result of not fitting in with the other mums:

> Being autistic and a parent, especially when they were in primary, was awful and isolating. I just wanted to have them invited to parties and play dates and as I didn't have easy friendships they didn't get that. At that age it seemed like the parents led the friendships … I didn't have that easy school gate thing so my kids didn't get invited to play dates or parties in the early years where it's about the parent friendships ... so stressful to just walk in, stand waiting (do you smile? Do you talk to someone?) and then leave. I cringe when I think how often I suggested a coffee or a catch up and never having it accepted.

As Jenny and Clare explained, not fitting in as a mother can result in our children losing out on social opportunities, creating an additional pressure to mask. Heyworth et al.'s (2022, p. 9) research into the lockdown experiences of parents (95% were mothers) suggested that it was "doubly damaging for their well-being" for parents to be "masking for their children as well as themselves."

Some participants did manage to reduce this double burden of masking, for example, Rosie described initially forcing herself to interact with other mums, because she felt she had to and that it would benefit her children:

> Social interaction at playgroups and school has always been incredibly stressful, but I've forced myself to do enough to facilitate the children's social lives. Beyond that I no longer bother. I did baby groups when they were little because I thought I should and I'd read and been told that children need socialising. It was awful and looking back I wish I hadn't done it. I felt so anxious and inept every time and I think the children would have benefitted far more from having a calmer happier mum than social interaction with other toddlers in a noisy overwhelmingly busy church hall.

Rosie managed to find a balance where she could “do enough” to benefit her children, but not so much that she was overwhelmed and anxious. Similarly, Janet has found a way to facilitate her children’s social lives without compromising her own well-being:

> I don’t have a group of school mum friends, and a lot of the other mums avoid me as I'm the strange one who doesn't follow the latest fashions, arrives at the exact same time every day, has birthday parties in her home instead of soft play or trampoline parks (as I don't cope with crowded places, it's easier for me to host at home) I don't initiate conversations with the other mums unless I'm asking one of the ones I get along with if the children can have a play date, and I only speak to them because they spoke to me first! So, I'm definitely seen as different to them and avoided.

Finding ways to ameliorate the double masking burden of motherhood, as demonstrated here by Rosie and Janet, has the potential to significantly improve the well-being of autistic mothers. Furthermore, without a model for what mothering well autistically might look like, autistic mothers are reliant on normative constructions of motherhood, increasing the pressure to mask and camouflage their autism and making it harder to forge their own autistic paths.

Sub-theme 2.2: I'm the queen of camouflaging

This sub-theme explores how, despite wanting to desist from camouflaging and masking their autism, and recognising such behaviours as harmful, participants paradoxically considered masking to be a potentially beneficial skill in some situations. Victoria, for example, is very aware of the impact of long-term masking, having masked extensively for many years until she experienced burnout, but continues to use short-term strategic masking where she feels it will benefit her daughter:

> So, the ability to manage those social relationships and social situations without being too obviously autistic struck me as a good thing. I changed my mind on that after a major autistic burnout which was the result of too many years of masking … So I would say masking is useful as a short-term emergency measure - like at a children's party where you just have to manage for an hour or so - but it ended up being very poor for my mental health in the long term.

This strategic form of masking, deploying masking behaviours as a means to an end, is presented as particularly useful when supporting and advocating for our children. However, rather than masking primarily to avoid stigma and to fit in on a more social level, as discussed in the previous sub-theme, here masking is used as a more explicit and strategic form of "impression management" (Goffman, 1990a, p. 203) and as a way to project credibility and competence.

Whilst camouflaging and masking behaviours are types of impression management (Schneid and Raz, 2020), for some participants there was a qualitative difference between masking to fit in and the use of strategic masking to achieve goals. Participants discussed ways they had used masking strategically, with varying results, some more successful than others. Audrey was one of the participants who found ways to effectively use masking as part of a toolkit of strategies to make life easier, telling me how she has found masking to be “incredibly beneficial” for some situations:

> Despite the fact I don’t think autistic people should have to mask, I do think my ability to mask has been incredibly beneficial to me. It means, for instance, I have always tended to do well with things like interviews.

Like Victoria, Audrey is able to deploy short-term strategic masking when she thinks it will be useful and productive. Clare suggested that “masking is fine for conferences, work meetings, one off events. I can do a really good impression of normal and confident. But I’m a one trick pony” demonstrating how masking like this is unsustainable for longer periods. Interestingly, Rosie describes being better at masking since learning about masking:

> [Masking is] very useful in many situations. At work, or with friends, when meeting new people etc. I actually don't know how not to mask in those situations anymore because I've been doing it since I was about 3. Now I'm aware of doing it and the reasons why, I'm even better at it.

Such experiences, of re-framing masking as a positive and useful skill, supports the claim made by some participants in Schneid and Raz’s (2020, p. 5) study that “impression management was seen as a legitimate, although contrived practice”, in comparison to camouflaging which was considered coercive.

This does not mean, however, that any type of masking, camouflaging or impression management behaviours and actions are benign. Such acts are almost certainly underpinned by an awareness that failing to appear socially credible will be more harmful than the exhaustion such masking typically generates. As autistic mothers of autistic children, presenting as a credible informant in relation to our children's needs has the potential to result in access to support and services which vastly improve theirs and our own well-being. In such instances, then, we might view the trade-off as worthwhile.

Indeed, wanting to be seen as a credible informant and a competent parent and advocate was a key motivator for participants actively choosing to mask. Hope, still working through her diagnosis, talked about how she adjusts her communication style and masks to appear "normal" at her children's school:

> I really have not worked out how much I mask. I think I do, having answered some questions. I want to be seen as normal to school so I think I must try to mask, still working diagnosis through. I think I try to be less direct and to the point in emails but probably not enough.

Janet, who has worked with pre-school children, faced similar pressures to mask in her workplace and when out with her own children. She described how, despite masking less than she used to, she still masks as a way to appear less "strange" and to prevent being stared at:

> I do still mask in certain social situations ... Definitely for work. I didn't want to come across as strange to the parents leaving their children in my care. I worried they'd demand another key worker for their child, despite me being perfectly capable ... Now I don't mask as often, it exhausts me when I do and I need a few days to recover afterwards but I know that now and can factor that in for if I need to mask, for example going to the zoo with the children, I mask there so that people don't stare.

In both accounts, there is an awareness of the stigma around being autistic, of wanting to *be seen* as “normal” and not “strange”, but also of making an active choice, albeit somewhat of a Hobson’s choice[11] in the circumstances.

Participants described mixed experiences of strategic masking. Lydia considered herself to be an effective masker, explaining how “masking is good because it keeps people away from me and makes me look like I have high levels of competence and this is also why it is bad!”, and, likewise, Emily told me that she is the “queen of camouflaging” able to “integrate into any group I am interested in and usually find/talk to/identify which people are the important ones.” Such accounts are consistent with Leary and Kowalski’s (1990) observation that:

> When a person is dependent on others for valued outcomes, the impressions he or she makes on them are more important, and the individual will be more motivated to engage in impression management. As a result, people are more likely to ingratiate themselves with their bosses and teachers than their friends and more likely to ingratiate these authorities when they have greater power to dispense valued outcomes. (Leary and Kowalski, 1990, p. 38)

Participants were very aware that how they presented matters, however, as Lydia explained, this can come at a cost, “I am also a very direct communicator and well-practiced at masking my true feelings, so while I was effective with school and LA staff, I was not liked.” It is possible that despite our best efforts at masking, other people still sense something different about us. And, as Katharine reflected, her efforts at conforming were not always “convincing”:

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[11] A situation where there appear to be different options to choose from, but where realistically there is only one option available.

> There are times when I try to conform, mostly when the children are involved as I don’t want them to think I’ve let them down somehow. This is a choice; it now doesn’t come naturally at all and feels fake and exhausting. I don’t think it’s convincing either.

Others, despite believing they were not really successful at masking, still felt compelled to try, as Jenny told me:

> I'm not a particularly good masker. I think I might have managed at some points in my life, to a degree, but not really as an adult. I do a similar thing like 'trying to force myself to conform to what is expected of me' but it is more about my behavioural choices than how I present in terms of gesture, affect, voice tone, personality etc. When I did mask, I was suicidal so I'm not sure it suits me.

While other participants appear to have found ways to ameliorate the impact of strategic masking, for Jenny it effected a considerable toll on her well-being, reflecting the results of Cage and Troxell-Whitman’s (2019) research, which found that part-time camouflaging was equivalent to full-time camouflaging on anxiety and stress measures.

Ultimately, all masking, camouflaging, compensatory and impression management strategies have an impact in one way or another. Yet, whilst acknowledging that “camouflaging may lead autists to gain a greater level of survival in a non-autistic society … non-autistic persons remain oblivious of the mind of the ‘autistic person’” (Shneid and Raz, 2020, p. 7), as mothers we want to do the best for our children and, at times, this means putting our children’s needs before our own well-being.

Summary and conclusion

This theme has considered participant experiences of masking both as a way to fit in and as a potentially useful skill. Participating autistic mothers described how masking often began in childhood and how they were often unaware that they were masking until much later as part of the sense-making process of realising they were autistic and learning about autism. Participants recalled how during childhood they had copied, both consciously and subconsciously, the popular and successful children as a way to fit in and to avoid being bullied, and how these often-entrenched masking behaviours continued into adulthood as a way to avoid being seen as weird, rude or difficult, and to avoid the stigma of being different. Participants discussed how a lifetime of masking had resulted in distress and identity confusion and a sense of not knowing or of having lost their true self. Perhaps unique to autistic mothers, as we are typically the main carer for our children, participants demonstrated a double burden of masking as they were often compelled to mask for themselves and for their children. As well as masking to fit in participants also described masking as a useful skill, particularly in relation to dealing with professionals and when advocating for their children. In this context masking was presented as a means to an end, and where a lifetime of developing masking skills could be put to good use by autistic mothers to benefit their children. As a form of impression management, this strategic, and highly conscious and tactical, form of masking was still exhausting but appeared to be considerably less impactful on identity and sense of self for most participants.

My analysis in this theme has demonstrated the significant role of masking in participant lives and how it results in tensions which are perhaps unique to autistic mothers who mask not only for themselves, but also to benefit their children. In the next theme, I will be exploring participant experiences of support, where masking is often a hurdle to accessing support, and how participants have found ways to create their own support networks and learned to un-mask among other autistic women online and in-person.

6. Theme 3: Women like me ‘fall through the gaps’ of support

Introduction

The previous themes have illustrated how participating autistic mothers navigated the realisation that they were autistic, and of coming to terms with being autistic, which was often done without external support. This theme considers participant experiences of needing and accessing support. Reflecting Camm-Crosbie et al.’s (2019, p. 1439) findings that less than half of their autistic participants received the support they needed for “mental health, mentoring and social activities”, participants here articulated a frequent dearth of quality support. Participant experiences of accessing support will be explored in the first sub-theme ‘It’s hard to get support from anyone who understands my kind of autism’, where the complexities of accessing support as an autistic mother of autistic children are discussed with reference to burnout, misdiagnosis, and masking, alongside a consideration of increased autism awareness, the right to reasonable adjustments and concluding with examples of good practice. In the second sub-theme ‘I’ve had to make my own support network for myself’, participants share experiences of how they have filled the gap left by the lack of formal supports with informal and community-based support networks and through practising self-care.

Sub-theme 3.1: It’s hard to get support from anyone who understands my kind of autism

This sub-theme focuses on the complexities around participant experiences of support. Participating autistic mothers identified burnout and masking as important factors in relation to support needs and provision and discussed their experiences of different types of support and requesting reasonable adjustments to facilitate accessibility. Getting support right is important as bad experiences can push autistic mothers away from services, both for themselves and their children, as articulated by Katharine:

> Every time I've had contact with a professional it's pushed me further away from being able to access any help, even during times when I really wasn't coping. This also means that my children aren't accessing support that they need.

As discussed in Chapter 2, there is plentiful research into the well-being and support needs of assumed non-autistic mothers of autistic children, but this fails to take account of the different, and potentially more complex, support needs of autistic mothers of autistic children (Dugdale et al., 2021; Pohl et al., 2020).

A significant indicator of the paucity of support available and accessible to autistic mothers of autistic children is the number of participants who experienced burnout. Autistic burnout can be characterised as "a long-lasting pervasive state of exhaustion, loss of function, and reduced tolerance to stimulus that is conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate support." (Raymaker, et al., 2020, p. 141). Here, Victoria provides an evocative account of her experience of burnout:

> The burnout is hard to describe. I don't recognise signs of stress in myself very easily until it passes and then I am able to say, "I must have been stressed because I suddenly feel able to breathe / think." But I will have a go. It felt as though I was under siege. I was constantly fighting against overwhelm and I thought this was just how people felt when they were "busy at work." I was very tearful and spent a lot of periods of time dissociating. I could sit in front of a screen for hours with

> my brain whirring but unable to move my hands to type. I had a lot of shutdowns. I was anxious to the extent of having frequent suicidal thoughts. It didn't occur to me to see my GP because again I thought this was just how people felt when they were "busy at work." I couldn't manage the social relationships in the workplace or the way it was structured, or the unspoken expectations, all of what I now know were masking techniques just failed. Eventually - thank goodness - I was fired and I spent a couple of months at home mostly sleeping, I felt so tired my bones were heavy.

It is evident that the impact of this burnout on Victoria was extensive, such that she became incapacitated by overwhelm and unable to work. Other participants also experienced lengthy periods of burnout, for example, Rosie told me:

> I've had 3 MH crises since becoming a parent due to autistic burnout and needed therapy, medication and an Early Help key worker to get myself and family life back on track. Because there are so few resources for autistic parents it has been trial and error and, at times, disaster, before finding effective ways to cope.

Lydia recounted a similar experience:

> Every call threw me off my axis and I was finding it hard to cope emotionally. I started getting bouts of labyrinthitis. I was constantly stressed and deflecting repeat attacks on me from education services. I look so strong to everyone but inside I am just constantly crumbling and a seething mass of emotions I don’t really understand ... serious health problems started that have escalated for the last four years to the point I have completely withdrawn from my MA, have no life outside of my family and am virtually housebound. I am about to employ a PA through social services for 22 hours a week because I can no longer care for myself.

These accounts, describing participant experiences of burnout, are consistent with previous research on autistic burnout (Raymaker et al., 2020; Mantzalas et al., 2021), and demonstrate the extent of harm which can result from unmet support needs.

A further harm evident in the literature, and particularly pertinent for autistic women, is of misdiagnosis (Gould and Ashton-Smith, 2011; Gesi et al., 2021). For Audrey, the combination of masking, unmet needs and of not knowing she was autistic resulted in a diagnosis and treatment for depression:

> I do think [masking] has affected my mental health. I think it has led to 'autistic burnout' several times throughout my life. I was diagnosed with depression, but I do often wonder whether I have ever truly had depression or whether it's always been burnout. I feel fairly sure that there are times when having my sensory needs met, having some help with executive functioning skills, and a better general knowledge of the fact I was autistic and what that meant, would have made a huge difference. And I think it's why antidepressants have never really helped long-term, and I just kept getting my dose upped - because it wasn't depression.

Recognising the difference between depression and autistic burnout, which Audrey had to work out for herself, is important if autistic people are to get appropriate support. As Raymaker et al. (2020, p. 141) found in their autistic burnout research, whilst "[d]escriptions of autistic burnout share some superficial similarities to depression [they] strongly believe that it is a distinct condition." Furthermore, and adding weight to the importance of recognising autism, strategies for coping with burnout might be different for autistic and non-autistic people. Whereas for typical burnout, avoidance is considered maladaptive, and recovery requires actively addressing the stressors, autistic burnout might actually be better served by avoidance and withdrawal as a way to restore and replenish, in the form of "adaptive attention" (Mantzalis et al., 2021, p. 10), and some examples of how participants have managed to carve out time to accomplish such recovery and replenishment are provided in the next sub-theme.

Masking was identified by most participants as a barrier to accessing support and this appears to link to the fear of being judged. A fear of judgement can result in autistic mothers masking as a way to present as competent and capable but in turn this means that issues of well-being and support needs are hidden. This tension was articulated by Lydia, "Women like me 'fall through the gaps' of support as I am not under mental health services, or any others and I manage well enough to be functional at great detriment to myself and my own mental health", who also described her experience with counselling:

> I think trauma and autism have created a massive repression in me, mixed with self-blame and intrusive thoughts. Because I hold all of this in, I don't see how I can ever get help for it. I have been seeing a counsellor for about 8 months but even this just sends me a bit batty, because I have to talk about emotions and I don't understand my own, let alone anyone else's. I think I have adapted cognitively to show outwardly I am fine and social and this in itself is a barrier to being understood or helped with things. I also find it hard to get support from anyone who understands my kind of autism (e.g., masking), and I don't feel heard in most therapeutic spaces.

Essentially, participants are stuck in a double-bind situation, wanting to be seen as doing fine, or habitually presenting as fine, suggesting that there are no support needs, whilst continuing to mask their often-considerable struggles with coping and well-being. As Camm-Crosbie et al. (2019, p. 1438) point out in their study of autistic adults' experiences with accessing mental health support, "assumptions were made about autistic people being 'high functioning' and perceived as coping when in fact they were struggling." Moreover, this doesn't just apply to mental health, as Audrey's encounter with a specialist dental service illustrates:

> There is a service locally that I qualify for because I'm autistic and it would be a much more accessible service for me than registering with a typical dentist.

> However, because the dentist there knows me as the mother of two of her patients and I have masked during appointment, she is insisting I get a letter from my GP to access the service and keeps mentioning how it is for ‘people who really need it’.

The inability of the dentist to see past Audrey’s masking behaviours demonstrates the effectiveness of Audrey’s masking. Masking helped Audrey with getting her sons’ needs met, but it made it harder for her to have her own need for support acknowledged. This highlights how poor understanding of autistic behaviours and presentation can result in additional barriers to support (Camm-Crosbie et al., 2019), even in specialist services.

Participants reported on increased autism awareness and were often grateful when support was provided without asking, especially as they often found it hard to ask for support. However, despite increased autism awareness leading to more service providers making efforts to encourage and support autistic access, some participants questioned the extent to which this results in genuine inclusion. Bethan commented on special events for autistic children, “like dinosaurs at the natural history museum for autistic kids. They are always at the crack of dawn! I feel bad as at least they are trying but we aren't vampires”, and Hope, a lone parent, described being “wary of places that say they offer support but actually only provide something that is rigid one size fits all”. She provides an example of her experiences with two churches:

> Old church had a notice up on the wall about how parenting was hard, and people needed support, yet as a single parent of disabled children none of this so called support was available as there was no other parent at home to allow me to attend the groups in the evening, nor the seminars they went on, nor join in with the group when they moved to meeting one week a month outside ... New church has been a lot more helpful and supportive, despite never claiming that this is what they would do. The little old ladies at the post service cafe exuded such love and

> care and understanding. They got me through one of the most difficult periods of life so far.

Hope's mixed experience echoes Waldock and Forrester-Jones' (2020) research exploring the attitudes of ministers and churchgoers towards autism, where they found evidence of both supportive and derogatory attitudes regarding autistic people. Hope's account also indicates that formal supports can sometimes be less accessible and effective than informal supports, which are more likely based on flexibility than a one-size-fits-all approach.

One route to accessing individualised support is by requesting reasonable adjustments under the provisions of the Equality Act (2010). Participants most commonly requested reasonable adjustments to support communication needs. It's not unusual for autistic people to struggle with anxiety when using the phone (Howard and Sedgewick, 2021) and Katharine asks "for texts/emails rather than phone calls, but this rarely happens sadly!". Janet, who has long struggled with her mental health, describes how she has not met her psychiatrist of three years in-person despite "being under the early intervention team for the last 3 years. My last interaction with him was a phone call despite myself and my care coordinator both telling him I struggle with phone calls". Lydia, describing her difficulty in communicating the seriousness of her medical needs, reflects on whether being known to be autistic is enough to warrant understanding of the need for adjustments in communication:

> I was thinking about how hard I find dealing with the medical profession, how often my symptoms get written off as anxiety when they are tangible and physical. Especially my heart condition, despite being hospitalised with heart rate of 210

> twice, GPs would still prescribe beta blockers for anxiety. It's making me wonder what would happen if I asked for adjustments in a more formal way rather than relying on saying 'I have autism' and expecting help. I suppose that in itself is wrong, as there should be enough understanding of the condition to know that I will at least struggle in some way with social communication!

Her experience indicates that being known to be autistic is, indeed, probably not enough by itself, that she is actually expected to be explicit about the adjustments she needs. This aligns with the results of Brede et al.'s (2022, p. 18) systematic review findings where "participants' accounts ... suggested that conflicting perceptions and stereotyped views of and lack of specialist training/expertise in working with autistic individuals held by clinicians may interfere with successful service provision for autistic adults."

In contrast to the mostly disappointing experiences of support reported so far in this sub-theme, participants also provided a number of examples of good practice, which made interactions less stressful and more useful. Generally, participants found it easier to recall bad experiences, and required more prompts to remember positive encounters. Participants had some good things to say about autism specialist services, where standard practices reduced the need to request adjustments. The team assessing Victoria's daughter "agreed to email rather than phone me without batting an eyelid" and Rosie described feeling "much more comfortable" when attending her assessment because:

> They have little staff bios on their website with a picture, they send a map and photos of the building. They also say they understand the need for some people to only use email, or not phone up a patient without prior warning.

Katharine had a similarly positive experience with her son's assessment:

> He was sent a leaflet that had photos of the room used, a simple map to the department within the hospital, pictures of the waiting room ... The leaflet aimed at my son was as helpful to me as it was to him.

Providing information about the people and the setting made a positive difference for Rosie and Katharine. Autistic people often struggle with unexpected change (Wigham et al., 2015) and providing information ahead of time helps reduce anxiety and stress, as Janet testified when discussing her “amazing” CBT therapist:

> [He] knew I don’t like phone calls, so he comes out in person regardless of covid, and he asked me on our first meeting what I need from him. I explained my need for clear language and for routine ... He also makes a plan with me at the end of every session with a little bit about what we'll discuss the week after so that I have a week to prepare myself mentally for what we will talk about.

As well as respecting her preferred means on contact, he also supported her need for clarity and preparation. Positive examples are particularly important as they both recognise good practice and have the potential, as Jenny suggested, to provide a “menu of things that have helped in the past” which others can learn from.

Sub-theme 3.2: I’ve had to make my own support network for myself

Despite participants generally bemoaning the lack of available and accessible support, as demonstrated by the previous sub-theme, most have managed to develop their own support networks and strategies. This sub-theme examines the ways some participants have ‘filled the gap’ through informal and community-based supports, and by practising self-care to promote personal well-being.

A significant source of support for several participants was their own mum, with Victoria describing her mum as “a huge source of support” and Audrey recalling how she “relied very heavily on my own mum for support when [she] first became a mother.” Janet, who has multiple disabilities, also talked about the valuable support and care she receives from her mum:

> My mum is a huge part of our lives. As my carer she is at our home at least 3 times a week ... She’s my carer, and supports my needs as best as she can. She knows I struggle with social interaction and phone calls and where possible will make phone calls for me or speak for me. She comes with me to new places and helps me navigate as I'm awful with directions and knowing where I am. I'm easily disoriented ... My mum is a huge support. She's always on the end of the phone if I need her for anything and reassuring me that I'm doing a good job.

Janet’s mum is clearly filling considerable gaps in her care and support needs, which are not being met by statutory agencies. Furthermore, and as discussed in the previous sub-theme, Janet finds phone calls difficult, and a lack of reasonable adjustments to meet Janet’s communication needs and preferences reduces her agency and ability to advocate for herself. For participants with supportive mums, this was an invaluable source of in-person support, as participants were often fairly isolated from local community support.

Overall, participants described few instances of community support and engagement, which is consistent with research showing that autistic adults are less likely to engage in community activity than non-autistic adults (Song et al., 2021). However, church was an important source of support, providing a “welcoming” community, for both Hope and Victoria, as Victoria explained:

> I'm C of E and take my daughter to church. I find this really helpful to me. It's a combination of the sensory input which I associate with calming memories (the smell, sounds, repetitive words, familiar sights and tunes) along with the strong sense of social justice there. The church is very welcoming to me and my daughter and I feel they value me AS an autistic mum, not DESPITE me being an autistic mum, if that makes sense.

The inclusive environment of their churches for Hope and Victoria provides an important community and sense of belonging, and as Memmot (2021), in her guidance for autistic inclusion in churches, points out:

> We know from informal research that most churches who enable autistic people to belong have congregations that grow faster, and flourish. Why? Many factors, but generally things that help autistic individuals are the things that help nearly everyone else too. (Memmot, 2021, p. 6)

This suggests that encouraging and enabling access to churches for autistic people will produce a thriving and supportive church community for all, not just autistic people. However, not all autistic people either have an inclusive church nearby or, indeed, are interested in attending church.

Lydia is part of a supportive local community for women whose support needs fall outside statutory services:

> I am lucky that there is a local charity group ... that is set up for people like me who fall between services. I attend a women's group on Zoom twice a month, am part of a book club and hope to meet up with some of the women in real life soon. It is a lifeline for me as I have no other friends, and there are a lot of women in my position who were diagnosed later in life. The facilitators of the group are really supportive, and I get a one to one once a month with them, where I can

> vent and get support. They are especially good with navigation and advocating with local services for me.

Accessing communities of autistic women, in-person and virtual, was particularly highly valued by most participants, supporting Tint and Weiss's (2017, p. 6) finding that "I [i]n the absence of effective formal services, many women highlighted looking outside the box for social support, and described positive experiences with in-person and online self-advocacy and support groups." Audrey joined an autistic women's network and told me that "going along to one of their in-person meets felt like coming home" and Jenny recalled an experience where she could be comfortably autistic with other autistic people:

> I remember being more comfortable around other autistic people. When the special Olympics was in Glasgow, I felt comfortable enough around autistic young people to do things like go on a bouncy castle that would usually have been more difficult. I think it's partly being around people who don't mask and don't hide their stims, as I had been told to suppress mine and by around age 8, I did this fairly reliably for a while.

Jenny's experience shows how being with other autistic people isn't just about support, but also an opportunity to be yourself, without inhibition, demonstrating the importance of finding your tribe and being your authentic self.

Acceptance and understanding underpinned participant experiences of support and friendship with other autistic women, as Janet explained, "I also find support through groups of other neurodiverse women who understand my struggles and my quirks and differences as they also have struggles themselves, and their own quirks and differences." Whilst not all participants had experienced supportive and positive autistic-only space, for those who had, their experiences supported Crompton et al.'s (2020, p. 1446) claim that "[s]pending time with other autistic people was ... important for building resilience to manage day-to-day life, improving well-being, and as a source of happiness." Importantly, "spending time with" was not restricted to time spent in-person, and time spent online was considered just as valuable, particularly for participants who were more socially or geographically isolated, as Katharine explained:

> Advice and support tends to have come from online sources. The most valuable friendships have been women I've met in these places. The best advice comes from those who have lived experience of autism, and these sources have been incredibly helpful. Books recommended from those who had used them were better than those recommended by teachers/professionals ... It's far easier as we have a better idea of what each other is going through, and advice is given thoughtfully, knowing there's a big chance it might not work.

Katharine's account encapsulates the experience of most participants, who have found "valuable friendships" and received their "best advice" in online spaces. Janet described the online communities as "very supportive and understanding if I post needing advice or tips on how to deal with a situation, or even just to let me vent because I need to get something off my chest" and Rosie told me how "for the last 6 or so years I've used autism websites and a Facebook group for neurodiverse women, who are all mothers." Furthermore, supporting Mazurek's (2013, p. 1712) claim that "electronic and asynchronous social media may provide a uniquely comfortable medium for enhancing existing relationships" and Chan et al.'s (2023) finding that online interaction can lead to meaningful in-person socialising, participating autistic mothers have used online interaction to develop and enhance in-person friendships. Moreover, participant interaction in online spaces for autistic women and mothers could be seen to represent a form of feminist consciousness-raising (Anderson and Grace, 2015) where sharing experiences and expertise is both affirming and empowering.

As well as support from others, a significant contribution to well-being for participants came through the practice of self-care, which can be defined as “the actions that individuals take for themselves, on behalf of and with others in order to develop, protect, maintain and improve their health, wellbeing or wellness” (Self Care Forum, 2023). For participants, self-care was dependent on understanding their own needs which required understanding themselves as autistic, as explored in theme 1: ‘Knowing I’m autistic helps me to understand myself’. This was articulated by Audrey:

> Simply learning more about autism has helped me hugely. I support my sensory needs better now; I better recognise when I’m dysregulated and try to implement better self-care rather than reaching crisis point. I beat myself up a lot less when I need to rest, and I am getting better at finding executive dysfunction solutions.

For Audrey, understanding herself as autistic and learning about autism has enabled her to recognise and contextualise her sensory, emotional, and organisational difficulties. As a result of this understanding, she is better able to implement self-care strategies, such as the need to rest.

Finding time for rest and solitude was an important element of self-care for several participants, but finding the time could be challenging due to prioritising other demands. Katharine described how she has managed to carve out time for herself by sacrificing sleep:

> Self-care is a tricky one, but I'm not sure how much is from juggling life or simply me being autistic. I can't sleep until I've been able to wind down completely, this usually means well after the boys are in bed. I then have to be up early, so tiredness is most likely playing a part in this too.

Rosie uses a number of self-care strategies, including reduced working hours which enables her to spend time on self-care, including sleep and time alone:

> At the key worker's suggestion, I cut my working hours down on my week when I have the children so I'm not so emotionally and socially drained. I have a meal plan on those weeks, so I don't have to think about what to cook each day, I use The Organised Mum Method for housework, so it doesn't become overwhelming and I don't have to think about what needs doing as it is all written down for me. I take naps whenever I can fit one in to replenish my energy (I have always napped when I go into autistic shutdown) ... I still don't always manage to work the hours I intend to each week, but at least now I'm not on the verge of burnout all the time. Spending time alone each day is essential, which I usually spend listening to audiobooks and playing solitaire on my tablet. I seem to need a lot of time just doing very little!

Rosie's account shows how she has developed sophisticated strategies to enable her to take care of her own well-being and, like other participants, finding time to be alone is a key element in practising self-care. And yet, despite the value placed on self-care by participants, there is a scarcity of relevant research, as autistic well-being research tends to focus on access to formal supports and community-based support, not self-care. Furthermore, consideration needs to be given to whether self-care promotes personal well-being or serves to renew energy which is used to support their children.

Importantly, as demonstrated in this sub-theme, participating autistic mothers are, despite considerable challenges and demands on their time, finding ways to fill the gaps of support. The informal supports outlined in this sub-theme serve to both replace and supplement inadequate or inaccessible professional supports.

Summary and conclusion

This theme has explored participant experiences of needing and accessing support. Participants typically reported challenges in accessing support and found that support and provisions available for mothers of autistic children often failed to take account of the potential or likelihood of mothers of autistic children also being autistic. Poor awareness of autism in women and mothers was shown to result in misdiagnosis of mental health conditions as well as resulting in burnout which contributed to poor mental health and well-being. Masking was identified as a significant barrier to support, presenting a double-bind for participants who often masked the difficulties which might require or benefit from support because, as mothers, they did not want to be judged or appear incompetent. Furthermore, where provisions had made attempts to be inclusive of autistic mothers (and autistic people in general) experiences were mixed, as were responses to requests for reasonable adjustments. A common request for communication adjustments was for alternatives to phone calls as most participants found talking on the phone particularly difficult and stressful, but requests for alternatives were not always respected. Nevertheless, participants also shared experiences of good practice, including providing information about people, services and locations, providing additional and clear information about what to expect, and agreeing to communicate by email instead of phone.

As a result of the paucity and frequent inadequacy of available support, participants described how they found their own ways to ‘fill in the gaps’ and develop their own support networks and practices. For several participating autistic mothers, their own mums were a significant source of support, through providing direct care and advocacy as well as ongoing support and encouragement for themselves and their children. Support from inclusive churches and community provisions were also valuable sources of support. In-person groups for autistic women were particularly valued by participants where they were available as they enabled participants to be themselves, by reducing inhibitions about being autistic and reducing the need to mask. Perhaps the greatest and most significant support came from online communities and interactions, where participants reported developing deep connections with other autistic women and mothers which developed into virtual and real-life (in-person) friendships. Online interactions were particularly valued by participants who were isolated geographically and/or where their own or their children’s disabilities made accessing local and community supports difficult. A final element for filling in the gaps was through practising self-care which participants undertook in a variety of ways. Self-care for participating mothers was dependent on having a good understanding of their own needs as well as the freedom and flexibility to incorporate it into their daily lives. Participants reported how they made adjustments to their work and domestic lives, developed strategies to carve out time to rest and recuperate, and how understanding themselves as autistic was key to effective self-care.

My analysis in this theme has shown how poor understanding of autism in the under-acknowledged cohort of autistic mothers contributes to inadequate or lack of support, and how participants found ways to develop their own support networks and prioritise self-care. In the next theme, where I will explore participant experiences of mothering, the consequences of poor support will be particularly evident in the context of balancing multiple and competing demands and needs within participants' families and wider lives.

7. Theme 4: A good mum wants the best for her children

Introduction

Thus far, the themes have focused primarily on the experience of discovery and coming to terms with being autistic and how current services often lack in provision for autistic mothers, but with an overall focus on autism experiences rather than mothering experiences. This theme considers the role of mothering and how, despite different and sometimes traumatic routes to motherhood, participants describe aspiring to be a good mother and the joys and challenges of raising their autistic children. There is a broad pattern, expressed across the dataset, of participants adapting to their children's needs, embracing their shared autistic identity, and presenting autistic mothering as perhaps different, but certainly not deficient. The first sub-theme 'You have to squash down your own needs' explores participant experiences of balancing competing demands whilst prioritising their children's needs. The benefits of 'insider information' for autistic mothers of autistic children are considered in the second sub-theme 'Being an autistic mother feels like having insider information'. The third sub-theme ''Against the norm' mothering' presents the challenge for autistic mothers of doing mothering their way, knowing that they may face judgement for mothering differently.

Sub-theme 4.1: You have to squash down your own needs

The idea that children's needs are paramount was expressed across the dataset, where participants articulated navigating the often-complex balance of conflicting needs and demands, often to the detriment of their own well-being for, as Rosie says, "having to squash down your own needs in order to meet those of your child, especially if that child is also high needs, is potentially very damaging." Underlying this statement is the notion that children come first, no matter what, and that mothers must set their own needs aside if necessary to facilitate that, no matter what, as Janet explained:

> It's often autistic mothers who are dealing with autistic children, which isn't easy as their needs can clash with ours, making it a recipe for disaster! Someone is going to end up upset and without their needs met, and as mothers it's not going to be our children.

This sub-theme builds on the sentiments expressed here by Janet and Rosie, exploring some of the ways participating autistic mothers manage, and attempt to balance, competing needs and demands.

Participants described experiencing sensory clashes with their children which contributed to heightened stress and overload. Sensory processing difficulties and differences are common among autistic people, and can include being over- or under-sensitive, or a combination of both (National Autistic Society, 2023a), and over 80% of autistic people are estimated to experience sensory difficulties (Schaaf, et al., 2011). Thus, when Janet's son needs help to calm down, he "needs a tight hug and a soothing voice, which is hard to do as when he's having a meltdown it physically hurts my ears and sets my nerves on edge so I'm on the verge of meltdown too." Supporting our children's sensory needs, then, is something we know is important, but can result in us neglecting and suppressing our own, which increases stress and, in turn, can increase sensory sensitivity (Talcer et al., 2021). For mothers who don't know they are autistic when their children are born the sense of assault on our senses can be immense, and not understanding why we feel like we do can result in considerable distress, as Rosie remembered:

> I was in shock, shutdown, and mute, and utterly terrified once my baby arrived and needed me. His crying made me panic, his snuffly sleeping noises kept me awake and I cried for a midwife to take him out of the room for a few hours so I could sleep. She was bemused and said, 'but he's not crying right now'. My sensory sensitivities were unrecognised, and I was made to feel like a bad mother.

Hence, despite Rosie suspecting she was autistic before her first son was born, she was still unprepared for the impact on her senses and how this would make her feel like a "bad mother". Rosie's experience reflects the results of Donovan et al.'s (2023) study which highlighted the importance of understanding that autistic mothers might need more time to recover and acclimatise to motherhood, and that bonding might take a little longer for new autistic mothers. Bethan also identified the baby stage, alongside lockdown when everyone was home, as particularly challenging times, "the sensory overload is huge though. Especially that baby phase when they are physically on me all the time. And the noise. Lockdown was so hard!". These accounts are consistent with Winnard et al.'s (2022, p. 2319) finding that "individuals with sensory sensitivities who are parents are managing extra sensory demands which can potentially cause stress, anxiety and physical pain and hence, impact on psychological wellbeing and mental health", illustrating the risk to autistic mothers of neglecting our own sensory needs.

As well as the challenge of balancing sensory needs, participants also struggled with balancing family demands and day-to-day organisation, planning, admin, and domestic tasks. Audrey explained how she finds "balancing being a mum and other demands incredibly difficult and [I] always feel like there are several areas of life where I am behind/not coping", and Jenny described how she often felt like she was "failing in all arenas of life". When discussing balancing demands, participants often talked about the notion of "overwhelm", for example, both Rosie and Bethan described feeling overwhelmed by housework:

> I really struggle with managing my time and general organisation skills. I have to use apps to manage the housework, or I become overwhelmed by it, then do nothing and I have a to-do list on the go all the time. (Rosie)
>
> Balancing with other demands. I'd say this is my main difficulty and I find things overwhelming that others don't. I find it hard to do housework and cleaning especially when it's got into a state I don't know where to start. I've got an app I can tick things off and I have a trello board. (Bethan)

Audrey's response to being asked about balancing demands also evokes the notion of overwhelm:

> I find balancing being a mum and other demands incredibly difficult and always feel like there are several areas of life where I am behind/not coping, though which specific area that is tends to vary (household chores, spending time with the boys, work, caring for the pets, keeping in touch with friends etc.).

Katharine's account of the overwhelm resulting from "too much going on" articulates the impact on her sensory needs and her communication abilities, whilst alluding to an awareness that autistic stress responses are poorly understood, which then results in greater stress:

> When there is too much going on I tend to be overwhelmed and burnt out, which everyone acknowledges and expects that mothers can be, but when this manifests in non-typical ways, so struggling to talk coherently, having to stim/fiddle with

> hands, reducing eye contact, using pre-planned sentences as spontaneous conversation is beyond me, this can all be perceived as the wrong sort of burnt out, I should be able to continue as normal like other mothers. The stress of this tends to lead to more burn out which then affects relationships as I'm irritable and spending most of my time trying to recover, it means that the amount I can do in a day/week is severely reduced.

The sense of overwhelm and feelings of failure expressed by these participants were common, and accords with Pohl et al.'s (2020, p. 9) research which found that "autistic mothers reported greater difficulty with multi-tasking, organisation and domestic responsibilities" with 62% feeling "that they needed extra support because of their autism." Moreover, participant experiences of overwhelming demands within the home often made it harder to take part in activities outside the home as the stress and burden of balancing demands resulted in abandoned ambitions and aspirations.

Several participants sacrificed their own education and careers to be more available for their children. Janet gave up on her university plans to enable her to focus on her and her children's health and well-being:

> My plans have had to go on hold as I can't cope with university at the moment, between dealing with my own mental and physical health problems and trying to pursue a diagnosis for [my youngest], I just don't have the mental capacity.

Likewise, Lydia gave up on her aspirations to continue her education in order to care for her children:

> I attempted to go back to Uni and complete an MA. I did really well and was getting distinctions and at the point where a professor was interested in getting one of my articles published. I kept having to take temporary withdrawals due to stress (mainly childcare/school related) as my eldest was out of school, my youngest was

> a baby/toddler and I was drowning in the responsibility of caring for them full time and trying to study. My husband tried to share the load but at this time he was starting a PGCE with the aim of becoming a teacher to get us a regular income. He found the process incredibly stressful so that added to my load ... I secured a position teaching Y1 Undergrad while I was still doing my MA and I was so happy as this had been my lifelong ambition and it was my passion. My husband had qualified as a teacher by then but unhappy in his post left to work as a supply teacher to support me in eventually becoming the primary wage earner. He couldn't get my youngest to go to playschool and was not as adept as me at dealing with my eldest, so I would get in from work with more work to do for MA and lesson planning and all the kids and him to deal with. I was heading for overload but trying to keep all the plates spinning.

Lydia's account of balancing work and education with caring for her children provides useful insight into the way families might deal with balancing priorities. Yet, despite an apparently supportive husband and some flexibility with her work and studies, ultimately Lydia became the default parent (which is explored in sub-theme 5.1: 'Mum is the one who keeps things in place'). Clare's reasons for giving up on her career echo Lydia's story as she described "needing to be on hand to collect my 2nd son from nursery and take to appointments all the time", and Katharine described how being overwhelmed and overloaded presents a barrier to ambitions and aspirations, and can result in social isolation:

> I have fleeting times of feeling very ambitious and positive about the future, with things I want to do, places I want to go to, but I usually end up exhausted, peopled out, and when it comes to it, I'd rather see no one and do nothing.

These accounts reflect the results of Davy et al.'s (2022) scoping review examining the impact of parenting an autistic child on parents' occupational (work, leisure, community and social) participation. Drawing on literature concerned with the quality of life and occupational participation of parents of autistic children, the authors highlight how parents, particularly mothers, cut back on their own occupational participation as a way to make time to meet the needs of their children.

Fortunately, and importantly if we are to improve autistic mothers' access to occupational participation, some participants have found ways to incorporate work through flexible work and self-employment. Audrey works for a small charity, and she explained how the flexibility of her employer and being granted autonomy over when she works are key to her being able to work at all:

> If I am struggling, myself, my hours are pretty flexible so I can also choose to have a day of rest and do more hours another time. The flexibility of my role, the autonomy I have over when I work my hours and the understanding attitude of the charity are key factors in me being able to work.

The importance of flexibility and autonomy is also reflected in accounts of participants who have chosen self-employment. Bethan, self-employed for five years, described how she "struggled with employment in the traditional sense", a sentiment also expressed by Emily, "I'm not great at working in employment so I'd rather have control and less money and flexibility" and Victoria, who told me:

> My autism meant I couldn't manage to stay employed, so I pursued self-employment which was a financial hit although I am really lucky to work in an area that is also my special interest and finances have recovered. I am not particularly interested in financial gain once I have 'enough' and tend to accept too much unpaid work. If I was [neurotypical] I would have had a very different financial trajectory, but I am also extremely glad I didn't.

Unsurprisingly, therefore, it is often a challenge to incorporate traditional employment into the seemingly never-ending series of demands placed on autistic mothers of autistic children. Clearly, it is possible to be an autistic mother and work, but the level of flexibility required and the time available for working can prevent full access to employment and career opportunities. Prior research has identified the "gender pay gap" (Rubery and Grimshaw, 2014, p. 1), the "disability employment penalty" (Berthoud, 2008, p. 129) and the "motherhood penalty" in employment (Correll et al., 2007, p. 1297), which provide partial explanations for some of the difficulties with employment faced by autistic mothers. However, they fail to take account of the multiple and intersecting barriers, hurdles and demands autistic mothers of autistic children (or, indeed, disabled mothers of disabled children more generally) are required to manage to even enable them to find time to fit work in (as per Gore et al. 2023).

One reason participants provided for struggling to do it all was executive functioning difficulties, with Audrey describing her "own poor executive functioning" and Victoria explaining how "it is difficult to describe the balance between parenting and other demands because I have always found executive function hard". Executive functioning can be defined as "a set of general-purpose control processes that regulate one's thoughts and behaviours" (Miyake and Friedman, 2012, p.8), meaning that it is the ability to organise ourselves, plan and carry out tasks, adapt and prioritise, "we use it when we need to exercise control over our thoughts and behaviour, especially when we are trying to do something that competes with our habits, impulses, and desires" (Doebel, 2020, p.1). Autistic adults are, by current measures, more likely to struggle with executive functioning (Johnston et al., 2019), so it is not surprising that participants considered it a reason for some of the challenges around balancing demands.

However, in framing this as an executive functioning problem, participants typically considered their poor organisation to be an inherent deficit, resulting in self-blame, rather than a response to being overloaded with demands which would be hard for anyone to manage. Non-autistic mothers of autistic children are also reported to struggle with balancing demands and sustaining routines (McAuliffe et al., 2019) but, as Katharine points out, “being an autistic mother means that more is required of you as you have your own disability to manage as well, or risk being burnt out. Or be burnt out and still have to manage it all!”. Hence, there is a need to be cautious about attributing problems with managing demands to inherent deficits like executive functioning for autistic mothers, when for non-autistic mothers the problem is generally attributed to there being too many demands in the first place.

Sub-theme 4.2: Being an autistic mother feels like having insider information

Participating autistic mothers described feeling deep empathy with their children alongside their understanding of what it feels like to be autistic “from the inside” (Williams, 1996, p. viii). The sense of empathy, and their identification with their autistic children, was a strong presence across the dataset. Not all participants’ children appreciated their mothers being autistic too though, as Clare told me: “I shared my [diagnosis] with my son when he was diagnosed, and it was the worst thing I could have done. He has no respect for me and so it didn’t make him feel better it made him see himself as similar to me which he hated.” Overall, however, participants were very positive about sharing being autistic with their children, and considered being an autistic mother to be an advantage in parenting autistic children, as Audrey expressed:

> I do think autistic mothers tend to be better at empathising with their autistic children because they are likely to have a lot of the same lived experience when it comes to sensory needs, communication differences, executive functioning struggles, special interest immersion etc.

Essentially, whether our children are happy about it or not, the depth of knowledge of autism and being autistic held by participants, as Audrey mentions, was considered beneficial for participants and their children. This sub-theme considers the benefits of being an autistic mother when raising autistic children, how being an autistic mother brings added insight which, whilst typically benefitting the child, can be detrimental to maternal well-being, and how rejecting pathologising discourses of autism can present a barrier to accessing assessment and support.

Participants highly valued their "insider information" (Katharine), which they felt enabled them to better understand what their children were experiencing and where they might need extra support. Emily spoke of how "my daughter and I are quite similar" and Rosie described how "being an autistic mother means I can relate to my children on their level." Hope, aware that autistic teenage girls are at greater risk of victimisation (see sub-theme 1.3: 'I didn't recognise the red flags'), described being able to reflect on her own teenage experience, as a way to support her daughter's safety and well-being: "[I] understand being an autistic teenage girl, which is good for [my daughter], can see where there may be problems and remember what it is like to be an autistic teen girl." Victoria explained how her own knowledge and understanding enables her to be "sympathetic" to her daughter's communication and sensory needs:

> I'm able to talk through our differences with my daughter. I am direct. I don't experience anger, so people remark on how patient I am with her. We use non-verbal communication as a matter of course in our household. The house is sensory friendly ... I'm so glad that I have the knowledge of what it feels like to experience sensory overload or the need to stim and so I am sympathetic to it in my child.

These accounts, of the beneficial nature of “insider information” (Katharine) when mothering autistic children, demonstrate how participants have been able to use their own experiences to better support their children. This reflects existing research which has found that autistic parents have a “heightened understanding and empathy with their children” (Crane et al., 2021a, p. 1166), a “unique insight, bond and level of understanding” (Winnard et al, 2021, p. 2320), and “a capacity to instinctively understand their autistic children in a way that neurotypical parents do not” (Marriott et al., 2021, p. 8). These are important findings, particularly in relation to maternal knowledge (see Theme 6: ‘*If you’re autistic it’s presumed you don’t know anything about anything’*) and mother blame (see Theme 5: ‘*Autistic mothers are judged and problematised by the same forces that police gender roles in society’*), highlighting further the need to recognise the maternal expertise of many autistic mothers.

The ability to be empathetic and sympathetic to an autistic child’s quirks and foibles is, to some extent, dependent on an autistic mothers’ self-awareness and recognising themselves as autistic, as well as her knowledge about autism. For example, Rosie described her sadness and guilt at not understanding her autistic child fully until she understood herself:

> I can see how learning how to recognise and express my needs and manage my emotions is having a positive effect on my children. They're much more able to express themselves than I ever was, and they feel safe doing so ... If I'd had knowledge of my own autism, I would have recognised the needs of my eldest child much sooner and would have known how to meet them. I didn't realise he had sensory issues until he was about 5 and cleaning his teeth as a toddler was a traumatic event. I was so worried about making sure his teeth were clean, because that's what you're supposed to do as a parent, that I resorted to pinning him down while he struggled and screamed. I feel intensely guilty and ashamed about not finding a way to make it more calm and tolerable for him. It's hard to write about.

Rosie’s account, which presents a before and after picture of autistic mothering, demonstrates the benefit for mothers and their children of understanding what it is like to be autistic. With greater understanding of her own autism, Rosie was better able to understand and respond to her child’s needs, which accords with Dugdale et al.’s (2021) research where some participants described an improvement in their parenting after they had been diagnosed. However, the deep empathy participants felt for their children was sometimes detrimental to their own well-being, as Lydia articulated:

> My problem is that I feel so much responsibility and empathy for my daughters that I can’t set myself time away for myself without feeling physically sick about it. Sometimes my husband will make me go and read or watch tv or just shut myself in my room for a break. I hide my illnesses from them and feel constant guilt and like a failure as a mum. I know this isn’t true rationally and that they are well cared for and loved but it niggles at me that I am somehow messing them up or that they feel rejected by me.

The sense of responsibility expressed by Lydia reflects the findings in the previous sub-theme and demonstrates the “intense connection and love” (Dugdale et al., 2021, p. 1973) autistic mothers can have for their children. This presents a rejection of the ‘lacking empathy’ models of autism (for example, Baron-Cohen, 2003) and supports Milton’s (2012a, p. 883) “double empathy problem” whereby autistic people, whilst struggling to understand or be understood by non-autistic people, have great insight into and empathy for other autistic people.

Furthermore, and central to narratives focused on mothers identifying with their children, was a rejection of the pathologising language and practices we often encounter in the course of our children's assessments, diagnosis, and therapeutic interventions. Participants reflected on the impact of these pathologising narratives and how they prevented prompt recognition of their children's autism. The frustration of not recognising your child's atypical behaviour as "aberrant because it is outside of usual parameters of social communication" (Lydia) and that "stuff we think is perfectly normal and OK might not be considered so by others" (Emily) was articulated by Jenny:

> There is anecdotal evidence about difficulties with diagnosis because children don't seem stressed or self-loathing enough ... I think taking [my oldest son] as a case in point- my middle child - he is so typically Asperger's-style autistic. He covered his ears when he was upset. He had and has very focused interests. For me, that all just meant I felt like I understood him and could care for him. I would have struggled to meet the needs of a more socially oriented child in the same way. I hated that I was expected to frame his personality and difficulties as problems he was somehow causing and that it annoyed me but I felt that was the expectation ... I think there were a lot of times people tried to get me to collude with problematising the children where I didn't pick up on this because they seem ok to me as long as their needs are met ... My pet interest is how autistic mothers find it harder to help their children with the diagnosis/assessment process. Like our children aren't as distressed maybe as we don't stigmatise them.

Jenny's articulation of the problem of not pathologising our children, of not seeing our children as not-normal, alien, or other, demonstrates how current deficit-based models of autism present a specific challenge to our own identity and sense of self when our children are just like us. Moreover, whilst rejecting the pathologising discourse is likely to be of benefit to our own and our children’s well-being and “identity-development” (Riccio et al., 2020, p. 8), it can present a barrier to accessing services and support.

Sub-theme 4.3: ‘Against the norm’ mothering

This sub-theme focuses on the tensions between wanting to avoid judgement for our, sometimes unconventional, mothering practices whilst knowing that our children benefit from us mothering differently. As Janet explained, “I think we're often seen as lax and lazy parents as we do things that make our lives and our children's lives easier instead of what is considered the norm”, highlighting how doing what we believe is right for our children can sometimes be quite different to the expectations of mainstream mothering.

Finding a balance to avoid unwelcome judgement whilst mothering in their own way was important for participants. Because we typically have more involvement with professionals than mothers of non-autistic (or otherwise non-disabled) children, we are likely to encounter greater intrusion and scrutiny of our mothering practices. This was articulated by Katharine:

> I think expectations on mothers as carers are more exacting - not only do we need to be caring and maternal, we need to be on top of endless paperwork [and] perform parenting in an acceptable way (often not possible with autistic children).

This idea, that we risk judgement for being seen to not meet “exacting” standards, was echoed by Jenny, who described how “being judged as a mother and as a woman in relation to being autistic are great sources of annoyance for me”, and that:

> I feel like I am always trying to ensure I've done necessary things to avoid problems e.g., clean house, lots of fresh, healthy food in fridge, clean bedding on beds etc. - things that social workers actually should care about on a home visit.

In making sure that her home would pass social work scrutiny, Jenny's experience reflects that of other mothers who have experienced social work interventions (Benson, 2023) where mothers might feel obligated to present their homes and their fridges at all times ready for inspection. Other participants worried too about how they and their children might be perceived, for example, Audrey worries "about the fact I haven't formally taught them how to use cutlery because it was so hard for them for so long (motor skills) and meals times were already a 'thing' due to restricted diet" and Rosie has felt judged for how she plays with her children "in a very physical way, like climbing trees together or wrestling." Victoria described feeling judged for "failing to control my child when she's had a meltdown in public, or when I've let her stim happily, or where I've responded to her when she's communicated non-verbally rather than 'making her use her words'." These accounts appear to demonstrate how judgement is often passed without understanding, as Bethan experienced:

> The Headteacher was saying about how I should consider reducing [my son]'s screen time. She's never asked me how much does he have. Or what. She has literally no idea. It's also calming anyway for him at times. I find that kind of thing hard, judgment without collecting any facts.

Reflecting Dugdale et al.'s (2021) research, judgement typically came from non-autistic people and was often founded on poor understanding and knowledge. Moreover, as Pohl et al. (2020, p. 8) point out, fear of judgement and the "stigma and fear of being viewed as a ‘bad parent’ might deter autistic mothers from asking for much needed tailored support.”

Importantly, and despite the fear of being judged as a ‘bad mother’, participants were very positive about their experiences of mothering, with most telling me that they loved being a mum and spending time with their children. Bethan told me how “I do love them loads and pluses definitely outweigh any negatives by lots” whilst Emily was “surprised” to find she loved motherhood “as I hated children for most of my life, especially babies.” For Lydia, being a mum enables her to be free to be herself as “the thing I love about being a mum is having two people who understand me and I can be totally myself with, we have in jokes and chats and just laugh, and it feels happy to be with them more than I am with anyone else” alluding to how some participants mothered differently in public and private, echoing Rich’s (1986, p.195) “outlaw” mothering. For example, Rosie discussed why her mothering might appear different when in public:

> I've heard people talk about the supposed lack of empathy that us autistics apparently have and that we would make cold and unemotional parents. Personally, I do tend to come across as reserved and unemotional when out in public because I'm just trying to hold it together. When I'm just with my family I'm very warm and emotionally demonstrative, exceedingly so.

Hence, whilst Rosie’s public mothering might appear “reserved and unemotional”, in private she feels able to express her love and care for her children. The idea that autistic people “would make cold and unemotional parents” harks back to the ‘refrigerator mother’ theory of autism, which will be explored in the next chapter, and how its legacy can impact public perceptions of autistic mothering.

Some participants described being aware of the expectations on mothers to mother in particular and prescriptive ways, but did not always comply, as Victoria explained:

> There is a right amount of screen time, sweets, when and how to correct your child if they misbehave in public, what expectations there are around your child's adherence to social rules. I don't always understand them, and when I do understand them, I don't always follow them, because I think some of them are harmful. For example, I would never stop my child stimming as long as it's a harmless stim like flapping rather than anything potentially injurious.

Like Victoria, Lydia has chosen to reject some of the expectations and restrictions which act as socially acceptable markers for 'good parenting', in favour of prioritising well-being and autonomy in her daughters:

> I don't care about things like restricting computer access, or screen time, or homework. I will let my older child watch more grown up tv/films if I think she is able to deal with it maturely and so far, this has been fine. I talk to them about structural inequality, on all levels: sex, class, race etc. but also how I think teachers can be unfair and aren't an ultimate authority. I don't care if they don't want to clean their teeth, or only eat spaghetti for 6 months. I do care about whether they are decent human beings and whether they have respect and reasoning. I don't care whether they succeed academically so long as they end up doing something they like and can earn enough money to live. I don't push them, though they are both academically able. My younger child is very talented musically but didn't want to carry on piano lessons or practice, so I didn't force her. I think a lot of parents push their children at school and clubs for some kind of social capital, a bit like driving a Volvo or bragging about holidays. I hide a lot of this from other parents and will even tell my children they can't have the tv/computer on if it's a playdate, so I am not 'found out' about my lax boundaries.

However, Lydia's awareness of the judgement faced by mothers who mother "against the norm" means that, like Rosie, she mothers differently when she is being observed, even in informal situations like playdates. These accounts reflect the findings of Marriott et al. (2021, p. 9) who suggested that “home was used as a place to hide away from a world which was perceived as highly blaming of these parents and highly judgemental of their children’s behaviour.” Furthermore, mothering differently in public and private represents a form of masking, as participants sought to avoid judgement for their mothering practices.

In spite of concerns about judgement and awareness of how mothers are expected to mother, participants typically mothered their children in ways that met their needs, even if this went ‘against the norm’. Participants spoke of being “less conventional” (Lydia), “unfettered by social norms” (Rosie) and doing “what I thought was right” (Emily) in their mothering practices, demonstrating both a rejection of standard mothering practice and confidence in their own mothering. Hope provided a series of examples which highlight how mainstream parenting norms and professional advice can conflict with meeting the needs of our autistic children who often require a different approach:

> I think that sometimes autistic parents can adapt to their children's needs more, e.g. [my son] hated warm baths, he liked tepid water, so I gave him tepid water. an NT friend could not understand why her kid didn't like warm baths but persisted with warm baths, maybe because there was some "should" in there ... In a training session psychologists were talking about food and that parents should try and increase the foods a child will eat even if they are getting all nutritional needs from the range they do eat. They could not give a reason; it was just because it would be nice. I think there was some the kid should fit more NT expectations (obviously if they are not getting their needs from food, it is different) ... Some of my parenting choices seem really questionable if viewed from a NT perspective, for example: [my son] has lemonade to drink at breakfast ... So the choice was not between lemonade and more appropriate drink such as milk or water, but between lemonade and nothing with dehydration headaches and autistic meltdowns thrown in.”

In choosing to reject certain expectations and norms, the “should” mentioned by Hope, participants made active and confident choices in how they mother their children, despite risking censure. Furthermore, and reflecting the results of Dugdale et al.’s (2021, p. 1981) study where their autistic mother participants “described needing to be ‘all in’ and fully committed to being as good a parent as possible”, participating mothers demonstrated a deep commitment to their children, to do the best for them even when this might go against the norm.

Summary and conclusion

This theme has considered the highs and lows of participant experiences of mothering their children. Participating autistic mothers described and demonstrated throughout their accounts a strong sense of putting their children first, even when it was detrimental to their own well-being. Maintaining a semblance of balance with the competing demands and needs of their families was an ongoing challenge and was particularly evident in relation to sensory needs and day-to-day domestic tasks, family organisation and administration. Participants typically had their children before realising they were autistic, therefore they were unaware that the distress caused by, for example, the upheaval and sensory distress of a new baby was exacerbated by being autistic themselves. The sense of overwhelm that resulted from trying to manage multiple competing demands often resulted in burnout and participating mothers often sacrificed their own plans as a way to reduce the load. Whilst executive functioning difficulties were frequently considered the reason for struggling with multiple demands and tasks, I suggested the reason might actually be that there are too many demands for anyone to manage, noting that research into non-autistic mothers of autistic children highlights similar problems and that non-autistic mothers are not considered deficient, or pathologised, for struggling with many of the same challenges.

Despite the challenges, however, participants described many benefits of being an autistic mother to autistic children. Having insider information as an autistic person was particularly valued by participants, where it resulted in high levels of understanding and empathy for their children, in stark contrast to lacking empathy models of autism, and contributed to a rejection of pathologising narratives which render autism and being autistic to be a problem. Instead, participants supported and encouraged a positive autistic identity in their children and were able to reflect on their own experiences as autistic children and teenagers to inform their mothering practices. Moreover, in describing their mothering practices, participants highlighted the tensions between prescribed notions of good mothering and the mothering they actually did and considered best to meet their children's and their families' needs and circumstances. Importantly, participants overwhelmingly were positive about being a mother, sometimes to their own surprise, and confident in their mothering abilities. However, this was tempered to an extent by awareness of the expectations of mothers and the fear of being judged against standards they could either not meet or choose to disregard because they considered them irrelevant or harmful.

My analysis in this theme has shone a light on the experiences, practice and art of mothering by participating autistic mothers, where I have highlighted the particular challenges of autistic mothering, recognised the benefits of being an autistic mother for autistic children, and demonstrated the skilled maternal practice of participants. In the next theme, I will shift from the practice of mothering to the ways that socially constructed and enforced norms of motherhood both reinforce the sexist expectations which result in mothers bearing the parenting load, and result in mother blame when mothers are unable or choose not to conform.

8. Theme 5: Autistic mothers are judged and problematised by the same forces that police gender roles in society

Introduction

Where the previous theme examined participant experiences of mothering practices, this theme explores the expectations of motherhood and the manner in which participating autistic mothers, as evidenced across the dataset, describe an almost universal experience of doing it all and of blame and judgement for their autistic children's difficulties and for mothering 'wrong'. The first sub-theme 'Mum is the one who keeps things in place' centres around the idea of mothers as the default parent, exploring participant accounts of sharing the parenting load, and examines the impact of sexist assumptions around parenting. The second sub-theme 'We get blamed a lot for our kids' considers participant experiences of mother blame and considers how the legacy of the 'refrigerator mother' and accusations or fear of being accused of fabricated or induced illness (FII) presented particular concerns for some participants.

Sub-theme 5.1: Mum is the one who keeps things in place

Participants were asked about the parental sharing of responsibilities for supporting and advocating for their children's needs and participating mothers were almost always the default parent in matters concerning their children's support and welfare. The balance of parenting and domestic responsibilities within families has long been of interest to feminist scholars, for example, Oakley (1976) challenged the hegemonic notion that women’s place was in the home. Yet, despite increased equality and more women in the workplace, from around 52% in 1971 to around 72% in 2023 (Statista, 2023), the gendered division of labour in the home continues. Indeed, both McCrory Calarco et al. (2021) and Robertson et al. (2019) highlight the unequal sharing of childcare and the mental load of parenting and domestic work, which typically falls to mothers rather than fathers, a division which continues to be perpetuated socially and culturally. This was articulated by Bethan:

> I think a lot of this is cultural such as people like school and when kids were younger people like the health visitor would call me rather than [my husband] as default. Even if I was working and he was at home with the kids, and I say to call him they still call me. I think it's just what happens to call the mum.

The idea that becoming the default parent is “just what happens” is central to this sub-theme, as it considers how participants described sharing the parenting load and how, despite mothers often being almost wholly responsible for their children and some fathers absolving themselves of responsibility, paradoxically, fathers were sometimes revered and respected in a way that mothers were not.

The sharing of the parenting load varied across the dataset, with some participants describing equitable parenting, whilst most considered themselves responsible for the majority of parenting, whether by choice or by ‘accident’. Bethan described sharing “most of the responsibilities pretty well I think” with her husband and children’s father, whilst for Rosie, who is separated from her children’s father, sharing the parenting load has been formalised through a 50/50 residency sharing arrangement, combined with effective communication and shared parenting values:

> I share 50/50 residency with my ex-husband, who has married again, and the children alternate between the houses a week at a time. Friday is change over day and whoever is next having them picks them up from school. The parent who has just had them takes all their stuff to the other house after work. My ex and I co-parent really well, and we talk on the phone/via WhatsApp nearly every day about the children. All major decisions are made together. Each household is run with slightly different rules, but essentially our overall values and expectations of the children are very similar. If one of us feels the children need something addressing with school, we talk about it and one of us will send an email/make a phone call. We will attend meetings at school together. We both advocate for the children and work together to make sure their needs are being met. At times it has caused tension, but we resolve disagreements with lots of discussion.

Victoria, who lives with her female partner and co-parent, and reflecting a trend in lesbian families towards egalitarian parenting roles (Ciano-Boyce and Shelley-Sireci, 2003), explained:

> Both of us are responsible for advocating for [our daughter] and making sure needs are met. I probably do much more of the admin side of it because it is my skill set. I am also better at remembering appointments. My partner's PDA makes her less good at dealing with authority figures but brilliant at teaching [our daughter] to advocate for herself. Her executive function is better than mine, so she is in charge of filing documents.

Victoria and her partner have made an active choice to share parenting based on their own strengths and weaknesses and, furthermore, understanding themselves as autistic has contributed to the allocation of tasks and responsibilities. Whilst Victoria is not the only lesbian mother here, she is the only lesbian participant who chose to have a child while in a lesbian relationship, and she described the extensive planning, including “spreadsheets where necessary”, undertaken to become a mother. This ‘intentional’ nature of having a child, and the extensive planning and preparation required, reflects prior research into lesbian motherhood, where 'intentionality' is a common theme (Gall, Softas-Nall and Eberle, 2019; Mezey, 2008).

In contrast, though still reflecting an intentional choice regarding parenting roles, both Audrey and Clare chose to adopt "traditional roles" with their husbands working and responsible for household income, while they would stay at home to take care of the house and children. For Audrey, the choice was made before having children:

> When we initially discussed having children, it was always the plan that [my husband] would largely provide financially and I would take time away from employment to raise the kids and do the lion's share of housework.

However, for Clare the decision came later when the needs of her youngest child became too great for her to combine with full-time employment:

> [My husband] wasn't really able or willing to risk that at the start of any career I tried so I couldn't stay late/go away etc. When [my youngest son] was very ill we actively chose to hold these roles - I had knowledge of send etc. and was confident in meetings (I'm very good at facts and advocacy) and he wasn't. He said he was worried he'd say the wrong thing and I was better able to be productive and not angry.

Whilst these accounts are in no way generalisable, it is of note that for both heterosexual couples who made an active choice in the sharing of parenting responsibilities, that the outcome reflects the broader gendered nature of parenting. Mothers typically undertake a greater share of domestic and child related work in the home (Lachance-Grzela et al., 2021) as well as the 'mental load' (Dean et al., 2021) of 'cognitive labour' (Daminger, 2019), the thinking, planning and decision-making tasks which participants often found particularly challenging, as seen in the sub-theme 4.1: ‘You have to squash down your own needs’.

For those participants who had not made active choices about how they would share the parenting and domestic responsibilities, in most cases resulting from separated or absent fathers, a similar gendered division of labour was evident, as Katharine articulated: “Women tend to take on more of the caring, the learning how to help our children, the admin involved, the meetings. (Not that fathers don’t get involved, but in my experience it’s predominantly mothers who do this ...).” For participants who had separated from their children’s fathers, apart from Rosie whose experience of shared parenting was discussed earlier, it was common for mothers to have primary residence and to become the default parent because, as Hope said, “often the dad has bogged off and is doing very little.” For Katharine, “being separated works far better for me as I have no illusions that [my ex-husband] will contribute to the trickier aspects of parenting.” Emily is separated from both her children’s fathers, with neither sharing the parenting load:

> Daughter’s father was a nightmare. Divorced when she was 2. Very in and out of her life. Long periods where he didn’t see her. He is now trying to be more involved, but she is not interested/finds him intrusive. Son’s dad has no 'dad' reference and although present throughout son’s life is not at all hands on. Came from a farming household so mum at home around all the time and dad doing the outdoor stuff. He is kind but he doesn’t parent.

While some separated fathers took little interest, rather concerningly for some participants, some were able to undermine medical and professional advice which then presented difficulties for mothers in caring for and advocating for their children. For example, Janet’s younger son has coeliac disease, a lifelong and serious autoimmune condition which is treated by excluding gluten from the diet, yet:

> His dad completely disregards his dietary needs so [my youngest son] comes home unwell and grumpy. This means he's much more likely to lash out and become upset, and he will stay that way until he feels better a lot of the time.

Jenny’s ex-husband has been able to block her pursuing an autism assessment for her youngest son, despite professional recommendation and support: “My third was going to be assessed for autism and had seen 2 professionals who were happy to put him forward, but his dad obstructed the process.” Thus, whilst Janet and Jenny were keen to follow medical and professional advice, they were undermined by their children’s fathers, despite both mothers, at the time, being the default parent responsible for day-to-day parenting. Interestingly, in both Janet’s and Jenny’s cases there is a history of domestic abuse which, combined with mothers’ vulnerability, difficulties being taken seriously by professionals, and research which indicates that coercive behaviours often continue post-separation (Tutty, Radtke and Nixon, 2023), contributed to considerable problems around shared parenting and supporting and advocating for their children.

In stark contrast, some fathers were reported to provide a useful, supportive, and authoritative role when advocating for children by participants who had recognised the way that men are often taken more seriously than women in what Sieghart (2021, p. 22) has termed the “authority gap”. Audrey described her frustration at feeling the need to take her husband to an important meeting:

> I did take [my husband] along for a multidisciplinary meeting once, purely because I (frustratingly) thought I'd be taken more seriously with a man there. I instructed him on what to say before the meeting. I did 'get me way' in that meeting (it was the final meeting to decide whether [my son] met requirements for a diagnosis) but it was a close thing and I do suspect having [my husband] there made a difference even though he barely spoke.

Similarly, Katharine recalled the way that her ex-husband's presence in meetings about the children was celebrated in a way that her own presence was not:

> The rare instances that my children's father has deigned to involve himself with any meetings he is treated very differently - almost congratulated for being a caring dad and simply being there, even when he had nothing to add and held up meetings by talking too much.

Here, participants have taken advantage of the gendered assumptions about credibility, and co-opted their children's fathers to add legitimacy, even when participants have far greater knowledge and expertise than their children's fathers. The inherent bias of the "authority gap" (ibid.) means that even though participating mothers held considerable expertise, fathers' knowledge, typically resulting from coaching by mothers, was more revered. Importantly, fathers often absolved themselves of responsibility for learning to support their children while mothers developed expertise and knowledge, as Lydia told me, "My husband would support me if I asked but I do it best and understand them/the system a lot better." This experience was echoed by Audrey, who explained:

> Obviously, the more I was at home with the kids and doing all the advocacy stuff, the more intimately I was aware of what they needed and what the procedures were etc. so the more sense it made for me to continue doing that.

Essentially, for most participating mothers, the more they did, and the more they learned, and the more expertise they developed, the more they were relied upon to continue, further reinforcing their role as default parent. Furthermore, whilst the unequal division of labour within heterosexual relationships is well recognised (McCrory Calarco et al, 2021; Robertson et al., 2019; van Hooff, 2011), the extra emotional, physical, and cognitive labour required of autistic mothers of autistic children has the potential to create an even more unequal balance when mothers are the default parent. Indeed, most participants had not actively chosen to take on the bulk of domestic and parenting responsibilities, and, importantly, those who had did so without full awareness of what might be expected.

Sub-theme 5.2: We get blamed a lot for our kids

This sub-theme focuses on mother blame, the idea that mothers are ultimately responsible for any difficulties or problems with their children. mother blame is not new or exclusive to autistic mothering, and features extensively in Freud's psychoanalytic work (Azzopardi et al., 2017), which heavily influenced Bettelheim's (1967) work with autistic children (see Chapter 2). It is noteworthy that 'father blame' is not a concept present in the parenting literature, reflecting the sexism inherent in parenting roles and responsibilities, as discussed in the previous sub-theme. Participating autistic mothers frequently expressed frustration at the way professionals and others whom they encountered assumed that their 'against the norm' mothering was the cause of their children's struggles, rather than seeing it as the adaptive, responsive, and often creative mothering practice needed by their children. Participants spoke at length about their experiences of mother blame, often within the context of the legacy of the 'refrigerator mother' theory and experiences or fear of accusations of fabricated or induced illness (FII), previously known as Munchausen's syndrome by proxy (MbP), where parents or carers cause or exaggerate medical symptoms in their child (NHS, 2023a).

When talking about mother blame, participating mothers often described teachers as being particularly problematic, providing extensive examples where mothers meeting their children's needs was misinterpreted as causing problems. Teachers were often a key informant when participants sought referrals for their children, resulting in a gatekeeping effect when they disagreed with mothers who were trying to secure autism assessments for their children. As a former teacher, Hope provided some insight from the staffroom:

> There is a lot of prejudice in staffrooms still I think ... There was the attitude of problems in school were caused by problems at home. And if the kid left school and was difficult, that just proved it was home's fault (as a teacher this was the attitude of lots of other staff), never school the issue. It has not changed since I taught, I think, at least in some schools.

The attitudes of the teachers observed by Hope is reflected in multiple accounts, where participants recalled experiences where their mothering ability was questioned by teachers, for example, Katharine suggested that "it seemed to be that teachers/children's services had to explore whether the issue was poor parenting and treated it as that. That's what it felt like anyway." Janet, whose two older children are not autistic, told me how "they dismissed me for years as a bad parent despite both [my older children] being completely different behaviourally to [my youngest child]," and that by the time her youngest son was eventually referred for assessment:

> By this point [my youngest son] had learnt to mask better in school, the school said it was down to poor parenting and the psychologist believed that instead of asking about the behaviour of the other children who have been parented by the same people. He asked why I thought [my youngest son] may be autistic so I listed his traits and his similarity to me, explaining I'm autistic but was only diagnosed as an adult. Rather than ask how he could amend his practice to suit me, he just said 'interesting, it seems you could be projecting your anxiety around autism onto [your youngest son]'.

Janet's description of fairly overt mother blame with the psychologist assessing her son was not unusual among participants. Indeed, as Pohl et al. (2020) found in their research comparing autistic and non-autistic experiences of motherhood, autistic mothers have greater difficulties interacting with professionals, and experience more judgement of their parenting, compared to non-autistic mothers.

For some participants, being accused of pandering to or molly-coddling their children was used as a way to withdraw support, as Lydia recalled:

> I triggered my own EHCP request and that made them really angry with me. I think I was just too emotionally detached and focused for them. I pushed down all my upset and distress because I needed to be the one to get my daughter through this and eventually to some help. The school finally did something at the end of the winter term, they arranged a TAC meeting ... It was horrible, they just said my daughter would be expected to attend full time with no support except class teacher from the January. They said I would have to be tough and let it get worse because it would get better, they said no support in class would help her. I was confused, livid, disappointed, and let down. In the meeting my weight was alluded to as a possible reason I made [my daughter] stay at home. I was working as a lecturer and studying, I had a full life and wanted to get [my daughter] sorted so I could continue this, they also said I had said 'I want to keep her locked in her room to keep her safe'. None of this was true. That treated me like an anxious, shut-in parent, who was mollycoddling my child. She was too terrified to speak to anyone so when I was speaking her words, for some reason they decided these were my words and I was somehow enjoying the entire process. They had started talking a lot about 'mum's anxiety' which was totally unfounded as I had such a calm and

> collected exterior, their words just made no sense to me. It was like this abstract thing that I was somehow doing to my child, where it was actually more the case that she couldn't settle in mainstream school, but it felt like no one really cared whether she could, they just said she should be able to and that was that.

Emily had a similar experience when her daughter, who has significant health needs as well as being autistic, was placed in a Pupil Referral Unit (PRU) and had her mothering abilities questioned:

> The head of this unit was also the woman in charge of home education in the local area. She was really hard on [my daughter] - initially I assumed she knew best - this was before ASD had been suggested to me - and she strongly felt that a firm hand - even to the point of dropping her there in her pyjamas and letting HER deal with her, was a good idea. She implied I was just weak, and that I may need referring to [social services] about my parenting, which I think may have been my turning point, as I knew that I had been involved with medical teams since [my daughter] was little, and apart from times when [my daughter] was very scared, such as having blood tests, she was a well behaved child who was progressing well, and nobody had ever questioned my parenting even with the very complex needs she had.

The implication within these stories is that in supporting their children's needs, professionals felt that Lydia and Emily were creating dependency and learned helplessness (Seligman, 1972), and not allowing their children to develop independence and self-efficacy. There is a sense that if we just tried harder, our children would be more 'normal'. Yet, research is clear that autistic people are likely to need support and adjustments across the lifespan (Lai et al., 2020), that autistic people require social and structural changes in order to flourish (Pellicano and den Houting, 2022), and that poor support for mental health can have significant and devastating effects on autistic mental health (Mandy, 2022). Through implying that needing support is an indicator of failure, where achieving normative expectation of adulthood and independence are valorised and held as ideal standards for successful parenting, whilst knowing that our children, like us, need support and adaptation, autistic mothers are often stuck between a rock and a hard place. If we mother according to normative standards our children struggle and suffer, and if we mother in a way that meets our children's, and indeed our own, needs then we are blamed.

In discussing mother blame, some participants discussed their awareness of the 'refrigerator mother' theory of autism (Kanner, 1949), the idea that mothers who were observed to be emotionally cold and distant were responsible for causing their children's autism. Here, Bethan reflects on her own mother's experience of raising an autistic child in the 1980s and how contemporary research can appear to promote similar-sounding ideas about mothers:

> I know the history of the 'refrigerator mother' and actually my mum had this experience with my brother in the early 80s. Whilst I think we've moved on in many ways I think we haven't. I saw a study on BBC news a few months ago ... about curing autism by teaching mums to smile or something. It was so infuriating and such a bad study.

Frustration at this mother-blaming narrative was also expressed by Jenny who suggested that the 'refrigerator mother' notion "was probably based on observation of autistic mothers," having been developed in a time when autistic women were largely unimagined and unimaginable by autism researchers and theorists. This highlights how poor understanding of how autism presents in adult women can result in assumptions about autistic mothers based on normative expectations of mothers (Hwang and Heslop, 2023), which relates to what Benson (2023, p. 15), in her research with autistic mothers' who have been subject to social work interventions, terms “compulsory neuro-normativity”, the idea that behaving ‘normally’ like ‘normal families’ will somehow remediate the challenges of being autistic in a non-autistic world. This is then related to ableism literature, which challenges often idealised notions of ‘normal’ which “erase differences in the ways humans express our emotions, use our thinking and bodies in different cultures and in different situations.” (Campbell, 2019, p. 10). Thus, when Katharine was struggling with her middle son, who is not adopted, she was sent on a course aimed at adoptive parents which focus on attachment and connection and promoted methods which failed to work for many attendees, and certainly failed to take account of her and her son’s autism:

> The course was not helpful at all, the leaders could not understand why so many parents struggled with it, and instead of questioning the methods blamed the parents, many of whom dropped out, further cementing the opinion that we were being obstructive. With hindsight the whole premise of the course was offensive and doomed to fail. Assuming that the mothers attending the course ... were having difficulties with their child because they had no bond with them surely harks back to horrific refrigerator mother theories of the past.

Katharine identified an implied mother blame narrative within the course teachings using her knowledge of ‘refrigerator mother’ and attachment theories. Underpinning attachment theory are “interaction expectations for mothers and their children” (Charles and Berman, 2009, p. 181), which are based on normative expectations of mother and child and represent ableist notions of normative motherhood and mother-child relationships. In the context of autistic motherhood, normative good mothering ideals fail to take account of the differences and nuance of autistic families, which can result in autistic mothers and their children being subjected to standard parenting interventions, for example, in Mitra's (2022, p. 39) autoethnographic account she recalls that "[t]he strategies suggested by the family support worker were often for neurotypical children rather than someone with a PDA/ASD diagnosis." This is ableism in action, where autistic mothers are expected to use normative strategies and interventions with their autistic children, and then blamed when the children fail to meet normative expectations of children.

Within this context of implied mother blame, some participants experienced fear of or, indeed, direct accusations of causing their children's difficulties as a result of fabricated or induced illness (FII). For Katharine, the most overt accusations of FII have come from her family, who did not understand her middle son's behaviour:

> I've dealt with this by dropping the people who judge ... I have dropped family members because of this, which has been difficult and hurtful, and is still perceived as my fault, even though their behaviour was making a difficult time even worse, particularly when they played devil's advocate constantly to point out how I was doing things wrong, and in suggesting (and telling extended family members) that I had MbP.

Katharine was able to "drop" the family members who were unsupportive and accusatory, however, this is not a viable option when the accusations come from professionals who support our children. Participants who experienced this felt the accusation of FII both unfounded and threatening as well as rooted in poor understanding of autism, and even the awareness of FII had a deleterious effect on some participants, as Hope explained in the context of having two children with multiple medical conditions that are often misdiagnosed:

> It was only when I needed an assessment for interacting with professionals, read an article in autism eye or some such magazine about parents getting accused of FII (because a lot of people have not kept up with academic research and don't know the link between hypermobility and increased chance of autism, asthma, allergies, PoTS, gastric issues, bowel and bladder issues, ad infinitum) and I have a child who has allergies - anaphylactic to nuts, asthma like symptoms (not asthma, just found out that it might be the allergies and dysfunctional breathing) but I have also just read that EDS [Ehler's -Danlos syndrome] can cause asthma like symptoms - I met another parent on a course that had been accused of FII as well as two of her children are autistic.

Hope's fears of an FII accusation are resonant of what the Royal College of Paediatrics and Child Health (2021) have identified as "perplexing presentations" (PPs), where parents, typically mothers, are considered to be erroneously reporting symptoms such as "challenging behaviour, autistic traits, pains, allergies, epileptic fits or gastrointestinal problems [including] diagnoses which are difficult to confirm or have disputed aetiology such as Ehler's-Danlos Syndrome or PoTS" (Davis et al., 2018, p. 3). Gullon-Scott and Long (2022), in their appraisal of the evidence base for FII and PPs, highlight the paucity of evidence to support the prevalence of FII and question the implicit bias of PPs which categorises seeking clinical investigation into thus-far-unexplained concerns about a child's behaviour, health or development as an indicator of child abuse. Despite the lack of evidence for FII guidance, it has been widely assimilated into child safeguarding discourse, which can result in "emotional and psychological trauma to the families ... being investigated and viewed through the lens of child abuse" (Gullon-Scott and Long, 2022, p. 4045), as Lydia experienced when she was accused of FII and reported to social services in the course of trying to access help for her daughter:

> I was hoping for help but I just got accused of FII and it took a year of my life battling the LA as I missed the threshold for legal aid by £5 a month ... I knew what [my daughter] needed intrinsically, but due to their lack of understanding I

> was accused of FII rather than being listened to ... I was at a Legoland Christmas event with all the family. I got a call and answered, and it was Social Services. The head had referred me for child neglect, and they were initiating child protection proceedings. I think it was one of the worst things that ever happened to me. I said I couldn't talk for long, the one thing I did find out was that the school hadn't mentioned [my daughter's] autism diagnosis ... I was still terrified that I would lose both of my daughters; I was so scared. I still find it hard to think about. The next day I called the social worker over and over again 'til I got through and spoke to her, it felt really horrible as it was like I was the one on trial. I pleaded my case and eventually she agreed to postpone any action unless there was another referral made. The social worker didn't even know what an EHCP was but accepted that as proof I wanted my daughter in school. The social worker didn't really know much about autism either ... I found out that the EHCP had been so difficult because I had been labelled as FII by the school SENCO and Inclusion teacher and head.

Lydia's experience encapsulates the fear of many autistic mothers who are aware that suggestions and implications of FII could have profound implications. Moreover, that the initial FII 'label' initially came from school staff, who are not clinically trained, raises concerns about professional over-reach, which have, at least in part, been addressed though the latest iteration of the RCPCH guidelines which require support from medical staff when making allegations of FII. However, over-simplified lists of 'red flags', the alerting signs of FII, continue to present a real risk to mothers of children with complex or 'perplexing' presentations,

What is clear from the accounts here and across the dataset, is that participating mothers consistently demonstrate extensive knowledge and skill in supporting and meeting the needs of their autistic children. Nevertheless, the way that participants often mothered 'against the norm' was often interpreted as 'bad mothering' and contributed to participant experiences of mother blame.

Summary and conclusion

This theme has explored participant experiences relating to the social role and the social expectations of motherhood, with a focus on mothers as the default parent and experiences of mother blame. Whilst a minority of participants had agreed on adopting traditional parenting roles before having children, the majority entered parenting with an expectation that they would share the parenting load with their partners. However, in most cases these mothers still did most of the parenting, hence, even when they had not actively chosen to, they became the default parent by doing it all, a role which became further embedded as they developed expertise and became the first point of contact for professionals involved with their children. Participant accounts of their children's fathers' involvement in shared parenting was mixed, with examples of both successful and unsuccessful sharing of the parenting load. A particular concern raised by some participants was the ability of separated fathers to undermine both the mother's and professional recommendations, which could result in lack of recognition or support for children's needs. For some participating mothers, fathers presented a useful authoritative presence in meetings with professionals, where they were typically taken more seriously than mothers, despite participants having coached the fathers in what they needed to know and say.

The sexist and gendered assumptions implicit in the way that mothers become the default parent are reproduced in narratives and experiences of mother blame, whereas father blame is absent from such discourse. For some participants, the legacy of the 'refrigerator mother' theory of autism was felt to contribute to the blame they experienced for causing their children's difficulties, as their own autistic interactions and behaviours, and the ways they mothered, were interpreted and judged through a neuro-normative lens. Thus, participants described how their ‘against the norm’ mothering practices were, at times, considered to be the *cause* of their children’s difficulties, rather than a *response* to their children’s needs, resulting in implied and sometimes fairly direct experiences of mother blame. Teachers were identified as a particular source of mother blame, with some participants accused of mollycoddling their children and creating dependency and learned helplessness, which resulted in dismissing mothers’ expertise and contributed to fears and experience of FII accusations.

My analysis in this theme has demonstrated the way that dominant ideologies and discourses of motherhood influence and create an, at times, hostile environment for autistic mothers of autistic children. I have shown how enduring sexist societal norms and compulsory neuro-normativity have resulted in participants being expected to ‘do it all’ and then face judgement and blame for what they do. In the next and final theme, I will examine further how poor professional and clinical knowledge of autism and autistic mothers and mothering impacts participants’ lives and, importantly, highlight the depth of knowledge held by participants which informs their mothering practice and is often disregarded or minimised by themselves and others.

9. Theme 6: If you're autistic it's presumed that you don't know anything about anything

Introduction

Previous themes have explored participant experiences of being autistic mothers, through an analysis of their experiences in relation to autism, mothering and motherhood, and the enduring influence of poor understanding and awareness of their lives. This final theme is particularly interesting as it demonstrates the high levels of autism knowledge and expertise held by participants, which contrasts with experiences of some very poor autism knowledge held by some of the professionals they have encountered. The first sub-theme 'All sorts of myths float around to make up for outdated knowledge' considers how often outdated and stereotyped autism knowledge among professionals and clinicians impacts upon participants. In the second sub-theme 'They just see us as mum, who knows nothing', participants describe how they are often not taken seriously and how their knowledge about autism and being autistic is often disregarded, which can hinder access to services and support. In recognition of the extensive knowledge about autism and being autistic demonstrated by participants across the dataset, the third sub-theme 'I have a need to know exactly what something is about', explores how participants tend to downplay the knowledge required to be a mother, whilst evidencing throughout their interviews deep understanding and knowledge around autism and supporting and advocating for their autistic children.

Sub-theme 6.1: All sorts of myths float around to make up for outdated autism knowledge

A significant challenge for participating autistic mothers was in their experiences dealing with professionals who had poor, outdated, and stereotyped knowledge of autism. In chapter 2 I demonstrated how, throughout the history of autism, autism knowledge has been dominated by crude stereotyping which has resulted in the delayed recognition and diagnosis of autistic mothers. As Katharine pointed out, “mainstream autism training is inadequate, and people tend to expect all autistics to be easily recognised and showing stereotypical traits.” Outdated stereotypes of autism, despite being well-challenged in research, continue to impact autistic mothers, and this sub-theme explores those experiences and their impact.

Participants were forthcoming in discussing experiences of autism stereotyping, particularly among professionals they encountered either for themselves or their children. Janet suggested that things would have been easier for her when she was contemplating whether she might be autistic “if autism in women and girls was better understood and if autism wasn't seen as a male condition.” The following extracts from Lydia’s and Rosie’s interviews present rich examples across several clinical disciplines where poor understanding of autism in women is demonstrated:

> When I first approached a GP about my own autism, I was dismissed very promptly and disparagingly. He held a lot of misinformation/misunderstanding about autism, especially female presentation. Eventually, I was referred and diagnosed but ever since I do not feel that any adjustment is made in terms of my autism with medical professionals ... I think there isn’t enough time during consultations to deal with anything other than the immediate issue and I think

> this is especially difficult for autistic women, when there isn’t training or understanding of our presentation or masking. (Lydia)
>
> [I] was assessed by a junior psychiatrist at a mental health department at the local hospital, who had no experience with women on the spectrum. She said that because I could make eye contact and interacted 'fine' I couldn't be on the spectrum, and that I probably had social anxiety disorder ... My key worker was very skeptical because I didn't behave the way she expected an autistic person to behave. She said she'd known a few men on the spectrum, and they didn't make eye contact, show consideration for others and were very socially awkward ... When I finally got my diagnosis and told her she was gobsmacked. The surprise and disbelief on her face was palpable. Months later when I was having my final wrap-up session and discharged from MH services, I told her how her reaction to my request made me feel. I told her skepticism was invalidating, that if I hadn't been so determined it could have resulted in long-term negative consequences for my MH. She explained that in a former job she worked with young men on the spectrum who needed daily support and that I was nothing like them, that she didn't know that presentation in women was different due to masking skills, and eventually apologised. (Rosie)

These experiences, and others like them, where poor autism knowledge acts as a barrier to women accessing diagnosis, reflect prior studies examining poor diagnosis rates for autistic women, thereby, putting “the individual at risk of not receiving the support they require” (Driver and Chester, 2020, p. 200). As was shown in the sub-theme 1.2: ‘Affirmation of my autistic identity has been helpful’, almost all participants placed great value on being diagnosed as autistic, but, disappointingly, the route to diagnosis continues to be hindered by gatekeepers and other clinicians whose autism knowledge is all too often outdated and inadequate.

As well as challenging the stereotype of autism as a male condition, participants also challenged the stereotype that confines autism to childhood. Victoria‘s family dentist was understanding and happy to adapt to meet her daughter’s needs, but struggled to transfer that awareness to meeting Victoria’s own needs:

> After my child saw the dentist and I explained she was autistic and had sensory differences the dentist was really good, stopped asking questions about dummies, checked in with me about what she could and couldn't do. Same dentist when told that I am autistic and I warned her that I struggle with dentists and might have a shutdown which would prevent me from speaking: "Well, if you feel you're having one of those, just tell me, ok?" She plainly didn't believe that adults could be autistic!

The notion that autism is a condition of childhood can also result in infantilising behaviours, as Audrey discovered when attending a hospital appointment with one of her children:

> I explained to the receptionist that I was autistic and was getting close to a meltdown. She immediately became really patronising and started speaking to me like I was a child. She said it wasn't my fault I had 'got confused' by the appointment being rescheduled in a really condescending tone and had 'misread' the letter.

A significant part of the difficulty for understanding appears to stem from some people's inability to reconcile the stereotyped obviously autistic child with the apparently competent and responsible, and almost certainly heavily masking, adult presenting to them.

Participants acknowledged that people often struggle to understand how their perceptions of autism as a childhood condition could be transposed onto the presenting autistic adult, as Jenny found when she was provided with an appropriate adult when she reported domestic abuse, and "the appropriate adult was like 'oh I have an autistic daughter so I know about autism, but she isn't like you'." hinting at poor awareness of the heterogeneity of autism and how autism can present differently across the lifespan.

As Janet said, “I think understanding that autism isn't a childhood only thing is a big thing. People often forget that you can be autistic and have a life.” This is linked to poor understanding of what is often called a ‘spiky profile’, articulated here by Jenny:

> A spiky profile isn't recognised properly. I'm excellent at a lot of things and I am less good than average at other things. The problem is that I'm excellent at unusual things (speaking in public from a well-informed perspective, writing policy documents, developing evidence-based training and delivering it with good group facilitation skills) and poor at things like remembering to eat or staying sane while a light flickers.

Likewise, Emily also described an uneven profile of “skills and abilities”:

> I think it’s very difficult, because the way that ASD affects people is so varied, and so varying in regards the skills and abilities. So, you may be fabulous at some stuff, but leave big gaping holes in your parenting, because you lack those skills yourself (i.e. my self-care/house management is pretty dire, but form filling and advocacy is phenomenal).

This autistic “spiky profile” (Jenny) is a concept identified, though not named as such, in the earliest autism literature (Kanner, 1943). Autistic children were recognised to present with very mixed abilities in IQ tests (Lockyer and Rutter, 1970) later becoming known as a “spiky profile” (Frith and Happé, 1994, p. 116). Since then, the spiky profile has been conceptualised to include a broader range of attributes, as Milton (2012b) explains:

> One of the key aspects of the experience of being autistic is that of having a ‘spiky’ or ‘uneven’ set of abilities and capacities. It is the feeling of many on the spectrum however, that this spiky profile is often unrecognised by service providers and support workers. Verbal ‘autistic people’ are often incorrectly assumed to be capable in areas in which they struggle, whilst those with less verbal skills are often incorrectly assumed to be lacking skills, ‘strengths’, ability or potential. (Milton, 2012b, p. 8)

For participants in this research, this broader conceptualisation of the ‘spiky profile’ is highly relevant, as participating mothers discussed how poor recognition of their, and autistic people’s in general, inconsistent abilities affected how they were perceived by others. Victoria described how some people “have been dismissive and said I can't have ‘real’ autism”, whilst Bethan suggested that a lot of people “don’t think those of us that just about manage really count” which makes it “certainly hard to get support.”

Furthermore, poor autism knowledge in clinical staff can result in adverse health effects (Doherty et al., 2022), including disengagement from routine screening, as Bethan explained:

> One thing I find tricky with medical is they ask about pain and I can't answer well. They might say 'what type of pain is it' or 'how bad on a scale' I don't know really, my pain response is quite weird ... Last time I had a smear test about 5 years ago with the nurse. The whole appointment was horrible. I said they usually hurt me and she was quite dismissive. Then it did really hurt me more than any other and she said she was nearly done and didn't stop it. To be fair I can't remember what I actually said I may have been unclear there. Then I was bleeding. It's put me off ever going again, although I know I should.

Bethan’s experience of struggling to articulate her pain was echoed by Janet, who explained how her GP failed to identify her urinary tract infection (UTI) because she does not show pain in the “expected” manner:

> He dismissed me and told me I couldn't have a UTI as I didn't look in pain. I told him I'm autistic and often don't present as being in pain. He still dismissed me ... I'd like GPs to have a better understanding of autism. For them to realise that neurodiverse patients don't always express their feelings and emotions in the "expected" way.

These stories support Doherty et al.’s (2022) research which identified significant barriers to healthcare for autistic adults, including untreated health conditions, missing out on routine health screening, and delayed treatment, all contributing to poor health outcomes and reduced life-expectancy for autistic people. Thus, an improvement in professional and clinical knowledge and awareness of autism could result in significant outcomes for the health and well-being of autistic mothers (and autistic people in general).

Sub-theme 6.2: They just see us as mum, who knows nothing

This sub-theme is built on accounts of participants not being taken seriously and having their often-extensive knowledge, and their understanding of autism and being autistic, frequently minimised and dismissed. Whilst there are some overlaps with the previous theme, including sexist assumptions about the social role of women, the focus here is specifically on mothers’ knowledge, whereas there it is about mothers’ behaviour. Not being taken seriously is an important issue for autistic mothers of autistic children as we are typically the main driver and informant when navigating the assessment, diagnosis, and support processes for our children. Furthermore, failure to secure support for our children contributes to stress and anxiety, hence, if we are not considered to be credible informants, our children’s needs can go unrecognised and unaddressed, and our own mental health and well-being can suffer.

Several participants struggled with having their concerns about their children’s development and their suspicions of autism taken seriously. Janet was “convinced” her youngest son was autistic and yet, despite her experience as an early-years worker, being autistic, and having a deep knowledge of autism, her concerns were dismissed for several years:

> The preschool staff dismissed my concerns despite him not making friends while there, refusing to engage in activities with a large group of children, struggling to make eye contact, not understanding role play, and not liking other children making noise near him or touching him ... He struggled in school socially and behaviourally as he entered reception, but excelled academically ... He still struggled to make friends and he lashed out when expected to do something he wasn't comfortable with such as a group activity. I again mentioned to school how I was convinced he was autistic and was told he was just badly behaved. Then he entered year 1 and still struggled to find friends among his peers, and was a handful behaviourally, often becoming very upset at what to others seemed a minor irritation, such as a child touching his arm, or another child moving a toy he was playing with or had placed somewhere specifically. I finally managed to convince the school to refer him for assessment ... School shouldn't have the final word on the traits and needs of a child, parents should. We are always told how we know our children best, but if you're autistic it's presumed you don't know anything about your children, or about anything really.

Janet’s son’s behaviour and difficulties were categorised as bad behaviour and therefore not in need of assessment. Conversely, Victoria found that a focus on positive behaviour, and minimising atypical and “bad” behaviour by nursery and school staff also resulted in resistance to recognising a need for assessment:

> I think the main things I want professionals to hear is that it IS okay to agree with a parent that their child is autistic or at least to agree that they have observed the same thing. Teachers and nursery staff are so keen to give the child praise / note the good points that sometimes they won't mention the "bad" at all and it leaves the parent feeling very isolated and disbelieved - particularly if family members or friends are saying the same.

Moreover, to highlight the discrepancies in responses to participants’ concerns about children’s development, the early years team did take Victoria’s concerns seriously:

> They took me seriously. They listened to what I was saying and agreed - not rubberstamping what I was saying, they were clear where they didn't see an issue or saw something different to me as is appropriate for independent professionals. But the RELIEF to hear someone say, "Oh yes, I saw her flapping while we were talking" or similar and feel that I wasn't talking into a void.

Victoria's emphasis on the "RELIEF" she experienced here highlights how being believed and being treated and respected as a credible informant reflects how autistic mothers often expect to be disbelieved and discredited and are surprised when they are taken seriously, and the sense of vindication when they are. Not knowing whether you will be believed or have your concerns dismissed appeared to be a considerable source of stress for participating autistic mothers, echoing Dugdale et al.'s (2021, p. 1978) study of autistic mothers where "[a]ll participants spoke of feeling misunderstood, judged or dismissed, leading to difficulties in receiving support for themselves or their child." Pohl et al.'s (2020) research found that over 70% of autistic mothers in their study reported mental health conditions, compared to only 41% of non-autistic mothers, indicating that addressing stress, which might exacerbate or precipitate mental health difficulties, should be a key concern for autistic mothers' well-being.

Overall, participating mothers described some considerable struggles interacting with professionals, believing that both being autistic and knowing a lot about autism made it harder to advocate for their children, as Katharine explained:

> I read a blog when going through assessments with my son. It was telling parents how to get the best out of professionals. How to flatter them and use specific wording so you didn't come across as knowing what you are talking about. I find this horrific. I am rubbish at flattery, if I know something about my child, I shouldn't have to not discuss it because a [doctor] might see me as an insufferable know it all. Professionals working with autistic children should know that the mothers they

> see are very possibly autistic too, and as such will have researched the hell out of whatever is going on.

Despite her horror at the advice, Katharine felt she had to hide her knowledge of autism as a way to "flatter" professionals as a way to not appear too knowledgeable and arrogant, sensing that her "knowledge of autism" went against her. Hiding your own knowledge and expertise in an attempt to improve outcomes is another facet of impression management, but instead of adopting it to project competence, as explored in sub-theme 2.2: 'I'm the queen of camouflaging', here it is used to project incompetence and deference.

Whilst Katharine attempted to downplay her knowledge to appear more amiable, Lydia wanted to avoid being seen as too emotional, or "hysterical", and to appear as knowledgeable. In fact, Lydia was "told off" by a headteacher for "questioning her expertise" when she requested classroom adjustments to support her daughter's needs, and found that it was more productive to present in a more "detached" manner:

> When I was going through the EHCP process with my eldest daughter, I always made myself act in a detached an unimpassioned way so I wouldn't be accused of being hysterical, but the school's staff took offence at this and my knowledge of SEND laws.

As these experiences demonstrate, working out how to communicate with disbelieving and dismissive professionals presents a challenge for autistic mothers as they try to find ways to be taken more seriously. Furthermore, guidance aimed at supporting advocacy for non-autistic parents, as Katharine found, can be impossible to implement by autistic parents.

These experiences potentially evidence sexist attitudes which are influencing how autistic mothers are perceived by professionals in relation to gendered role expectations. Using social role theory (Eagly and Wood, 2011), which explains the social roles for women and men as socially constructed with women expected to be more communal, nurturing, and passive (i.e., feminine), and men more agentic, assertive, and dominant (i.e., masculine), there is scope to consider Katharine, Lydia and other participant experiences of not being taken seriously to be rooted in expectations of gender. Borrowing from research which examines impression management using social role theory in organisational contexts, this quote articulates the conflict for women:

> Feminine-typed impression management tactics, which are often successful in a social setting, may not necessarily create the desired impression in an organizational setting, where traditionally masculine-typed behaviors (e.g., assertiveness) are usually rewarded. In addition, even when men and women use the same impression management style, they may be perceived differently due to gender role expectations. For instance, although some women learn to behave in a more assertive, masculine-typed manner (e.g., engaging in self-promotion rather than modesty), these kinds of impression management tactics are a violation of normative expectations based on gender roles and may lead to negative consequences rather than to rewards. (Guadagno and Cialdini, 2007, p. 485)

Thus, feminine-typed behaviours fail to “create the desired impression” to be taken seriously and masculine-typed behaviours result in “negative consequences” (ibid.) As autistic women often struggle to conform to gendered role expectations (Kourti and MacLeod, 2019) this can result in yet another double-bind for autistic mothers who face distrust (of their information) when they hide their knowledge and are ‘just a mum’ and equally face disapprobation (of their behaviour) when they assert their knowledge and are not ‘mum-enough’.

Sub-theme 6.3: I have a need to know exactly what something is about

Participants were asked to talk about the knowledge required for mothering generally and for being a mother of autistic children. When asked directly, most downplayed their knowledge, despite their interviews demonstrating extensive, deep, and thorough "authoritative knowledge" (Landsman, 1998, p. 82) relating to autism, autistic mothering, and advocating for autistic children. This sub-theme considers participants' drive to develop specialist knowledge and expertise to help with supporting their children, and how special interests support effective advocacy.

In response to being asked whether mothers need a lot of knowledge to do it well, participants were fairly consistent in their responses that little knowledge is required:

> No, I don't think so. Factual information to keep them alive so things like safe sleeping etc. (Clare)
>
> I don't think all mothers necessarily need to have a lot of knowledge about raising children to do it well. (Audrey)
>
> I'd say the right knowledge and support rather than amount of knowledge. (Bethan)
>
> I think children need a warm, safe home with food and clean clothes, and parents who listen to them and take their needs seriously. I found parenting hard, so I researched a lot, but it wasn't necessary for parenting really. (Jenny)
>
> You do need some knowledge, such as when to contact a GP, when to seek help if there is something wrong with the child, basic first aid, knowing where to ask about stuff. (Hope)

These extracts reveal the often hidden and undervalued knowledge required of mothers, as participants spoke of learning to understand their children's needs, safe sleeping, feeding and nutrition, and medical and first aid awareness. The knowledge and skills required of mothers have previously been conceptualised as ‘maternal thinking’ (Ruddick, 1989, p. 13) and ‘motherwork’ (Porter, 2009, p. 191), where the maternal expertise of mothers is presented as specialist and complex work, thus challenging the idea that mothers’ knowledge and skills are of little value and come from nowhere. In fact, women learn this maternal expertise from a rich range of sources, including family, friends, books, medical advice, and online forums alongside their own experience (Whidden, 2012).

Participants were, however, more forthright about the additional knowledge required for mothering their autistic children, and started to talk about developing their expertise, as Janet explained:

> I think it certainly helps to have that knowledge, but I don't think it’s necessary to have it beforehand to be a good mother. A lot of mums learn as they go. But I do think that mothers need to learn one way or another about their own children and what they need, or the child won't be supported in the best way possible ... I do think [being an autistic mum of an autistic child] requires more knowledge. More understanding of why your child behaves differently, why they may present differently to you, and you need to understand that what works for you may not work for them.

Janet’s observation that “a lot of mums learn as they go” is an important one and, as most participants were unprepared for having an autistic child, or being autistic themselves, they had to learn about autism as they went. Bethan talked of the “different knowledge” needed to support an autistic child:

> I think different knowledge is needed. Especially how to navigate the school stuff. No one teaches you about EHCPs and IEPs and SENCOs it's like another language.

> That's the system making it hard though. I actually don't find the parenting as hard as those things ... It's all really hard to navigate.

As participants discovered, there was a lot to learn, for “[h]aving a disabled child is typically an unfamiliar experience and families start from scratch on an unexpected journey.” (Runswick-Cole and Ryan, 2019, p. 12), and participants considered their tendency towards developing ‘special interests’ to be advantageous in this quest.

Autistic ‘special interests’, traditionally located alongside ‘repetitive behaviours’ in medical texts and diagnostic schedules, are often considered a “hallmark of autism” (Krauss, 2023, para. 1). In such framing, special interests are often qualified as *autistic* special interests as a way to differentiate from *non-autistic* special interests, which are more commonly termed “hobbies” (Jordan and Caldwell-Harris, 2012, p. 391), a somewhat more benign and considerably less pathologising label. However, the level of specialist expertise developed by participants who talked about their special interests in autism and related matters does not easily fit into the realm of hobbies, as these excerpts demonstrate:

> I learnt the SEND Code of Practice and could quote it at any point. I also liaised with the head of a national SEND charity and my local MP who brought pressure to bear. It consumed my every waking moment for 18 months. (Lydia)
>
> I've also developed a [special interest] in SENDIST law while going through the EHCP process, which was helpful. (Victoria)
>
> My special interest in autism (which grew into a job role) definitely initially stemmed from my own children being autistic. (Audrey)
>
> When I understood that my son was likely autistic, I spent as much time as possible reading about it, reading various blogs, books, parenting books, charity websites. Through this I learnt more about PDA and spent hours every day trying to find

> information to try to persuade my son's teachers to help him. This led to becoming a PDA society trainer ... I also went to university with the aim to gain a Master's degree in autism. I stopped after the first year as I couldn't juggle the work with childcare. I'd like to think that one day I will use what I've learned in a paid role. (Katharine)

In these extracts, and across the interviews more broadly, participating mothers demonstrated extensive and specialist knowledge and expertise relating to autism, child development, education, learning, interventions and SEND law. This is aligned with Schall's (2000, p. 415) research into families of autistic children where she commented on the "highly technical terms" and "highly technical strategies" used by parents of autistic children. Furthermore, this also supports the findings of Gillespie-Lynch et al. (2017, p. 11) who "demonstrate[d] that autistic people should be considered 'autism experts' as they often build upon insights derived from the lived experience of being autistic by researching systematically." Importantly, participants were able to use the knowledge they gained through their special interests in their support and advocacy for their children.

One of the questions on a popular autism screening tool, the Autism Spectrum Quotient (Baron-Cohen, 2003, p. 215) is "I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.)." This question is designed to elucidate information about special interests but it fails to recognise that autistic people do not just collect knowledge as if it were things, but that we use our special interests to enhance our lives (Grove et al., 2018). For participating autistic mothers, actually using knowledge about autism, education and law is key to successful advocacy. Clare described herself as "a determined advocate for their health issues -

researching, learning, asking etc. and have not given up" and Lydia told me how "I just can't stop [until] I think everyone is doing what they should and will keep problem-solving to get the right outcome e.g. make friends with MPs and heads of SEND charities." Likewise, Emily explained:

> I think I have been their major advocate, and with the 'dog with a bone' attitude, I make sure we get what we need one way or another. Plus, obsessive interest in an interest can come in handy if that interest is autism ... I have a need to know exactly what something is about.

The use of the phrases "have not given up," "just can't stop." and "dog with a bone" reflect the tenacious advocacy of participating autistic mothers, who are, as demonstrated earlier in this theme, undertaking their advocacy in an often hostile and disbelieving environment. Whilst participants did provide examples of respect and recognition for their knowledge, for example, Emily spoke highly of her GP who "has always taken any issues seriously and listened, and always followed up on things, referred me to specialists etc. I've never felt undermined or ignored", such experiences were in the minority. As Landsman commented in 1998, "[t]he ability to be angry enough to assert one's own knowledge about one's child, as opposed to accepting medical professional's opinions automatically, becomes for many the hallmark of nurturing and mothering a disabled child." (p. 83). Indeed, considering participant experiences of poor autism knowledge among some professionals, mothers of autistic children have little choice but to get angry and learn what they need to support and advocate for their children.

Summary and conclusion

This theme has considered participating autistic mothers' experiences in relation to their own and to other people's knowledge of autism. As the final theme developed here, it pays tribute to the extraordinary display of skills and knowledge exhibited by participants, evidenced in part through the use of longform excerpts from participant transcripts which serve to showcase the deep and thorough knowledge, thinking and awareness that participants have about autism and being autistic. Participant accounts of interactions with professionals were often hindered by outdated professional knowledge, stereotypes and myths of autism, where poor understanding of autism across the lifespan and the typically spiky profile common among autistic people presented barriers to accessing support, recognition and understanding. This was particularly problematic when accessing healthcare, where participants experienced disbelief about, for example, being in pain or discomfort, as they were not considered to be exhibiting expected external signifiers of their internal pain or discomfort, resulting in them not being taken seriously.

Not being taken seriously was a particular concern in participating mothers' role as the main informant in relation to their children, where being disbelieved about the nature of their children's difficulties and support needs resulted in a lack of support and, in some cases, lack of access to educational provision. Not being taken seriously was a source of considerable stress for some participants who found ways to try to minimise the dismissal of their observations and interpretations of their children's difficulties and behaviour. Participants were keen to avoid being seen as 'hysterical', resulting in some presenting as cold and clinical or overly compliant as they used impression management strategies when advocating for their children, or minimising and hiding their often-extensive autism and mothering knowledge. It is of note that participating mothers often downplayed their knowledge, which accords with broader societal assumptions that mothering is menial work, despite it requiring specialist and complex skills, as evidenced throughout, and even more so when mothering autistic and disabled children who require additional expertise from those who care for them. Importantly, despite considerable hurdles and barriers, participants were able to use the 'authoritative knowledge' they developed in the course of their mothering practice to become tenacious and effective advocates for their children.

My analysis in this theme has argued the case for recognising the often-hidden and marginalised knowledge, expertise and skill-set of participating autistic mothers of autistic children. I have demonstrated how participants develop considerable and authoritative knowledge which is often not taken seriously, and how participants both use and mask their knowledge in the process of advocating for their children.

Having outlined and presented my analysis of the themes developed in this thesis, and in recognition of the intersecting nature of the themes, the next chapter will present a cross-theme and theory-informed analysis and discussion to consider how I have answered my research questions.

10. Discussion: Theorising autistic motherhood

Introduction

This thesis has used reflexive thematic analysis to explore the experiences of autistic mothers of autistic children. The first three chapters introduced, situated and then presented the whys and hows of the actual research undertaken for this thesis. The previous six chapters have presented each theme in turn and, through the development of those six distinct yet connected themes, I have provided an important insight into the lives of the 12 participating autistic mothers. Throughout the process of theme development my research questions were at the back of my mind, providing a way to guide my thinking as well as giving me an occasional nudge when my thinking went too far off-piste:

- How do autistic mothers negotiate being autistic?
- How do autistic mothers navigate motherhood?
- How does being autistic affect experiences of motherhood?

Earlier in this thesis, I concluded Chapter 3 by reflecting on my theme development and how I might do it differently if I had my time over. Certainly, the theoretical discussion I present in this chapter could be incorporated into theme write-ups, though that would require a re-development and re-structure of the themes. Equally, however, the thinking which gave rise to this chapter would not have been possible without first developing, constructing and writing-up the themes. Such thinking serves to highlight the retroductive, recursive and reflexive nature of my methodological and method choices as my thinking and writing goes backwards and forwards. Furthermore, when I started to think about how to actually present the answers to my research questions, it was not as straightforward as particular themes and sub-themes answering particular questions, as this failed to take account of bigger picture patterns across the thematic analysis. Therefore, in this chapter I present some cross-theme patterns, a meta-analysis of sorts, developing and building on the knowledge created within the themes and sub-themes, as I consider conceptual and theoretical insights both to answer my research questions and to contribute to further understanding of autistic motherhood. To avoid in-text interruption and to aid clarity, Table 3 provides a schematic overview of research questions and associated sub-themes.

Table 2: Schematic overview of research questions and sub-themes

Research question	Associated sub-themes
How do autistic mothers negotiate being autistic?	
Neurodiversity and autistic 'homeplace'	*1.1. Affirmation of my autistic identity has been helpful* *3.2. I've had to make my own support network for myself* *4.2. Being an autistic mother feels like having insider information* *4.3. 'Against the norm' mothering* *6.3. I have a need to know exactly what something is about*
A consideration of masking	*2.1 There's a lot of pressure on mothers to 'fit in'* *2.2. I'm the queen of camouflaging* *6.2. They just see us as mum, who knows nothing*
Finding time to be autistic	*1.1. It was like a lightbulb* *1.2. Affirmation of my autistic identity has been helpful* *4.1. You have to squash down your own needs* *5.1. Mum is the one who keeps things in place*
How do autistic mothers navigate motherhood?	
A matricentric feminist lens	*4.3. 'Against the norm' mothering* *5.1. Mum is the one who keeps things in place* *5.2. We get blamed a lot for our kids*
The same, yet different	*4.1. You have to squash down your own needs* *5.1. Mum is the one who keeps things in place* *6.2. They just see us as mum, who knows nothing* *6.3. I have a need to know exactly what something is about*
Being the 'good mother'	*2.1. There's a lot of pressure on mothers to 'fit in'* *4.1. You have to squash down your own needs* *5.1. Mum is the one who keeps things in place* *5.2. We get blamed a lot for our kids* *6.2. They just see us as mum, who knows nothing*
How does being autistic affect experiences of motherhood?	
Dis/abled mothering	*2.1. There's a lot of pressure on mothers to 'fit in'* *3.1. It's hard to get support from anyone who understands my kind of autism* *5.2. We get blamed a lot for our kids* *6.1. All sorts of myths float around to make up for outdated knowledge*
Autistic 'culturework' and activist mothering	*3.2. I've had to make my own support network for myself* *4.2. Being an autistic mother feels like having insider information* *4.3. 'Against the norm' mothering* *6.3. I have a need to know exactly what something is about*
The 'autistic mother advantage'	*1.2. Affirmation of my autistic identity has been helpful* *1.3. I didn't recognise the red flags* *4.1. You have to squash down your own needs* *4.2. Being an autistic mother feels like having insider information* *6.3. I have a need to know exactly what something is about*

How do autistic mothers negotiate being autistic?

This question seeks to ask how autistic mothers make sense of, and negotiate, being autistic. All of the study participants recognised themselves to be, or were diagnosed as, autistic during adulthood, typically following the recognition or diagnosis of their children. As a result, participants were often coming to terms with their own autistic identity whilst simultaneously supporting their autistic children with their own. With minimal, and often inadequate, post-diagnosis support, participants found their own ways to learn about autism and about being autistic. Importantly, despite the dominance of autism material based on a deficit-model of autism (Pellicano and den Houting, 2022), on the whole, participants embraced their own and their children's autism through a strengths-based model and the neurodiversity paradigm (Kapp et al., 2013). To answer the question posed above, this section will begin with a look at autism through a neurodiversity lens and how participants have incorporated the idea of neurodiversity into their lives and homes; before recognising the importance of masking as a core element of participants' autism stories; and will end by presenting an exploration of the challenges faced by autistic mothers of autistic children to meet their own autistic needs.

Neurodiversity and autistic 'homeplace'

As introduced in Chapter 1, the idea of neurodiversity is generally credited to Judy Singer (Graby, 2015; Milton, 2020; Singer, 2017) who conceptualised the term as a way to capture the vast diversity of human neurotypes. Rather than autism being viewed as something aberrant and a diversion from the norm, from within the neurodiversity paradigm, autism is just one of many variations of the norm where, like the biodiversity of the natural world, heterogeneity is valued and considered crucial to sustaining life.

Thus, neurodiversity “includes everyone: both *neurodivergent people* (those with a condition that renders their neurocognitive functioning significantly different from a ‘normal’ range) and *neurotypical* people (those within that socially acceptable range).” (Kapp, 2020, p. 2). The neurodiversity *paradigm* underpins the neurodiversity *movement* and represents, and seeks to uphold the human rights of, neurodivergent people, as Graby (2015, p. 233) explains:

> The neurodiversity movement grew primarily out of self-advocacy by autistic people, which began to emerge in the 1990s in response to the growth of a parent-dominated ‘autism advocacy’ lobby. In response to the latter’s search for a ‘cure’ for autism, neurodiversity activists argued that it and similar conditions should be seen not as pathologies needing a ‘cure’ but as natural differences which should be accepted and accommodated.

The influence of neurodiversity, as paradigm and movement, can be seen across the dataset. Participants frequently used neutral or positive terms to describe being autistic and autism in general (neurodiversity paradigm) and pushed back against negative perceptions from their experiences with other people and professionals through self-advocacy, influenced, supported and aided by the wider autistic community (neurodiversity movement).

Through their self-advocacy and advocating for their children, autistic mothers are undertaking vital, and often hidden, activist work as part of the neurodiversity movement. This can be seen in participant accounts of battles with schools to support their children’s needs, where mothers advocate for their autistic children’s right to an education, something often denied contrary to Article 26 of the Universal Declaration of Human Rights (United Nations General Assembly, 1948). Importantly, and aligned with the neurodiversity movement, participants were not seeking to cure or change their children, rather they were advocating for their inclusion through adaptation and respect for their differences. At times this presented a conflict for participants who felt forced to use pathologising and deficit-based language and concepts to describe their children as a way to access services and supports, whilst in private, in autistic and neurodivergent spaces and at home, autism and neurodivergence were accepted and valued as their 'normal'.

Home, especially, was a place of acceptance for most participants, though not without its own challenges and conflicts of needs, of course, but often providing sanctuary and respite from the world outside (Marriott et al., 2021). In such accounts, home is presented as a place for participants and their children to be themselves, to be unfettered in their autistic being, and free of the restrictions and expectations imposed by neuro-dominant norms. I am reminded of bell hooks' description of 'homeplace' as "a site of resistance and liberation struggle" (2015, p. 43), where black women created homes which provided nurture, care and "a safe place where black people could affirm one another and by doing so heal many of the wounds inflicted by racist domination" (p. 42). Participant descriptions of their family homes as places where autistic identity is accepted, celebrated and unchallenged, where family members can be autistically autistic, and not mask, camouflage or stifle their autism, where defiance at normative expectations is expressed, and where the work of advocating for their children's rights begins, presents a picture of an autistic homeplace.

A consideration of masking

Masking was an important feature in participants' autism stories, where autistic mothers described a double-burden of masking as they masked both for themselves and their children. Participants described how they had masked largely unconsciously until learning about autism and realising they were autistic, how masking was a hard habit to break, and how it could have a deleterious effect on mental health and well-being, but also that it was a useful skill, which they could utilise in specific situations to achieve specific goals. During the course of interviewing, I began to notice these two potentially distinct forms of masking in participant accounts and started to use the term 'strategic' to describe the latter form of masking, which resonated with some participants. Likewise, Seers and Hogg (2022, p. 7) described how for their participants, "masking was presented as a natural, subconscious performance and a deliberate, strategic behavioural tool used to manage and cope with social interactions." Thus, in Theme 2: '*Masking is a real double-edged sword*' I explored the distinction between masking to fit in and masking as impression management' and here I want to briefly reflect on this distinction and consider whether it forms the basis of a different, and perhaps useful, way to think about and theorise masking.

Masking, or camouflaging, the terms are often used inter-changeably, can be described as "the use of strategies by autistic people to minimize the visibility of their autism in social situations." (Schneid and Raz, 2020, p. 2). Masking research typically considers how autistic people mask in social settings, with their family and friends, and in education and the workplace (for example, Cage and Troxell-Whitman, 2019), the sort of settings where autistic people might spend sustained or repeated periods of time, and where the potential burden of masking can be extensive. Distinctions between types of masking are represented in the literature, for example, as “natural and planned” (Seers and Hogg, 2021, p. 8), relational and conventional (Cage and Troxell-Whitman, 2019), “impression management and social camouflaging” (Schneid and Raz, 2020, p. 6), and “conscious and unconscious” (Bargiela et al., 2016, p. 3290), but I would like to propose an alternative which, based on my participants’ experiences, and my own interpretations, presents a different way to think about types of masking.

Fundamentally, masking is a form of imitation, “where the acts of another person serve as a model” (Uzgiris, 1981, p. 2) in this case where autistic people attempt to be more like or more liked by neurotypical people. Drawing on previous research on imitation and conformity, Over (2020) outlines the social process of imitation and defines *social* imitation as using imitation as a way to integrate into social settings, and *instrumental* imitation as using imitation as a way to develop skills. Framing masking as both and distinctly social and instrumental provides an opportunity to consider the benefit of masking as a skill, without disregarding the impact on well-being and identity which comes from masking to assimilate. In this framework, social masking is the type of masking which is typically the focus of masking in autism literature, where autistic people attempt to mask or hide their autisticness as a way to fit in or to be unobtrusive. Social masking represents the lifelong “pretending to be normal” (Holliday Willey, 1999, p. 14) experienced by most late diagnosed women, and which is well known to be detrimental to well-being (Cage and Troxell-Whitman, 2019) and have a negative impact on identity (Miller et al., 2021). Instrumental masking, however, theorised here as brief, time-bound, situation specific and where the potential benefits greatly outweigh the costs, was used by participating mothers in their interactions with professionals, through learning the language, culture and expected norms of professionals and how best to present as an advocate for their children. Whilst it was often exhausting, and required preparation beforehand and recovery time afterwards, instrumental masking did not appear to have the same effect on well-being and identity that resulted from social masking.

Finding time to be autistic

Theme 1 '*Knowing I'm autistic helps me to understand myself*' examined the 'biographical disruption' (Bury, 1982) of self-realisation or being diagnosed as autistic in adulthood experienced by participants, and which resulted in considerable reflection and adaption as participants came to terms with actually being autistic. Elsewhere, participants reported often neglecting their own autistic needs as they juggled their work, home and family life, typically prioritising their children's autistic needs over their own. Hence, finding time to adjust to their new identity, to meet their own sensory needs and pursue their interests was all too often neglected. In their roles as mothers of autistic children, participants experienced the "temporal layers of caregiving" (Dash et al., 2023, p. 9) as both a daily and potentially lifelong responsibility, needing to pause or slow down life-plans resulting in the shifting, interrupting, slowing and halting of time, perhaps experiencing "crip-time" which "refuses to define itself in terms of either the ideal or the average: Schedules for work, parenting and the social are thus shaped by individual needs, desires, and abilities, rather than by regimented economic and cultural imperatives" (Samuels, 2006, cited in Kafer, 2013, p. 34). Such temporal disturbance is reflected in our mothering journeys, as our children tread their own developmental pathways, the forwards and backwards and typically atypical and unpredictable trajectories of what is normatively termed ‘progress’. And at every stage, on every day, for as long as is necessary, we are on-call, resulting in much of our time being spent in anticipatory fragments.

These temporal disturbances are, of course, not exclusive to autistic mothers of autistic children, but this thesis is concerned with autistic mothers and, in this context, autistic inertia (Buckle et al., 2021) and monotropism (Murray et al., 2005) present useful conceptual tools to explore how autistic mothers do and don’t find time to meet their own autistic needs. Autistic inertia “describe[s] difficulties both starting and stopping activities, which are commonly experienced by autistic people” (Buckle et al., 2021, p. 2), where we get stuck and are unable to move from one thing to another, even if the new thing is enjoyable or important, irrespective of intrinsic or extrinsic motivation, and often resulting in distress. Buckle et al.’s (2021, p. 14) research found that autistic people “found it easier to do anything where another person was depending or counting on them … and most difficult to do something only for themselves” and this might account for how autistic mothers are able to quickly task-switch to respond to their children’s needs, but often struggle to switch off from focusing on their children’s needs to find or make time for themselves and to meet their own needs. Autistic inertia draws on work on monotropism (Murray et al., 2005), which presents an interest based model of autism, where autistic interests are focused across a narrow yet deep area, in contrast to the typically broad areas of interest held by non-autistic people, resulting in and explaining the “all or nothing thinking” (Murray, 2018, p. 1) stereotypically typical of many autistic people. Importantly, immersion in interests can result in a positive and replenishing flow state which, when disturbed, requires time to settle. Thus, in the context of participants tasked with managing the multiple requirements of mothering their autistic children, as Lawson writes in Murray et al. (2005, p. 152) “the demand of having to ‘pay attention’ to so many things, simultaneously, is a nightmare.” Monotropism also helps to explain how interest in autism was often described as a special interest by participants, frequently leading to high levels of expertise, but may also contribute to the heightened stress and anxiety some participants experienced, as being on-call frequently results in interruptions, creating difficulties with maintaining flow states. Being aware of the disruption of interruption can mean we are hesitant to commit to our own interests or sensory needs for fear of being interrupted, further reducing the time available for us to attend to our own autistic needs and to *be* autistic.

How do autistic mothers navigate motherhood?

This question seeks to ask how autistic mothers make sense of, and navigate, being a mother. Mothering is a valuable, though not always valued, role, and participant stories were overall positive about motherhood whilst also realistic about the challenges and impact of mothering on their lives. Most participants became mothers before recognising that they were autistic, or that their children were also autistic, meaning that they entered motherhood with expectations of how it would be, but which would need to be adjusted as they learned more about autism and being autistic. At the time of writing, studies of autistic motherhood have tended to sit within the bounds of autism research and have yet to fully engage with mother-centred, matricentric feminist research. To address this and to answer the question posed above, I intend here to first situate autistic motherhood within the matricentric feminist tradition which asserts that "mothers need a feminism of their own" (O'Reilly, 2019, p. 13); and then to consider how autistic motherhood is both the same and different to normative motherhood; and end with a look at the influence of "intensive mothering" (Hays, 1996, p. x) and how cultural representations of mothers may influence autistic mothers.

Matricentric feminism and situating autistic motherhood

My choice to research mothers rather than the broader category of parents was both personal and political. Personal because I am a mother and political because I am a feminist. For autistic mothers and mothers of autistic children, where research often reports on parents, presenting research as "gender-blind" (Ryan and Runswick-Cole, 2009, p. 44) renders mothers invisible. To explore autistic motherhood through a matricentric feminist lens begins with recognising that the social roles of mother, father and parent are different, and that the category of mother is socially, economically and politically important. In my attempt to locate experiences of autistic motherhood within matricentric feminism, I am conscious that disability is largely absent from the matricentric literature (Douglas et al., 2021) and that when autism is included, the focus has been on mothers of autistic children (for example, Colón, 2022) rather than autistic mothers. Nevertheless, matricentric feminism offers the study of autistic motherhood a way of theorising mothering and motherhood as a socially situated and skilled practice, as O'Reilly (2019, p. 16) explains:

> [M]atricentric feminism understands motherhood to be socially and historically constructed, and positions mothering more as a practice than an identity … central to matricentric feminist theory is a critique of the maternalist stance that positions maternity as the basis of female identity … matricentric feminism challenges the assumptions that maternity is natural to women … and that the

> work of mothering is driven by instinct rather than intelligence and developed by habit rather than skill.

Thus, to mother raises different connotations than to father, and the social expectations placed on mothers are especially felt by mothers who, like the participants here, do their mothering 'against the norm'. Furthermore, whilst mothering is often a private act, for autistic mothers of autistic children our mothering practices are frequently on show, for public and professional view, and mother blame exerted a strong presence across the dataset. Participants were often left feeling unfairly judged and blamed for their children's difficulties and differences, reflecting Caplan's (2007, p. 592) work on mother blame and how "it seemed that there was nothing that a mother could do that was right." My focus on mothers, rather than fathers or parents, is also especially relevant in the context of the backdrop and legacy of autism literature which held mothers responsible for their children's autism, including the 'refrigerator mother' theory and the works of Bettelheim and others, as shown in Theme 5: '*Autistic mothers are judged and problematised by the same forces that police gender roles in society*'. Despite advancements in understanding, these long-abandoned ideas often remain in the popular imagination.

Mothers, therefore, have a particular relevance and place in the historic, public, academic and clinical representations and accounts of autism, in ways that do not apply to fathers. Parenting is a heavily gendered occupation (Dash et al., 2023) where mothers are almost always the responsible parent with all or most of the responsibilities. We are expected to mother our children, but often without the freedom to choose how we mother, as O'Reilly (2016) points out:

> First, mothering is assumed to be natural to women, and childrearing is seen as the sole responsibility of the biological mother. Second, mothers are assigned sole responsibility for motherwork but are given no power to determine the conditions under which they mother. (O’Reilly, 2016, p. 17)

Yet when mothers can choose how they mother, freed of the restrictions and expectations of the dominant motherhood ideology, it can be liberating. O’Reilly (2010), drawing on Rich’s work, describes how when mothers are freed from the restrictions of dominant motherhood ideology, the normative expectations of motherhood, they can become “outlaws from the institution of motherhood” (Rich, 1986, p. 195). This is redolent of the ‘against the norm’ mothering practices described by participants, where private mothering was distinct from public mothering, and it shines a light on how participating mothers felt constrained by social expectations of mothers in their public mothering. A conflict between the expectations and experience of motherhood is a common theme in the motherhood literature (Maushart, 1999). Balancing what is expected with what is possible and desirable is often a source of conflict, for women are “...free as individuals and constrained as mothers.” (Bueskens, 2018, p. 168). Whilst women have made gains in the social, economic and political sphere, these gains are then lost, in full or in part, when women become mothers. Asher (2012) described how the gains women have made are predicated on women continuing to have and raise children and do most of the domestic work. Moreover, even when families are more equal, mothers are seen as default parent and, as participants here reported, nurseries and schools typically call the mother first if there is a problem, and it is mothers who are expected to take time out of the workplace to attend to children’s needs.

The same, yet different

In many ways, at its core, autistic mothering is little different to non-autistic mothering, with mothers striving to keep children safe from harm, to encourage their development, to equip them for adulthood, and often to mediate between these distinct but interconnected and sometimes even competing demands. This work of motherhood was theorised by Ruddick (1989, p. 13) as "maternal thinking", as "what mothers do rather than upon what we are" (Ruddick, 1980, p. 346) and she is clear that the work of mothering need not be exclusive to women. Hence, she separates "birthing labour from mothering" (Ruddick, 1989, p. 49) on the basis that pregnancy, birth and breastfeeding can *only* be done by women but, in theory at least, everything else *could* be done by men, including maternal thinking. Her interest is in the way mothers think, and how our maternal thinking develops from demands placed on us, our own values and interests, and societal expectations. For Ruddick, maternal thinking is a form of "disciplined reflection" (1989, p. 24), analogous to scientific and religious enquiry and practice (1980, p. 348), and she positions mothering as a "highly complex form of work which, like all other types of intricate and specialized labor, involves complex intellectual and ethical challenges" (Edmonds, 2009, p. 204). Furthermore, maternal thinking locates this complex cognition within mothers, and not just "experts", as Ruddick (1989, pp. 10-11) remarks, "[a]s a young mother, the only 'maternal thinking' with which I was familiar was thinking about mothers and children by experts who hoped to be heard by mothers rather than to hear what mothers had to say."

As was seen across the dataset, and in particular expressed in Theme 6: '*If you're autistic it's presumed you don't know anything about anything*', where the knowledge, expertise and experience of participants was highlighted, maternal thinking for autistic mothers of autistic children extends over and above that which is required by non-autistic mothers of non-autistic children, becoming a sort of, to use a colloquialism, 'maternal thinking on steroids'. If anything, participants generally downplayed the knowledge and expertise requirements of typical mothering, as they were required to know and be able to do so much more than is typical. Recognising the skilled work of mothering matters, though, and the "belief that mothering requires no special skills says more about how we conceptualize skills than it does about motherhood" (de Marneffe, 2019, p. 98). Maternal thinking, therefore, provides a means to theorise, recognise and understand the vast array of skills required of mothers, including the additional requirements when mothering an autistic (or otherwise disabled) child and provides a rejoinder to those who consider motherhood to be un-skilled and menial work.

However, mothers don't just mother, many also maintain employment or self-employment and, again, whilst many of the pressures faced by autistic mothers of autistic children are akin to those faced by mothers of non-autistic children, participating mothers demonstrated the added challenges of autistic motherhood. The conflict between the responsibilities and expectations of mothers to both mother well and to work outside of the home has been widely reported and researched. Originally published in 1989, Hochschild's 'The Second Shift' (2012) presents research conducted between 1976 and 1988, providing an analysis of the extra work women do on top of their paid employment as part of their role as mother. Others have described the paradox of combining full-time work with full-time mothering (DiQuinzio, 1999) and how women enter motherhood thinking they can *combine* work and mothering and end up having to learn how to *juggle* work and mothering (Maushart 1999), because women are led to believe they can *have* it all, but quickly realise that they must *do* it all (Bueskens, 2018). Sayer et al. (2009) built on Hochschild's work with their comparative study of total work time in the USA and Australia, contending that the second shift is not easily separated into two discrete shifts, but that women incorporate their motherwork into their working day. Bueskens (2018) describes this as more of a double shift than a second shift, with mothers managing multiple workloads throughout the day, and this certainly represents the experiences of employed and self-employed participants here where flexible working accommodates the need to be on-hand for their children. Indeed, the often-extensive work required to develop expertise and to advocate for our autistic children could be considered to contribute to a third or triple shift[12] as many participants manage the usual work in and out of the home, as well as the work of supporting and advocating for our children, and not forgetting that several participants have multiple children with additional support and advocacy requirements.

Being the 'good mother'

> The difference between good and bad mothers is so vast and so far-reaching that it is no exaggeration to say that the good mothers of this generation are building the homes of the next generation, and that the bad mothers are building the prisons. (Barr, 1893, p. 408)

Notions of good and bad mothers are persistent and pervasive, from Victorians like Barr above, to Freud and Bowlby placing blame for any "disorders" firmly on mothers (Giles,

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[12] Previous studies have also indicated the presence of a 'triple shift' as an extension to work on the 'second shift' or 'double shift': Duncombe and Marsden's (1995) work adds in the emotional labour required of heterosexual women to maintain relationships with their male partners and keep their families happy; Schuldt (2011) uses it to describe the role of mothers who combine mothering with work and study.

2012, p. 123), to film and TV mothers showing us how to be a "supermom" (Douglas and Michaels, 2004, p. 132), and to social media's categorising of celebrity mothers as good, bad or good enough (Pedersen, 2016). The existence of "good mother myths" and "bad mother myths" contributes to the scapegoating of mothers (Caplan, 2007, p. 593), who are unable to achieve the expected standards, and who are blamed when things go wrong, a common experience for participating mothers and mothers of autistic children more broadly. Winnicott's (1986, p. 265) concept of the "good enough mother" provides a more realistic alternative to the unrealistic demands placed on mothers, suggesting that "it is unhelpful and unrealistic to demand perfection of parents, and to do so undermines the efforts of the vast majority of parents who are in all practical respects 'good enough' to meet their children's needs." (Hoghugi and Speight, 1998, p. 293). Yet, the pressure to be seen as a 'good mother' exerts a powerful influence over all mothers, which has been reflected in participant accounts and explored in Theme 4: '*A good mum wants the best for her children*'.

Hays' (1996) explored the phenomenon of what she terms "intensive mothering" (p. 12), which grew out of the post-war boom of interest in child development but really took off in the 1990s, and which she considers to be the dominant ideological model of mothering. Intensive mothering has three key demands: firstly, that mothers care for their children, and that if they are unable or unavailable then another woman should act as a stand-in; second, that mothers should expend considerable time, money and energies in raising their children; and third, that mothering is distinct from paid employment, rather it is something self-sacrificial and sacred. Mothers, expected to practise intensive mothering whilst simultaneously expected to work outside the home are, therefore, subjected to a “cultural contradiction” (Hays, 1996, p. 9) between the expectations of work and the expectations of home (reflecting DiQuinzio’s paradox of combining full-time work with full-time mothering noted in the previous section). Throughout her research, and echoing Ruddick, Hays presents a strong case for motherhood as a social construct, suggesting that it is “difficult to distinguish a ‘mother’s intuition’ from ideas arising from a woman’s social role, a woman’s upbringing, and the culture of motherhood” (Hays, 1996, p. 72). Douglas and Michaels (2004) build on Hays model of intensive mothering through their analysis of media representations of motherhood, which are often “...highly romanticized and yet demanding view of motherhood in which the standards are impossible to meet.” (Douglas and Michaels, 2004, p. 4). They use the term "new momism” (p. 4) to describe this phenomenon, where mothers are both celebrated and judged, alongside the expectation that mothers can and should do it all. The media representation of the “new mom” tells us that it is possible and desirable to combine professional dedication, ambition and achievement whilst holding the responsibility for raising a well-balanced and highly-achieving next generation. This is a big ask, and as Hays points out, it “suggests that all the troubles of the world can be solved by the individual efforts of superhuman women” (Hays, 1996, p. 177), which is reflected in the rise of the ‘feminine warrior autism mother’ (Douglas, 2013). Whilst there had been parenting books before, the emergence of neo-liberalist consumerism and the culture of individualism has meant that motherhood has become well and truly commodified, with expertise shifting from mothers themselves to ‘experts’ (Kawash, 2011), and what Ramaekers and Suissa (2012) describe as the “professionalisation of parents” (p. 23) conducted through magazines, books, parenting courses and policy. Mothering autistic children has not escaped this cultural shift, and participants spoke of the books, resources and training which they had consumed, in large part to enable better understanding of their children, but perhaps also to appear less emotional and motherly, and more professional and credible.

Despite attempts to present representative samples, and to reflect race and class in analyses, both “intensive mothering” and “new momism” largely reflect and project motherhood practices among the white, heterosexual, abled, middle-classes. Mothering practices outside of this demographic are all too often rendered deviant. This includes othermothering and community mothering, the formal and informal caring for a child within the community who is not her own, occurring among African-American communities in the USA (James, 1993). Runswick-Cole and Goodley’s (2018, p. 231) conceptualisation of the “disability commons” also presents a model for community mothering, as it describes how sharing care and planning for disabled children – the ‘maternal thinking on steroids’ described earlier – relieves some of the burden placed on mothers to do it all. For participating autistic mothers, often geographically and socially isolated, the use of online groups and forums were often key sources of support, where both autism and mothering knowledge and expertise were shared. Participants often developed a deep empathy and understanding of their virtual friends, supporting their advocacy and ‘against the norm’ mothering practices, and presenting a model of virtual community mothering to push back against the highly individualised mothering practices and unachievable demands of intensive mothering.

How does being autistic affect experiences of motherhood?

This question seeks to ask how autistic mothers' mothering experiences are affected by being autistic. It was evident across the dataset, and the analysis presented in the previous chapter, that being autistic was a significant factor in participant experiences of motherhood. For disabled mothers, faced with the pervasive ideal of the 'good mother', as Daniels (2019, p. 120) remarks, "it can take extraordinary levels of emotional and physical labour to try to perform the idealised mother role, and even more to resist and refuse such limiting narratives and forge new connections and resources for enacting motherhood." To consider how being autistic impacts being a mother I open with an exploration of the impact of disablism and ableism and draw upon the work of feminist disability studies to shed light on autistic women's experience of motherhood; I will then examine how being autistic and mothering autistic children has resulted in autistic 'culturework' and maternal activism; before presenting a case for the 'autistic mother advantage' in raising autistic children.

Dis/abled mothering

Participants experienced both disablism and ableism in their lives as autistic mothers of autistic children. Disablism, conceptually located within the social model of disability which distinguishes between impairments located in the person, and disability located in broader material structures and conditions, presents a "corrective to the medicalisation and individualisation of disability" (Goodley, 2014, p. 6), positioning disablement in the "social, economic and cultural barriers that prevent people with impairments from living a life like their non-impaired brothers and sisters." (Goodley, 2014, p. 7). Participant experiences of disablism are evident across the dataset, where accounts of discriminatory attitudes and practice, inaccessible services and provision, rigid and inflexible procedures, and exclusion or limitations in accessing education and work, result in barriers and restrictions which restrict and impinge upon full economic, social and community involvement. In contrast, ableism, which I touched on in chapter three when I discussed generative mechanisms, has been theorised by Campbell (2009) as being:

> …deeply seeded at the level of epistemological systems of life, personhood, power and liveability. Ableism is not just a matter of ignorance or negative attitudes towards disabled people: it is a trajectory of perfection, a deep way of thinking about bodies, wholeness, permeability and how certain clusters of people are *en-abled* via valued entitlements. Bluntly, ableism functions to 'inaugurat[e] the norm'. (Campbell, 2009, p. 5)

Ableism, then, according to Campbell (2009) presents an ontological alternative to disablism, where instead of viewing disability through a lens of normative and other, where normative must adjust to meet the needs of other, it challenges the normative/other binary. Instead, ableism is concerned with the valorisation of an idealised, abled, human type, "a belief that impairment or disability (irrespective of 'type') is inherently negative and should the opportunity present itself, be ameliorated, cured or indeed eliminated" (Campbell, 2009, p. 5). Ableism is also present in 'Internalised ableism' (Campbell, 2008), which refers to how "disability self-hatred" (p. 155) is internalised as a result of the hegemonic influence of ableism, that is, the idea that disabled people are other or lesser and that being 'able' is the desirable goal and expectation, becomes embedded in our minds. One potential example of this is through the practice of autistic masking (Pearson and Rose, 2021), where we suppress the visible signifiers of our difference as a way to appear 'normal', a practice which has had a profound effect on participant experiences of autistic motherhood, where the double-burden of masking for themselves and their children presents a compelling and often seemingly unavoidable force.

Having introduced the concepts of disablism and ableism and considered how these help with understanding how being autistic might affect experiences of motherhood, through disablist structural barriers and ableist dominant ideologies, I want to briefly explore the contribution of disabled motherhood scholarship. Where disablism helps us with understanding the barriers faced by disabled mothers (see Malacrida, 2009; Malacrida, 2019), including participating autistic mothers, ableism helps us with understanding the influence on participants of such idealised notions of what is normative, normal and acceptable, and contributes to the insidious and often unachievable, expected standards of 'good mothering'. Thus, Daniels (2019, p. 116), in her research into ableism and motherhood, asserts that "the 'approved' mother holds a number of valued characteristics: physical dexterity; fast pace; endless energy; emotional, mental and physical stability; and is self-contained, independent and autonomous" resulting in an idealised and ableist state of normative motherhood, which is inaccessible to many disabled mothers. She further argues that the devaluing of attributes of motherhood such as "kindness, love, support, tolerance, acceptance, interconnection and co-operation" (p. 116) in dominant mothering ideologies such as "intensive mothering" (Hays, 1996, p. x), which are evident in participant accounts, and discussed earlier in this chapter, contribute to ableist notions of the 'good mother'. Likewise, Spradley (2023, p. 120) explores how in the socially constructed requirements of intensive mothering the "good" mother is cast as the "biologically or medically abled" mother, however, as she points out, some mothers resist, creating their own cultural framing of what counts as ‘good’ mothering, as seen in the ‘against the norm’ mothering of participating autistic mothers.

Autistic ‘culturework’ and activist mothering

Rejecting or subverting normative mothering expectations is explored in Longman et al.’s (2013) comparative study of mothering practices with migrant and adoptive mothers in Belgium. She uses the concept of ‘culturework’ to describe how “mothers negotiate prevalent ideologies of mothering that are often exclusionary of their own and their children’s sense of identity and belonging” where “[t]heir mothering involves building new networks and strengthening their children’s identities in culturally creative ways” (Longman et al., 2013, p. 385). Such ‘culturework’ is evident in participating mothers’ accounts of supporting their children and as discussed earlier in this chapter, through creating an ‘autistic homespace’ where ‘against the norm’ mothering supports children’s differences and fosters a positive autistic identity. As Frederick et al. (2019, p. 174) explain, this culturework represents a way to push back against stigma and shame, presenting mothers with an opportunity to “cultivate resilience, patience, and problem-solving in their children.” For participating autistic mothers this presents an opportunity to provide our autistic children with an understanding of autistic identity from an early age, something those of us whose autism was late-diagnosed/recognised often feel we missed out on. Furthermore, values of social justice are embedded in this culturework (Frederick et al., 2019), representing a form of maternal activism located or initiated from within the household, and supporting Mendoza’s (2023, p. 3) “provisional understanding of maternal activism as an ongoing deployment of caretaking functions sustained through direct action inside the household and beyond." In the context of autism, maternal activism has tended to be most visible in the "feminine warrior" autism mother (Douglas, 2013, p. 167) who fights for cures, treatment and prevention of autism (Goldsmith, 2021), in stark contrast to the often-invisible maternal activism of the autistic mothers participating in this research.

However, participants did not appear to think of or describe themselves as activists or of doing activism and, in part, this might be the result of perceptions of activism and activists. As Craddock (2019) explored in her research examining the gendered nature of activism, the *ideal* activist "is male [and] narrowly defined by doing 'enough' of the 'right' type of activism (direct action)" (p. 138), whilst "women tend to face structural availability barriers to political participation that are related to caring responsibilities" (p. 148). Yet, for participating mothers and their children, resistance to normative and abled expectations, and the accompanying advocacy for their and their children's rights, begins at home and is *rooted* in their caring responsibilities. Indeed, were it not for my own child being autistic, I would not be conducting this research and presenting my own resistance to the norms of motherhood and neuro-normativity. Thus, participant accounts of advocating for themselves and their children, asserting and sharing knowledge with other autistic mothers about legal rights, often through the practice of online consciousness-raising and virtual community mothering, and generally demanding better for their children, represent forms of activism, embodying the aims of both feminism and the neurodiversity movement. If an activist is "someone who is active in campaigning for change, normally on political or social issues" (Council of Europe, 2023) then participating mothers are, indeed, activists.

The 'autistic mother advantage'

The idea of an "autistic advantage" was reported by Russell et al. (2019, p. 124) who found that, whilst autism "traits" can be both positive and negative, particular autism-associated skills such as "hyperfocus, attention to detail, good memory, and creativity" (p. 130) can be valued attributes, presenting a counter to the "tragedy narratives" (p. 130) of deficit-based understandings of autism. In Theme 4: '*A good mum wants the best for her children*' I suggested that autistic mothers of autistic children have an advantage due to our insight into being autistic, and earlier in this chapter I considered the benefit of monotropic interests in developing specialist knowledge to help and support our children. In combination with Theme 6: '*If you're autistic it's presumed that you don't know anything about anything*', where I highlighted the knowledge and expertise held by participating mothers, a pattern emerges of distinct advantages in being an autistic mother to autistic children, a pattern which challenges the dominant medical model of autism with its focus on deficits and impairments. As shown in Chapter 2, autism knowledge was, for a long time, located in the clinical and scientific domains, and it was not until much later that autistic people began to present their own knowledge of autism "from the inside" (Williams, 1996, p. viii). The growth of autistic scholarship[13] and participatory research has further contributed to and prompted alternative framings of autism research, which "view autism as a form of diversity rather than a pathology" (Gillespie-Lynch et al., 2017, p. 1) but, as I found for myself when I initiated my literature review, such research remains in the minority in comparison to the mass output of clinical and scientific autism research where autistic people are often treated as the

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[13] Autistic scholarship is defined broadly here and includes, but is not limited to, academic and non-academic writings, autobiographies, blogs and other informal works.

"anthropological object" (Tyler, 2020, p. 229) rather than as "critical autism experts" (Gillespie-Lynch, 2017, p. 1).

Participants' own experiences of being autistic, and of the perceived disadvantages of growing up not knowing they were autistic, presented a strong influence on how participating mothers engaged with autism knowledge with their children (as per Crane et al., 2021b). Participants were highly empathetic to their children's needs, recognising the distress of, for example, sensory and motor difficulties or food and clothing aversions, which might be difficult to understand for people who have not experienced this and who might dismiss autistic distress as over-reacting or attention-seeking. Furthermore, in refusing to pathologise their children's behaviour, difficulties and differences, participants' experience and knowledge contributed to a strengths-based approach (Urbanowicz et al., 2019), supporting their children in developing a neutral or positive autism identity, in alignment with the neurodiversity paradigm and, importantly, contributing to improved mental health outcomes for their children (Cooper et al., 2017).

Moreover, where existing research sometimes indicates that mothers of autistic children report lacking in knowledge and understanding of their autistic children's development and behaviour (for example, Papadopoulos, 2021), autistic mothers participating in this research demonstrated extensive "authoritative knowledge" (Landsman, 1998, p. 82) and "intimate expertise" (Lilley, 2011, p. 4) in relation to their autistic children, reflecting both their general autism knowledge and their intimate understanding of their children. Yet, as evidenced by participants' experiences with professionals, and as Macgregor

(2021, p. 597) points out, the “unorthodox knowing” of maternal expertise, i.e., the expertise gained through experience or other “unconventional” means, is often disregarded by professionals or “dismissed as subjective and unreliable.” The ‘autistic mother advantage’, therefore, represents a means to acknowledge the authoritative knowledge, intimate expertise and unorthodox knowing of autistic mothers as autism experts, countering the notion that expertise belongs entirely within the realm of professional ‘experts.’

Summary and conclusion

Drawing on my thematic analysis, both by expanding upon the conceptual and theoretical interpretations therein and through conducting this complementary and supplementary cross-theme meta-analysis, this chapter has presented ‘answers’ to my research questions. I have broadly located autistic motherhood within the theoretical paradigms and traditions of matricentric feminism and the neurodiversity paradigm, and within this framework I have been able to demonstrate how participating autistic mothers negotiate being autistic, navigate motherhood, and how being autistic affects experiences of motherhood.

In the next and final chapter, I will present a summary of this thesis, reflect upon its contributions and limitations, and consider the implications for research, practice and policy which result from this thesis.

11. Conclusion

The story so far

The aim of this thesis has been to contribute towards improving the understanding of, and knowledge about, autistic mothers of autistic children in the UK. Using interview data from 12 participating autistic mothers, I have used reflexive thematic analysis (Braun and Clarke, 2022) to answer the following questions:

- How do autistic mothers negotiate being autistic?
- How do autistic mothers navigate motherhood?
- How does being autistic affect experiences of motherhood?

This thesis has presented a series of overlapping stories, which cumulatively serve to answer the questions posed above. In Chapter 1 I opened with my own story of how this research project began with a somewhat terrifying presentation at a large conference, where I talked about being an autistic mother to an autistic child, and where I also outlined the social, political and definitional foundations of this thesis. In Chapter 2 I told a story of the research literature and asked, “what took you so long?” as I presented a storyline of my search for clues which might help with understanding why autistic mothers had been neglected and marginalised within autism research for so long, and to better understand some of the enduring assumptions and stereotypes which continue to haunt us, ending the chapter with an appraisal of the recent emergence of research exploring the experiences of autistic mothers. Chapter 3 began with the story of my thinking about doing this research, as I laid out the philosophical and methodological considerations and foundations of this research and explained why I opted for a critical realist ontological and epistemological approach to research, explaining how it enabled me to examine real world structural barriers and influences through the lens of participants' experiences, and to consider barriers and influences beyond those identified by participating autistic mothers.

Underpinning the whole thesis, as introduced in Chapter 1 and considered again in Chapter 3, was my commitment to conducting highly ethical research, informed by the feminist slogan “the personal is political” (Hanisch, 1969) and the disability rights slogan “nothing about us, without us” (Charlton, 1998), reflected in my commitment to participatory research and autoethnography and, through my use of friendship as method, my commitment to an ethic of care. Chapter 3 ended with the story of my data analysis and described how I used reflexive thematic analysis, a systematic yet flexible method of qualitative data analysis, to develop six meaningful themes and their associated sub-themes. Chapters 4-9 presented my interpretation and analysis of participating autistic mothers' stories through those six themes and their associated sub-themes. The themes and sub-themes each and together tell a story: of the lightbulb moment of self-realisation as autistic; the challenges of masking and accessing support; the joys and difficulties of mothering alongside the expectations of motherhood; and of finding ways to resist and kick back, finding creative solutions and developing expertise. Chapter 10 tells a different kind of story, as I conducted a meta-analysis and examined autistic motherhood through a consideration of cross-theme patterns and conceptual and theoretical insights and speculations. Organised around my research questions, the tenth chapter provided another layer to my interpretation of participant stories as I sought to further enhance understanding of autistic motherhood and consider new ways of telling participants' stories of autistic motherhood.

Answering the research questions

My pluralist approach to feminist and disability studies was particularly evident in Chapter 10's cross-theme meta-analysis where I sought to answer my research questions. Here, I was able to think bigger, and to think speculatively, as I began to identify different and sometimes novel ways to provoke thinking about and contribute towards understanding and knowledge of autistic motherhood. Before turning to the broader contributions of this thesis, I will briefly highlight the particular contributions to knowledge captured in my answers to the research questions.

How do autistic mothers negotiate being autistic?

To answer this question, I adopted a strengths-based and neurodiversity informed approach (as per Kapp et al., 2013), in alignment with existing autistic-led research on autistic motherhood and parenthood (for example, Dugdale et al., 2021; Gore et al., 2023; Heyworth et al., 2022; Murphy, 2021). However, to contribute to further understanding of the ways that autistic mothers promote a neurodiversity-informed approach to mothering, I introduced the concept of "homeplace" (hooks, 2015, p. 43) in order to articulate the efforts of participants to engender a sense of safety and sanctuary in the home, and where autistic family members could be themselves and be a place of resistance to neuro-normativity. A further contribution here was my theorising of masking as social and instrumental, drawing on research concerned with social imitation (Over, 2020; Uzgiris, 1981), and following my finding that some participants valued their masking abilities as a useful skill to deploy, and not solely as a way to mask their autism to fit in or avoid stigma, and how participating mothers experienced a double masking burden through masking both for themselves and their children. My final contribution to this question was a consideration of the impact of temporal disturbances and "crip-time" (Kafer, 2013, p. 34) and how, combined with the narrowed focus of autistic monotropism (Murray et al., 2005) and the stuck-ness of autistic inertia (Buckle et al., 2021), combine to limit opportunities for autistic mothers to meet their own autistic needs.

How do autistic mothers navigate motherhood?

To answer this question, I moved from autistic and autism theory towards adopting a matricentric focused approach. My combined use of critical autism studies and matricentric feminism in researching autistic motherhood is itself novel, and in answering this question a matricentric approach helped to enhance understanding of the gendered nature of the social construction of motherhood and its impact on autistic mothers. An important contribution was perhaps that whilst, at its core, autistic motherhood is not so different to any other *type* of motherhood, requiring many of the same core skills, the additional requirements and expectations placed on autistic mothers can be immense and overwhelming. My findings supported the idea that mothering is highly skilled, yet often undervalued, work (as per de Marneffe, 2019; Edmonds, 2009; Ruddick, 1989) and that the social pressures to both mother and work outside the home can result in a 'triple shift' (c.f. Hochschild's 'second shift') when the additional work of supporting and advocating for autistic children is considered. A final contribution to this question concerns my findings around the ways participants sought to both be and be seen as a 'good mother' and how dominant ideas of the 'good mother' contributed towards the seeking of knowledge and the use and development of supportive online spaces to share mothering expertise. Here I was able to draw on Black feminist conceptualisations of community mothering and othermothering (James, 1993) and the idea of a disability commons (Runswick-Cole and Goodley, 2018) and conceptualise autistic mothers' online communities of support and information sharing as a form of virtual community mothering.

How does being autistic affect experiences of motherhood?

To answer this question, I was interested to show how disablism (Goodley, 2014) and ableism (Campbell, 2009) intersect with the notion of the 'good mother'. Through my use of disabled motherhood scholarship, I was able to shed light on the disablist and ableist nature of the socially constructed 'good mother' (Daniels, 2019; Malacrida, 2009; Malacrida, 2019; Spradley, 2023) and, through my findings, suggest that autistic mothers are co-constructing their own cultural meaning of the 'good mother' through their 'against the norm' mothering practices. These practices, built around neurodiversity principles and located within an autistic homeplace' inform my claim that autistic mothers' 'against the norm' mothering represents a form of culturework (Longman et al., 2013; Frederick et al., 2019) and maternal activism (Mendoza, 2023) whereby participants sought to engender a positive autistic identity in their children and, through their advocacy work and resistance, fought for the rights of their children. My final contribution in relation to this question proposes that participants demonstrated an autistic mother advantage in recognition of the beneficial insight and understanding evidenced by participating mothers, and how adopting a neurodiversity-informed strengths-based approach to mothering benefited their children (as per Cooper et al., 2017; Crane et al., 2021b; Urbanowicz et al., 2019) and to recognise the "authoritative knowledge" (Landsman, 1998, p. 82), "intimate expertise" (Lilley, 2011, p. 4) and "unorthodox knowing" (MacGregor, 2021, p. 597) of participating mothers, who throughout the dataset displayed extensive knowledge and expertise relating to autism, being autistic and mothering autistic children.

Contribution to knowledge

The contributions to understanding and knowledge reflected in my answers to the research questions do not, however, fully represent the contribution to knowledge reflected in this thesis. What follows will demonstrate further how my in-depth, rich and illuminating account of autistic motherhood supports, complements and supplements existing research, and how it offers an original contribution to knowledge. My personal and subjective position as an insider, reflected throughout this thesis, has further contributed to originality as, inevitably, my subjective position is mine alone. In my introductory chapter I indicated the current gaps in knowledge about autistic motherhood and throughout this thesis I have attempted to contribute towards filling those gaps. What follows is a reflexive consideration of the key contributions made by this thesis.

Awareness raising

Raising awareness that autistic mothers exist, and that our experiences matter, was a key motivator for conducting this research. Despite the long-accepted mainstream autism science recognition of autism as likely hereditary and genetic in origin, the idea that mothers of autistic children might also be autistic was not, and is perhaps still not, a widespread consideration. An important contribution provided by this thesis is, quite simply, that it presents the stories and experiences of autistic mothers “from the inside” (Williams, 1996, p. viii). The importance of sharing stories by autistic women and mothers was demonstrated in the first theme, where several participants recalled discovering the possibility that they might be autistic through the reading of other autistic women’s and mothers’ first-person accounts. Furthermore, the third theme identified that the sharing of women’s autism stories and experiences present as a form of consciousness raising (Anderson and Grace, 2015) which can result in improved self-awareness, affirmation and empowerment, each contributing towards a positive autistic identity. Moreover, awareness raising serves an important role in contributing to improving the well-being and mental health of autistic mothers through better understanding of risks and vulnerabilities. Overall, this thesis contributes to awareness by providing a rich source of stories about autistic mothering and motherhood as a way to help with understanding our experiences, which is of benefit to both autistic mothers and the people we encounter in our daily lives.

Co-constructing autistic motherhood

The *idea* of the ‘autistic mother’ is relatively new, indeed, it is only in the last few years that research into autistic motherhood has become of interest within the academy.

Throughout the thematic analysis and discussion chapters of this thesis, and in answering my research questions, I have been able to contribute towards a deeper understanding of autistic motherhood and the idea of the 'autistic mother'. This matters because the normative, often ableist, expectations of motherhood and the 'good mother' who can do it all fail to take account of disability and difference, and often contribute to feelings of failure as well as fear and experiences of judgement and stigma. Autistic mothers are, therefore, currently mothering without a model of 'good *autistic* mothering' which means that we are, essentially, making it up as we go. However, and importantly, through the sharing of stories and research like this, conducted by and with autistic mothers, we are in the process of co-constructing our own ideal of the 'good autistic mother'.

What emerges is a picture of autistic motherhood that is rooted in care, resilience, advocacy and resistance. Firstly, and challenging the idea that autistic people lack empathy, this thesis has demonstrated participating autistic mothers' strong commitment to meeting their children's needs and supporting their development. Participants described the love they felt for their children and the distress they experienced when their children were struggling. Participating mothers considered their insider perspective highly beneficial in raising their autistic children, and self-awareness and reflection on their own experiences was highlighted as an important factor in understanding, supporting and caring for their children. Awareness of normative expectations of the 'good mother', and how mothers are often blamed for their children's behaviour, exerted a strong influence at times, with some participants mothering differently in private and public, for example, by keeping food in the fridge that their children refuse but which looks ‘healthy’ or concealing a child’s use of screens or engaging and playing freely with their children at home. Yet, despite experiences of judgement for mothering ‘against the norm’, participating mothers presented as confident, competent, creative and caring mothers, wanting the best for their children. Participating mothers were often treading a delicate line between mothering in a way that suited them and their children and mothering in a way that was not so far ‘against the norm’ that it would invite judgement. We know that sometimes our ‘good *autistic* mothering’ makes us look like a ‘bad mother’, but when we don’t tell our child off for stimming or having a meltdown or refusing to attend an activity which they have no interest in or for not speaking ‘with words’, we are not pandering, we are not lacking in discipline, or mollycoddling, and we are not causing our children’s behaviour. Mothering autistically means taking account of, respecting, and caring about, the interests, communication and sensory needs of our autistic children, even when that goes ‘against the norm’.

Secondly, this thesis has highlighted the immense resilience evidenced by participants, often against considerable challenges, in their desire to do the best for their children. Participating autistic mothers present a picture of a sophisticated juggling act in their balancing of the sensory, organisational and occupational demands of autistic motherhood and life in general, both within and outside the home, and often with minimal or no support. Unsurprisingly, my analysis revealed a dearth of support for autistic mothers, who often struggled with exhaustion and burnout and struggled to access support. This was compounded by the ‘double-bind’ of masking faced by some participants who wanted to be seen as competent and capable adults and mothers, and avoid judgement, particularly when advocating for their children, but found that this resulted in added barriers to accessing support for themselves as they were *too* good at masking their support needs. Whilst there were some examples of good practice in health and mental health services, on the whole, my findings indicate that key sources of support come from informal, often online, and community provision such as inclusive churches and charity-run groups, rather than formal and statutory providers, and through the use and development of virtual communities. Self-care, through engaging in hobbies and carving out time for reflection and to restore energy, was considered an important factor in promoting well-being and bolstering resilience for participants, but often resulted in sacrifices elsewhere, for example, cutting working hours or reducing sleep. Moreover, whilst the 'good autistic mother' might *need* to be resilient, and just because autistic mothers *are* resilient, does not mean that we *must* be resilient. The ability to repeatedly bounce back from the pressure of near breaking-point might well be useful and, indeed, it is often necessary to ensure that our children's needs are met, but it takes a toll, which is reflected in participant accounts of suffering with stress-related physical and mental health difficulties. Furthermore, in the absence of a model of 'good *autistic* mothering' participants are often holding themselves up, judging themselves and being judged against a normative model of 'good mothering' which fails to take account of the additional pressures and requirements of autistic mothering.

Thirdly, the requirement to advocate for their children, formally and informally, and the skills and knowledge required of and developed by participating autistic mothers represents a key contribution of this thesis. Participants' unique insight, resulting from their own experiences and reflections on their childhoods as part of the sense-making process of realising they were autistic also played a key part in their advocacy. Furthermore, participating mothers demonstrated often extensive and thorough knowledge developed through the course of mothering whilst autistic, giving credence to the idea that autistic mothers should be treated as credible informants in relation to their children’s autism and support needs, and respected as knowledgeable and authoritative stakeholders in matters concerning their children. This is especially pertinent as my findings indicated that professional knowledge of autism was often outdated and stereotyped, having failed to keep up with contemporary developments in autism research and knowledge. In their role as default parent, participating mothers had accumulated a wealth of knowledge, yet my findings suggested a tendency to downplay and minimise both their maternal expertise and their autism expertise. Furthermore, participants’ advocacy work was frequently hindered by not being believed or by concerns being minimised and disregarded, and through the experience of mother blame, a concept long associated with autism. My findings highlighted the particular problem of teachers, alongside other professionals, in perpetuating mother blame and how negative perceptions of autistic mothers appear to be rooted in notions of the ‘refrigerator mother’ (Kanner, 1949). An important finding relates to the rare but ominous ‘fabricated or induced illness’ accusation which, having made its way into safeguarding literature (Gullon-Scott and Long, 2022), participants experienced as an unfounded accusation or threat in encounters with family and professionals despite there being no evidence that autistic mothers are any less capable at mothering than non-autistic mothers (as per Pohl et al., 2020). Overall, participants presented as knowledgeable and astute advocates for their children, though, as discussed above, the additional demands and pressures of this contribute to added stress and impact autistic mothers' well-being. Therefore, whilst tenacious and effective advocacy appears to be a hallmark of 'good autistic mothering', most of us would prefer it to be unnecessary, and instead to see our children's rights be upheld as standard practice, not something we have to fight for.

Finally, this thesis showed how participating autistic mothers practise resistance in their daily lives. Resisting the pressures to mother in particular and expected ways, often unsuited to autistic children, was evident across participant accounts where autistic mothering often presented as resistance to the normative expectations of motherhood. The pressure to fit in was widely felt, but often resisted, as participants found ways to be themselves, by stopping, limiting and restricting their masking behaviours, in providing homes where they and their children were free to be themselves, and in finding and creating communities where support and sharing expertise bolstered their identity and legitimised their 'against the norm' mothering and 'against the norm' ways of being. None of this is easy, swimming against the tide never is, and participants resisted to varying degrees, some a little, some a lot, for the ever-present dominance of social and cultural representations of the 'good mother' exerts a powerful influence and resistance risks judgement. Yet, autistic mothers do resist, and within and emerging from that resistance we are creating, individually and together, new ways of thinking about autistic motherhood and what makes for a 'good autistic mother'.

Thinking outside the autism box

My use of a matricentric feminist approach to autistic motherhood presents a key original contribution to knowledge within this thesis. Existing research concerned with autistic mothering and parenting has typically been located within the analytical and theoretical traditions of neurodiversity and critical autism studies, and whilst feminist ideas have sometimes been used, overall, such research has not been positioned within the matricentric feminist tradition. Matricentric feminism has enabled me to explore autistic motherhood through a specifically mother-focused and gendered lens, facilitating a consideration of the intersection of autism and motherhood and how gendered social norms, such as those encapsulated in the idea of the ‘good mother’, influence autistic mothers and affect how we are viewed and treated. Moreover, and reflecting my pluralist approach to using feminist ideas to enhance understanding, intersectional and Black feminist literature have provided useful interpretative and analytical tools, highlighting that *how* we mother is culturally varied and important, and challenging the hegemonic dominance of intensive mothering as the accepted and acceptable mode of mothering in the West. Furthermore, drawing on intersectional and Black feminist work has enabled me to position autistic motherhood as socially, politically and culturally important, evidenced through my use of the concepts of homeplace and community mothering to develop a better understanding of the culturework undertaken by autistic mothers in their mothering practice. Thus, in taking autistic motherhood into new areas of thinking, I have provided new ways of thinking about autistic motherhood.

The wonders of WhatsApp

My decision to offer interviews by WhatsApp, with 10 of the 12 participants opting for this medium, has provided an important contribution to research methods and in researching within the autistic community. Like other researchers seeking to interview participants during Covid lockdowns and restrictions, I needed an alternative to in-person interviews and, unable to use phone or video interviews due to a lack of privacy at home, I embraced WhatsApp as my main mode of interviewing. At the time of my interviews there was no literature regarding using WhatsApp for qualitative interviews, therefore, I conducted a pilot interview to test the platform, which indicated that it was potentially ideal for my needs. As it turned out, using WhatsApp to conduct asynchronous virtual interviews provided a perfect medium for interviewing autistic mothers, as it enabled participants to dip in and out of the interviews as and when they had time and enabled me to be responsive and flexible in return. I was very conscious that my participants were already balancing multiple daily demands and that committing to taking part in research is time-consuming and often with minimal gain, at least in the short-term, hence, finding a means to conduct interviews where participants were fully in control of their time spent contributing was ethically valuable. A further benefit of WhatsApp was that it enabled participants to engage in different ways, and interviews could be conducted in part or in full in real-time, over days and weeks or even months, and with an ability to add pictures, voice notes and documents. The instant nature of WhatsApp for communicating also encouraged a more chatty and informal interviewing process which embodied the influence of feminist and relational ethics through an ethic of care and friendship, influenced by my commitment to friendship as method (Tillman-Healy, 2003), where research is a reciprocal and unhurried process.

However, despite its many advantages, particularly around functionality and flexibility, a consideration when using WhatsApp for semi-structured interviews is that it can result in participants giving considerably more of their time than when taking part in time-bound, and therefore clearly defined and finite, face-to-face interviews. My awareness of this during the interviewing process resulted in some reticence at times to ask too many follow-up questions as I was conscious of participants' busy lives and not wanting to become an unwelcome demand on their time. The potential starkness of using a text-based interview method, stripped of non-verbal communication and cues, requires care, consideration and reflection upon participant engagement throughout. Nevertheless, WhatsApp is proving to be a highly effective means of accessing hard to reach populations, including those who, like here, might struggle to participate in research which is dependent upon fixed times and locations.

Implications and recommendations

My own motivation for conducting this research, and my participants' motivation for taking part, was overwhelmingly driven by the desire to improve awareness and understanding of the lives of autistic mothers and, by extension, our autistic children's lives too. Often we are our children's best and only advocate, and 'the system' – social care, health and education among others – can be a tricky thing to navigate at the best of times. Throughout this thesis, I have shown the multiple ways that poor understanding of autistic motherhood impacts on autistic mothers, and now it is time to make a call to action to researchers, policy makers and practitioners to consider the implications of this thesis and to take action to support autistic mothers. I will end this section with a reflection on my participatory research practice and how this both influenced and improved this thesis, and the need for clear guidelines for doctoral researchers wanting to carry out participatory and collaborative research.

Research

Having outlined my contribution to research in the previous section, I will briefly summarise the implications of this thesis to research and to make recommendations for future research. Importantly, the findings from this thesis demonstrate the daily struggles faced by autistic mothers of autistic children as a result of poor understanding and awareness of autism in general and autistic mothers in particular. Whilst research concerning autistic women is now a fairly well-established field, and research concerning autistic mothering and parenting is emergent, further research is needed to better understand the social and cultural roles occupied by autistic women, including motherhood. Furthermore, through my explicit use of feminist ideas, theory and ethics, I have been able to provide new ways of thinking about autistic motherhood, which might act as a springboard for further research and analysis. Thus, as I have demonstrated, by adopting a matricentric feminist lens within a broader pluralist feminist analytical and theoretical approach, I have been able to shed light on autistic motherhood and its social and cultural situatedness, illuminating the intersection of being autistic and doing motherhood. Therefore, whilst this thesis complements existing research into autistic motherhood, it also reflects a paradigm shift by locating autistic motherhood both within critical autism studies, where it has so far typically sat, and also within matricentric feminism, where up to now it has been absent.

My recommendations for research are fivefold. First, there is a clear need for more research across the lifespan of autistic women, including motherhood. As the first significant generation of autistic mothers who know we are indeed autistic mothers, there is the potential to learn from our experiences to benefit the autistic mothers of the next generation. Moreover, through further development of a model of the 'good *autistic* mother', both current and future autistic mothers would benefit from a realistic model of good autistic mothering. Second, there is a very clear need for research which explores the experiences and raises awareness of autistic mothers with learning or intellectual disabilities. Third, we need research to better understand multi-generational autistic experiences. At least one participant in this research had a mother who was also autistic, and it is not surprising that some grandmothers will have their own lightbulb moment of autistic self-realisation following the diagnosis of their adult children and grandchildren. Fourth, we need research which considers other intersectional experiences, in particular, the experiences of Black and other minority ethnic autistic mothers where social and cultural experiences may highlight new and different strengths and challenges. Fifth, I want to urge researchers to disaggregate their data to reflect the different parenting experiences of mothers and fathers. Across the autistic parenting studies included in my literature review, where both mothers and fathers took part, mothers were overwhelmingly in the majority, which means that any specific experiences and needs of autistic fathers risk being subsumed into the autistic mother experience, and the gendered role expectations of parents are lost. Autistic fathers need a model of the 'good *autistic* father' which enables them to resist the gendered normative expectations of parenting *and* to fully share the parenting load.

Policy

At the present time, national autism policy, guidance and codes of practice across the UK fail to recognise the significance of autistic mothers, both as primary carers for our autistic children and adult children, as well as in our own right as autistic adults with specific needs and requirements. This matters because national policies trickle-down to inform and influence local policy and practitioner guidance. Moreover, despite national policy commitments to assessment, diagnosis and support across England and the devolved nations, participant accounts highlight the patchy and sometimes non-existent implementation at a local level. In addition, participant accounts of the additional workload, and associated stress and anxiety, resulting from poor experiences with their children's education, schools and teachers, highlights again the burden of advocating for our children, despite clear SEND law and inclusion policies. Policies designed to make our lives and our children's lives better must not be optional and should not require the often-extensive legal knowledge evidenced by some participants in order for them to benefit. Policy and guidance related to improving the lives of autistic children and adults must take account of developments in research and knowledge and must be implemented in ways that improve *all* autistic lives.

Practice

Translating policy into practice is typically done through developing training and guidance for professionals and practitioners, such as the recently published practice guide for social workers (BASW, 2023) which promotes a strengths-based approach to working with autistic adults and children, complementing existing autism resources and guidance[14] aimed at a range of professionals including education, social care, health, and prison staff. Yet, despite the growth in general and popular awareness of autism and of targeted practitioner guidance, participant encounters with professionals presented a

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[14] For example: https://www.autismeducationtrust.org.uk https://www.england.nhs.uk/learning-disabilities/about/useful-autism-resources-and-training/

mix of positive and negative experiences, often founded upon outdated knowledge and stereotypes. Moreover, participants' bad experiences were particularly redolent, often having a profound effect on their experiences of mothering, indicating that more must be done to improve practice. As was briefly discussed in Theme 3: 'Women like me 'fall through the gaps' of support', and despite fairly neutral questioning in regard to such encounters, participants often found it easier to recall negative and difficult experiences with professionals, and required more prompting to discuss positive experiences. It is possible that participants assumed I was interested in bad experiences due to a focus of this research being on improving the lives of autistic mothers or, perhaps more likely, and certainly reflecting existing research, participants overall experienced more bad encounters with professionals than good. Furthermore, and again in alignment with existing research, my findings have demonstrated how autistic mothers feel and are unfairly judged against normative expectations of the 'good mother' and how such expectations fail to recognise the often very good mothering undertaken by autistic mothers. Research such as this, therefore, plays an important role in raising awareness of the strengths and challenges of autistic motherhood, and where improvements could be made, whilst edging us forward towards a model of what might be the indicators of 'good *autistic* mothering'.

Reflecting upon participatory research practice

In Chapter 3 I outlined my approach to participatory research practices and explained how this thesis embodies an "ethos or ideal" (Milton, 2019, para. 6) of participation rather than being fully participatory and collaborative. Reflecting upon this decision now, I can see how this was influenced by the requirement of doctoral study to demonstrate "an **independent** and original contribution to knowledge [and the] exercise of **independent** critical powers [my emphasis]" (LSBU, 2022, p. 22). At first glance, this appears antithetical to fully collaborative and participatory research where the production of knowledge would lean towards collaborative and away from independent. For me, at the time a novice researcher, this dichotomy presented something of a minefield, and highlights the need for clear guidance for doctoral researchers wanting to conduct participatory research. I was also conscious that the requirements of such engagement could present a heavy burden for participating autistic mothers who are often, as has been demonstrated, struggling to manage the existing demands on their time. However, despite choosing not to undertake fully collaborative and participatory research, my commitment to participatory principles, and producing inclusive and ethical research, were evident in several areas, which may be of interest to doctoral and other researchers seeking to incorporate participatory principles into their research practice. First, I made an early commitment to ensuring that my thesis would be accessible to participants and other autistic mothers, through clear explanations of concepts, theories and methodological and method choices, and avoiding unnecessary jargon and niche terms where possible. Second, during interviews I sought to create an as level as possible space for engagement, through a rejection of positioning myself as an 'expert' and by respecting participant expertise, interpretations, communication styles and preferences. Third, I provided all participants with research updates at significant points, including during data analysis and theme development, and whilst writing-up. Fourth, as my updates were prompting engagement with the material, I invited participants to join a WhatsApp group as an informal space, explicitly not relating to data collection, where we discussed the research-in-progress and related topics. Fifth, two participants were involved in reading and reviewing the thesis during write-up, providing valuable sense-checking alongside thought-provoking insight and editing suggestions.

Limitations

It is impossible for any piece of research to be without problems and limitations, even more so perhaps for doctoral research where we are, in essence, undertaking an apprenticeship in academic research through learning on the job. In fact, I have found that finding ways to delimit, to impose limitations and boundaries, and choose what to include and what not to include, has played an important part in conducting this research. As there is so much we don't yet know about autistic motherhood, and infinite ways to interpret and analyse my data and findings, many limiting factors have been deliberate and purposeful, from my choice of research approach, questions and participants to my philosophical, theoretical, conceptual and analytical choices. Furthermore, this thesis is unapologetically qualitative, embracing my subjective position, and I make no claims to truth, objectivity, replicability or statistical generalisability, hence, I do not consider these factors to be limitations. I do, however, make claims to rigorous, reflexive and ethical research which, as discussed previously within this chapter, makes a significant and original contribution to knowledge about autistic motherhood. Nevertheless, here I will consider some of the limitations and problems which I did encounter during this research and consider what I could have done differently if I had the opportunity to start afresh. I will also consider how such limitations raise possibilities for further research beyond that already identified earlier in this chapter.

Firstly, a little over two weeks after gaining ethical approval to conduct my research and just as I was about to begin participant recruitment, we entered our first Covid lockdown. With no idea how long it would or could last, or what the implications might be, or how it might impact my life, and needing to manage such a sudden change in routines, I chose to prioritise family well-being over my research and, knowing I would be unable to conduct in-person interviews for the foreseeable future, took a break from actively doing my research. At the point when I was ready to commence recruitment and interviewing, some Covid restrictions were still in place and university regulations still prohibited me from conducting in-person interviews, meaning that I needed to reconsider my plan to conduct most interviews in-person. This was when I decided to continue with virtual interviews only and to embrace text-based interviews using email and WhatsApp. As discussed in Chapter 3, I had hoped to recruit at least some 'harder to reach' participants through charities and similar who provide support to autistic mothers in the course of their work. However, despite making contact by email, this was not successful, and the lack of opportunities to discuss my research with potential gatekeepers who could enable access to potentially hard to reach autistic mothers was unfortunate and limiting. I turned to online support groups and virtual spaces, where I was already a member, to recruit more directly, resulting in the recruitment of participants who I already knew in-person or online or who were given my details by someone who knew and could vouch for me. As it turned out, the limitations and restrictions which impacted interviewing and recruitment led me to embracing and being able to showcase the benefits of WhatsApp, as well as leading to my discovery of friendship as method (Tillman-Healy, 2003) which was influential in my ethical approach to research. My ethical and flexible approach also enabled me to invite Anna, who had been unable to fully participate, to offer a partial contribution which is evident in sub-theme 1.3: ‘I didn’t recognise the red flags’. Whilst this might indicate over-sampling, i.e., that one participant is considered to be over-represented, resulting in a potential for bias, it is clear that Anna’s experiences are contextually important and aligned with other participants’ experiences and the shared pattern of meaning reflected in that theme.

Secondly, and related to the challenges and restrictions of recruitment referred to above, my participant group might, at first sight, appear to lack heterogeneity. Most are white, British, articulate and literate, and able to communicate to a high level of written English. However, beyond this there is a mix of class backgrounds, educational attainment, employment and financial stability, co-occurring conditions and disability, family set-ups, and sexual orientation. Where I believe there are limitations in representation which could have impacted my findings and analysis are in that nearly all participating autistic mothers realised they were autistic after their children were recognised or diagnosed as autistic, none of my participants had a co-occurring learning or intellectual disability, all of my participants were white or white-passing and that, on the whole, participating mothers were positive about motherhood, valued their mothering experiences, and presented as being ‘good mothers’ with a strong awareness and knowledge of autism and mothering. The Covid related challenges I encountered with recruitment certainly impacted on my hopes to cast a wider net and to include a wider variety of both autistic and mothering experiences. Nevertheless, the participant accounts reported, interpreted and analysed within this thesis provide important insight into autistic motherhood, and have enabled light to be shed on a wide range of experiences of autistic mothers, many of which are likely to be shared by those who are not directly represented here.

Thirdly, I want to consider the limitations regarding the literature which has featured in this thesis. Whilst I have made some references to grey literature, through referencing newspaper stories, blogs and books by autistic women and mothers, with hindsight, and especially considering the scarcity of academic work when I commenced my research, an analysis of first-person accounts would have added background, depth and breadth to this thesis. Such accounts offer a key source of information for autistic women and mothers and my own interest in autism was piqued through such writings. Indeed, without them I doubt I or some of my participants would have even considered we might actually be autistic ourselves. Whilst I have endeavoured to include some of those autistic women and mothers who came before me and paved the way for this research, I regret that they do not feature more prominently.

Finally, I want to discuss generalisability. It is not uncommon for authors of qualitative studies to highlight generalisability as a limitation within studies (Smith, 2017) as part of what Guenther and Falk (2019, p. 1012) describe as the "discourse of self-justification" used in attempts to legitimise qualitative research findings against quantitative research criteria. For example, from a more quantitative-leaning perspective on research validity, it might be claimed that my relatively small sample is too homogeneous and presents limited variance, therefore, impacting the reliability and generalisability of my findings and analysis. However, I do not plan to do this, and in the introduction to this section I made it clear that this thesis does not claim to be *statistically* generalisable. Yet, this does not mean that the findings and analysis embodied within this thesis are not *actually* reliable, generalisable or transferable, for as Finlay (2006, p. 320) points out, "qualitative researchers … are concerned to show that findings *can* be transferred and *may* have meaning or relevance if applied to other individuals, contexts and situations." Indeed, as has been demonstrated throughout this chapter, the contributions to knowledge resulting from this research have the potential to improve awareness and understanding of autistic motherhood in specific as well as in more general ways.

Final reflection

Having checked that I have told the story of my research, answered the research questions, considered my original contribution to knowledge, made recommendations for research, policy and practice, and acknowledged the limitations of this research, it is time to bring this chapter and this thesis to a close. I started out with an idea of what I wanted to accomplish, and the sort of stories I expected to hear and would tell, but without any real idea of what the final thesis might look like. I don't think any of us really know what we are letting ourselves in for when we decide to do a PhD, I certainly did not. This is, in part, due to the fact that the very vast majority of people who undertake doctoral study only do it once, and also because every PhD is new and original in some way or another, bringing our own positions, perspectives and ideas. Looking back and reflecting upon this now near-complete product of six-years' work, I want to end with some final reflections.

So, now is the time to come clean and own up to choosing thematic analysis because it seemed straightforward.[15] I had encountered, though not used, Braun and Clarke's (2006) original thematic analysis paper during my MSc where the flexibility of their approach and the clarity of their writing had appealed to my pragmatic side, so I filed it away 'for later'. I re-visited it when I came to write my research proposal for this research, and it seemed to offer what I needed in my aim to conduct accessible and transparent research. As it turned out, it was the perfect method for analysing my data, and I have no regrets, but it was not an easy option at all. Braun and Clarke's version of thematic analysis, now known as *reflexive* thematic analysis (2022), requires the researcher to develop their own methodology from the ground up and to conduct data analysis through a systematic yet highly creative and iterative process, where much of the interpretative and analytical work is undertaken through the process of writing. As I would quickly discover, writing up my analysis was thought-provoking and often challenging[16] work but, equally, by embracing a reflexive approach, I was able to allow my thinking and writing to flex and morph and take me to unexpected places, sometimes feeling as if I was stuck in a choose your own adventure storybook, not knowing where each path would lead, but allowing the story to unfold to see where it took me.

Conducting reflexive research has meant that I am ever-present across the whole of this thesis, and whilst participant stories have often reflected my own story of autistic motherhood, my story is mostly absent from this thesis.[17] This thesis is more than *just*

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[15] aka easy.

[16] aka hard.

[17] As discussed in Chapter 3, I cannot tell my story of motherhood without also telling my son's story and, therefore, as I am not anonymous, I cannot afford him the same anonymity as granted to my participants and their children.

stories, though, and my interpretation and analysis, the work that makes this a thesis rather than an anthology, is that it goes beyond *just* giving voice, though that is important in itself. Rather, in building upon participant stories, it has provided an insight into autistic motherhood and ‘good *autistic* mothering’ from the perspective of autistic mothers. The idea of the ‘good *autistic* mother’, that autistic mothers can be, very often are, or have the potential to be, *good* mothers, is the message I want to broadcast. Good mothering is itself, like this thesis, an example of reflexive practice, and I want to caution against any notion that there is just one way to be a good autistic mother or a good mother of any other sort. Importantly, therefore, mothering ‘against the norm’ is not and should not be the exclusive preserve of autistic mothers, and perhaps all mothers, and their children, would benefit from mothering ‘against the norm’ once in a while.

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Appendix A: Participant Information sheet

London South Bank University
EST 1892

Participant Information Sheet

‘Being autistic and doing motherhood: experiences of autistic mothers of autistic children’

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What is the purpose of the study?

- As an autistic mum of an autistic child I realised that there is a lack of research into our experiences, even though more and more of us are getting diagnosed after our children. We are often misunderstood and judged by others who don’t understand us, and this can cause us problems. Stereotypes and assumptions about autism and motherhood mean people often fail to see our strengths and achievements. The aim of this study is to explore and analyse our experiences as a way to amplify our voices and to come up with ways that our lives can be made better through research, policy and practice.
- This is a qualitative study, which means I am interested in your stories in the way you choose to tell them. Your story, along with other participants’ stories, will be transcribed and anonymised and then I will look for patterns and themes, as well as differences and points of interest. You will have the opportunity to check and edit the transcript of your contribution before it is analysed, and you will be asked to choose a name for me to be able to identify you to protect your anonymity.
- The collection and analysis of your stories and the topics we discuss will continue until March 2022, and I expect this project to be completed by September 2023.

Who is taking part in this study?

- You have been invited to participate after expressing an interest in this study. All participants are autistic mums of autistic children and you all have different stories to tell.
- The overall number of people that have been invited to participate is unlikely to be more than 20 so that we have the space to explore the richness and depth of our lives.

How do I withdraw from the study?

- Please let me know if you wish to withdraw as soon as possible by email.

- If you withdraw, all information held on you will be deleted, unless you say otherwise, for example you may wish to withdraw some of your contributions and not others.
- It is very important to me that you are comfortable with the information you share, so please contact me to discuss any concerns.
- I will begin to formally write up my research from March 2022, so it is important that if you wish to withdraw that you inform me before then. Any information or contributions already used are unlikely to be able to be withdrawn, for example if your contributions have already been used in published articles.

What will I be asked to do?

- This study relies on your stories, and you will be asked how you would like to tell your story, for example, in a face-to-face interview, by phone or over email or WhatsApp.
- All interviews will be arranged to make it as easy as possible for you to take part. For face-to-face interviews, I can travel to you or we can arrange to meet somewhere neutral, for example, if you are in or near London we can meet at the university, or we can meet up if we are attending the same event.
- I will keep you informed of progress by email and hope to set up a Facebook page to share news and updates.

Possible disadvantages/risks to participation

- You might find it upsetting to talk about your experiences. I will provide information to help you find support if you need it.
- I fully understand that you might be anxious about what to expect and I plan to provide as much information as possible about what to expect, for example, I will send you an outline of what to expect in an interview.

Possible benefits to participation

- Many people find it helpful to tell their story in their own words to someone who ‘gets it’.
- This study will contribute to increasing understanding and challenging harmful stereotypes applied to autistic women, and especially autistic mums.
- As the first study of this kind, we have the opportunity to inform practice, policy and research.

Data collection and confidentiality

- All the information collected about you and other participants will be kept strictly confidential (subject to legal limitations).
- Data generated by this study will be retained in accordance with the University's Code of Practice. This means that all data collected will be kept securely in paper or electronic form for a period of 10 years after the completion of this study.
- Your privacy and anonymity will be ensured in the collection, storage and publication of research material.

What will happen to the results of the study?

- The results of the research will be used as the basis for my PhD thesis.
- I hope to publish findings from my research in academic journals which will be mostly read by other students and academics, as well as some professionals.
- I also plan to find other ways to share my research with professionals and the general public by writing for non-academic publications and speaking at events about this topic whenever possible.

- When the thesis is completed I will inform all participants how to access a copy.

Who is organising the research
- I am conducting this research study as a student in the School of Law and Social Sciences at London South Bank University.
- I am receiving no funding or sponsorship for carrying out this research.

Who has reviewed the study
- This research has been approved by the School of Law and Social Sciences at London South Bank University.

Who to contact for further information
- Researcher: Paula Sanchez email sanchezp@lsbu.ac.uk
- Supervisor: Professor Nicola Martin email martinn4@lsbu.ac.uk
- If you have any concerns about the way this study is conducted, please contact the School of Law and Social Science Ethics Coordinator: email lssethics@lsbu.ac.uk

Thank you for reading this information sheet. If you are interested in taking part in this study please contact me and we can discuss next steps. Please feel free to contact me with any questions.

Signed:

Date:

Paula Sanchez
sanchezp@lsbu.ac.uk
Doctoral Researcher
School of Law and Social Sciences
London South Bank University

Appendix B: Support information sheet

Thank you for your interest/taking part in this study. If you need any further support with issues related to this study, please either let me know and/or see if any of these organisations might be able to help. Whilst some of these services are based in particular areas, they may offer some or all services across the UK.

Free services:

National Autistic Society
www.autism.org.uk
Helpline: 0808 800 4104

Autism Services Directory
www.autism.org.uk/directory

Samaritans
www.samaritans.org
Helpline: 116 123

Scottish Women's Autism Network
www.swanscotland.org

Services where there may be charges:

The Autism Academy UK
www.autismac.com

Action for Aspergers
www.actionforaspergers.org

Lancashire Autism Services
www.lancashireautism.org

Parenting support:

Challenging Behaviour Foundation
www.challengingbehaviour.org.uk

Lives in the Balance
www.livesinthebalance.org

Bo Hejlskov Elven
www.eng.hejlskov.se

PDA Society
www.pdasociety.org.uk

Appendix C: Consent form

Research Project Consent Form

Full title of Project: 'Being autistic and doing motherhood: experiences of autistic mothers of autistic children'
Ethics approval registration Number:

Name:

Researcher Position: Doctoral Researcher

Contact details of Researcher: Paula Sanchez email sanchezp@lsbu.ac.uk

Taking part (please tick the box that applies)	Yes	No
I confirm that I have read and understood the information sheet. I have had the opportunity to ask questions.	☐	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without providing a reason.	☐	☐
I agree to take part in the above study.	☐	☐

Use of my information (please tick the box that applies)	Yes	No
I understand my personal details such as phone number and address will not be revealed to people outside the project.	☐	☐
I understand that my data/words may be quoted in publications, reports, posters, web pages, and other research outputs.	☐	☐
I agree for the data I provide to be stored as described in the information sheet and I understand it may be used for future research.	☐	☐
I agree to the interview being audio recorded.	☐	☐
I agree to the use of anonymised quotes in publications.	☐	☐
I agree to assign the copyright I hold in any materials related to this project to the researcher, Paula Sanchez.	☐	☐

Name of Participant ____ Date ____ Signature ____

Name of Researcher ____ Date ____ Signature ____

Project supervisor contact details for further information:

Professor Nicola Martin: martinn4@lsbu.ac.uk

Appendix D: Outline interview guide

Autistic motherhood interview guide

Please skip any questions you don't want to answer

About you

Can you tell me a little bit about you?

How old are you?
Do you have an autism diagnosis?
If you do have a diagnosis, was it before or after having children?
Do you have any other disabilities or long-term conditions?
What is your highest-level qualification/education?
Are you employed?
What is your job?
How would you describe your relationship status?
How would you describe your race or ethnic origin?
How would you describe your sexual orientation?

Can you tell me about your children?

How many children do you have and how old are they?
What diagnosis does your child or children have?
If your autistic child/ren is/are nursery/school/college age are they mainstream/special school/home educated/other setting?
If your children are adults are they in a supported setting/working/university/other?

Can you tell me about your family set-up?

Who else lives with you and your children?
If you are separated or co-parenting, how does or did that work?
Who is responsible in your family for advocating for your child/ren and making sure needs are met?
Can you tell me about your experience of balancing being a mum and other demands (eg work, elderly care, self-care)?
Have you or your child/ren being autistic had an effect on family finances?
Have you or your child/ren being autistic had an effect on your ambitions or life-plans?

About being autistic

Can you remember when you found out or first thought you might be autistic?
What made you suspect?
Did you get any help/support?
Did you tell anyone? How did they react?
What might have helped?

Can you tell me about getting diagnosed?
How long did it take you to ask for assessment?
What was the process?
Did you face any obstacles?

Did you get any post-diagnosis support?

Can you describe what impact diagnosis or realising you are autistic has had on your life?
Do you tell people? Family? Friends? Work? Professionals?
If you do tell people, how has that been?
If you don't tell people, can I ask why?
Can you tell me about your sources of support related to being autistic?

Is there anything else about being autistic you would like to talk about?

About motherhood

If you realised or got diagnosed after your child/children, can you tell me about it?
Do you think you might have made different choices if you had known earlier that you are autistic?
Do you think being undiagnosed autistic mattered? Did it make things easier or harder? Why?

OR

If you suspected or were diagnosed before having children, did being autistic affect your choice to have children?
Did you face any problems because you are autistic?
Can you tell me about any extra support you got or needed?

What does being an autistic mother mean to you?
What words does 'mother' make you think of?
What is good about it?
What is not so good?

Do you think mothers need to have a lot of knowledge about raising children to do it well?
Do you think being autistic and having autistic children requires more and/or different knowledge?
Can you tell me about your sources of support related to being a mum (this might be different to support for being autistic)?
Can you tell me about any special interests you developed related to being a mum?

Is there anything else about motherhood you would like to talk about?

About social and cultural expectations

Do you think social expectations of what is considered 'normal' affects how autistic mums are viewed and treated?
Can you explain why you think this?
Do you ever feel like you are being judged for being different?

Can you tell me about masking and/or camouflaging?
Can you think of an example where masking has been useful?
Can you think of an example where it has not been useful, or made things worse?
Has it had any effect on your mental health or well-being?

Can you tell me about how cultural expectations affect your experiences?
This might be due to family, religion or race/ethnicity/origin
Can you describe how your cultural values and expectations are helpful or not as an autistic mum?

Is there anything else about social or cultural expectations that you would like to talk about?

Interacting with professionals

I want you to think about experiences you've had and suggestions you would make for professionals you come into contact with either for yourself or your child/ren.

Professionals might include:

Medical: *GP/family doctor, paediatrician, consultant, nurse*
Other clinical services: *SaLT, OT, physio, psychiatrist, psychologist, counsellor, therapist*
Education: *teachers, school staff, autism outreach, specialist teachers/advisory support*
Social care: *social worker, children's disability/autism team*

You don't need to cover them all, but please pick 3 (or more if you want to) and try to answer these questions for each one (you can skip questions that don't apply and feel free to answer in any order):

Can you describe what was good about this interaction?
Can you describe what wasn't so good about this interaction?
Were you or your child given any information about what to expect?
Was there an opportunity to ask for adjustments for you and/or your child?
Can you describe any changes that were made to standard processes to help support you and/or your child?
If your requested adjustments were made, what difference did it make?
What would you like to change about the process?

Final questions

What do you want researchers to prioritise in any future research on autistic mothers?

Is there anything else you would like to tell me that I have not asked about?