Title: "*It has shown me how much I am capable of*": An Exploration of Autistic Burnout

Experiences in Motherhood

Ashton Ferguson[1], David Martin [1], and Amy Pearson[2]

[1]School of Psychology, University of Sunderland, Sunderland, UK.
[2]Centre for Neurodiversity and Development, Department of Psychology, Durham
University, Durham, UK.

Correspondence:

Amy Pearson

amy.pearson@durham.ac.uk

Centre for Neurodiversity and Development

Department of Psychology

Durham University

Durham

DL13HE

ORCID ID: 0000-0001-7089-6103
Twitter: @dramypearson

Keywords: Autistic burnout, motherhood, parenting, mental health

Manuscript word count: 6423

Abstract (245 words)

Background: Research has highlighted a relationship between autistic motherhood and autistic burnout, though autistic mothers' experiences of autistic burnout have not been explored in depth.

Method: To address this research gap, we used a participatory approach, and a qualitative methodology with the aim of understanding: (1) how autistic mothers experience autistic burnout in relation to their parenting role, and (2) what support they need to prevent and recover from this. We recruited thirteen autistic mothers via social media to participate in an online semi-structured interview. We analysed these interviews using inductive reflexive thematic analysis.

Results: We developed four main themes. Theme one, "Depletion", focuses on the contributory factors to autistic burnout. Theme two, "You have to just get up and keep going", demonstrates how autistic mothers continued to care for and maintain their relationships with their children whilst experiencing autistic burnout. Theme three, "New realisations", reveals how autistic burnout impacted on autistic mothers' self-understanding and self-awareness. Theme four, "We need support too", discusses the availability and accessibility of support for autistic mothers and their subsequent experiences of this. Findings highlight that autistic mothers' difficulties associated with their autistic burnout are compounded by a lack of autism acceptance and understanding from others, though they felt that burnout did not impact their parenting capacity.

Conclusions: We provide several recommendations to improve outcomes for autistic mothers, including a need for increased autistic-led training for professionals, and for the development of formal, autistic-led peer support services and community groups.

Community Brief (496 words)

Why is this an important issue? Autistic mothers experience a lot of pressures (e.g. social demands) which can be very stressful and might lead to autistic burnout (extreme exhaustion experienced by autistic people that can make it hard for them to think and act). So far we know very little about the experience of burnout in autistic motherhood. Knowing more could help us to put better support in place

What was the purpose of this study? We aimed to explore the experience of autistic burnout in motherhood.

What did the researchers do? We interviewed thirteen autistic mothers about their experiences of burnout. Our questions included things like "how did you first realise you were experiencing autistic burnout?" We used an inductive, reflexive thematic analysis. This is a form of qualitative analysis where researchers look at what people have said and develop common themes (or patterns) across participants.

What were the results of the study? We developed four main themes. In theme one, "Depletion", we focused on the things that led to autistic burnout, like feeling responsible for too many things at home. In theme two, "You have to just get up and keep going", we explored how autistic mothers continue to care for their children during autistic burnout. In theme three, "New realisations", we looked at how autistic burnout impacted on autistic mothers' self-understanding and self-awareness. In theme four, "We need support too", we explored where mothers went for support, whether it was helpful, and what would make support better in future.

What do these findings add to what was already known? Our findings show how the demands of motherhood might lead to autistic burnout among autistic mothers. We found that some things involved in maternal burnout (e.g. having a lot of things to remember) are the same as in non-autistic mothers, but some aspects of autistic maternal burnout are different (e.g. our mothers reported feeling closer to their children as a result, not more distant).

What are potential weaknesses in the study? We only interviewed a small number of people. While this is not an issue in qualitative research, it does mean that more research is needed to see whether our findings apply to a larger, more representative group. We did not explore the experiences of parents who do not identify as mothers and there are likely some unique aspects to these different experiences worth investigating.

How will these findings help autistic adults now or in the future? Our findings further the understanding of the unique features of autistic burnout, and contribute towards a growing evidence base that emphasises the need for well-resourced autistic community support networks. These networks provide insider understanding and emotional support, but are often reliant upon exhausted community members. We suggest that better support would include both professional aid (from well trained professionals with a solid knowledge of autistic burnout) and community knowledge to ensure more sustainable and effective support for autistic people.

Motherhood is inherently challenging,[1] reflected in the high prevalence rates of mental health issues[2] and maternal burnout.[3] Motherhood is more distinctively challenging for autistic mothers who are judged against neuronormative[4] and ableist[5] standards of "being" and "doing"[6] that deny them the power and privilege to mother authentically without being shamed and othered.[7] Autistic mothers have conveyed their difficulties in fulfilling normative expectations of motherhood[8] with discrepancies between their actual and ideal/ought selves[9] leading to increased negative self-comparison and self-judgement.[8,10,11] Autistic mothers of autistic children have also discussed the conflict that arises from wanting to mother in non-conforming ways that accommodate their children's autistic needs (such as enforcing fewer boundaries),[12] whilst also wanting to avoid negative judgement for these practices.[4,12] This is significant given the discrimination faced by autistic parents, i.e. that they are disproportionately more likely than non-autistic parents to have their parenting scrutinised by professionals,[13–15] despite there being no significant differences in their reported family outcomes (e.g. whether the child's health and developmental needs are met).[16,17] Griffiths and colleagues[14] found that 19% of autistic parents reported having their ability to care for their child questioned by an educational, medical or social work professional, compared to only 4% of non-autistic parents. Furthermore, 4% of autistic parents reported that professionals' concerns had led to them losing custody of their children, compared to less than 1% of non-autistic parents.[14]

In the context of their mother role, autistic mothers have reported challenges directly related to their neurodivergence, such as increased difficulty multi-tasking, adapting routines, and managing unpredictability.[15,18,19] They have also described the experience of extreme overwhelm resulting from aversive sensorium associated with attending to the physical and emotional needs of children,[13,19] for example breastfeeding.[11,18,20] In the context of autistic motherhood, sensory input is often unavoidable and uncontrollable (e.g. smells associated with nappy changes). This can lead to increased risk of physical and mental health problems, especially given the barriers to accessing any self-regulatory "downtime".[11,21] Autistic mothers' sense of overwhelm can also be triggered by their hyper-empathy towards their children, experiencing their children's emotions as if they were their own.[13,22] This is consistent with findings that a significant proportion of

autistic adults demonstrate a high degree of affective empathy[23] which can be both emotionally and physically distressing.[24]

Autistic mothers have also recounted difficulties managing the increased social demands of motherhood,[11,13] citing high levels of anxiety around unstructured interactions with other parents when dropping off or collecting their children from school,[12,19] and in settings such as baby groups, where social difficulties are compounded by sensory sensitivities.[11,12,18] Autistic mothers have described needing to "perform neurotypical parenting"[25] and mask in social situations with other parents,[26] maintaining that this supports not only their own social acceptance but that of their children, in this sense becoming a "double burden".[12]

Unsurprisingly, autistic mothers have reported poorer psychosocial outcomes compared to non-autistic mothers, such as significantly higher levels of stress, depression, anxiety, and isolation.[15,18] Pohl et al[15] found that 68% of autistic mothers often felt they were not coping in the context of motherhood. However, despite their difficulties autistic mothers are less likely to seek support, with anxieties around being judged as unable to cope or being misdiagnosed with mental health problems acting as barriers.[11,13,15,19]

The "relentless nature of motherhood"[18] combined with the unmet needs of autistic mothers[13,15,19] increases risk of autistic burnout.[27,28] Autistic burnout is predominantly characterised by exhaustion, social withdrawal, and heightened expression of autistic traits,[27,29,30] and can be acute as well as chronic in nature.[27] Autistic people have reported the negative impacts of burnout on their physical and mental health, functional independence, and quality of life, consequently leading to their increased suicidality.[27,29,30] Reducing demands, 'unmasking', and engaging with personal interests are identified as key factors that facilitate recovery from autistic burnout.[29,31] However recovery is a complex, ongoing process with experiences of burnout fundamentally changing how autistic adults understand themselves. Little is known about autistic burnout among autistic mothers.

Autistic mothers' narratives around autistic burnout that *have* featured within their broader accounts of motherhood[25,32] appear to distinguish this from parental burnout.[3] Autistic burnout may result from the overwhelming stressors associated with mothering, *and* the overwhelming stressors associated with mothering in a predominantly neurotypical world. In addition, the symptoms typically associated with parental burnout, such as emotional distancing from children, or a loss of parental efficacy,[3] have not been reported by autistic mothers, who have instead described their "intense connection and closeness" with their children.[13]

Autistic burnout is currently an emerging area of research,[27,29,31,33] and to our knowledge there have not yet been any studies that have focused exclusively on autistic mothers. Therefore, this study aims to understand how autistic burnout is experienced by autistic mothers in relation to their mothering role, with an aim to prevent occurrence, and aid support and recovery.

Method

Research Questions

We had two primary research questions:

1. How do autistic mothers experience autistic burnout in relation to their parenting role?
2. What support do autistic mothers need to help them prevent and recover from autistic burnout?

Participants

We used purposive sampling to recruit participants who were: (1) over the age of 18; (2) currently living in the UK; (3) formally diagnosed or self-identified[34,35] as autistic; (4) identified as a mother (birthing or non-birthing); [36,37] and (5) self-identified as having experienced autistic burnout (self-defined by participants) in motherhood. Our exclusion criteria stated that autistic mothers who had experienced a significant mental

health issue (e.g., suicidality) within the past 12 months could not take part, due to ethical restrictions.

We recruited 13 participants via social media channels (e.g. Facebook) with assistance from Maternity Autism Research Group and Autistic Parents UK, who shared the study details on their own platforms. Forty-two people completed the initial consent form, however eight of these did not provide a follow up email to arrange interview, 19 did not book an interview slot, and two did not attend the interview due to clashing commitments. The remaining 13 participants (see table 1) were aged between 34 and 52 years (M = 41.03, SD = 5.57). This study received ethical approval from the University of Sunderland Ethics Committee (022382) on 09/11/2023.

Table 1: Participant demographics

Name	Age	Gender	Sexuality	Ethnicity	Self/clinical ID	Years since identification	N (age) of children
Ash	43	F	Het	Mixed Heritage	Self	7	1 (5)
Willow	34	F	Bi/ demi	White	Clin	3	2 (10 and 7)
Ayla	40	F	Bi	Ashkenazi Jewish	Clin	21	1 (12)
Sage	39	F	Het	White Scottish	Clin	Unsure	2 (6 and 3)
Juniper	37	F	Het	Mixed Indian & Irish	Clin	2	1 (12)
Laurel	39	F	Queer	White	Clin	Unsure	2 (14 and 7)
Hazel	44	F	Het	White British	Clin	2	3 (11, 7 and 1)
Olive	38	F	Het	White British	Self	2	3 (10, 7 and 5)
Adair	52	NB	Bi	Not provided	Clin	15	1 (14)
Alder	34	NB	Pan	White European	Clin	7	2 (7 and 5)
Oren	42	F	Het	White British	Clin	4	1 child (2) 2 step-children (12 and 11)
Hollis	38	F/NB	Bi/demi/ asexual	British	Self	4	2 (12 and 7)
Aspen	50	F	Het	Caucasian	Clin	6	2 (15 and 13)

Materials and Procedure

We developed a semi-structured interview with questions centred around participants' experiences of burnout (e.g. *what do you think the triggers were that led you to experience autistic burnout in motherhood?)* and their recovery (e.g. *have you sought help from others to recover from autistic burnout?)* (for full interview schedule see supplementary materials).

We used Qualtrics (www.qualtrics.com) to present participants with the study information sheet and consent form. We asked participants to provide demographic details (e.g., age and gender) via open-text responses, and a valid email address to arrange interviews. We asked participants to share any accommodations they needed and offered a copy of the interview schedule in advance to minimise uncertainty.

We offered multiple modalities for participation (e.g. spoken or typed interview). We held synchronous interviews on Microsoft Teams, with participants giving either spoken interviews (n = 11), or using the Teams chat function to type their responses (n = 1). One participant emailed their answers in a word document. After the interview, we gave a full debrief, providing relevant details of support organisations.

We conducted all interviews in January 2024, with synchronous interviews lasting between 37 and 74 minutes (M = 51 minutes). After completion, we transcribed interviews verbatim, and re-checked these against the original audio recording to ensure accuracy. We sent anonymised transcripts back to participants for approval, with a reminder of their right to withdraw (for up to two weeks). At this stage, two participants provided follow up information to be subsequently added to their transcripts.

Researcher Positionality

AF is an autistic, white, cisgender woman with a young child; she also has lived experienced of autistic burnout in motherhood. DM is a neurodivergent, white, cisgender

man without children. AP is an autistic, white, cisgender woman who also does not have children.

Analysis

We used reflexive thematic analysis (RTA), following the six-stage method outlined by Braun and Clarke.[38] AF engaged in data familiarisation via the transcription process and re-reading of the transcripts. She then coded the data using an inductive approach based on both semantic content (including in-vivo coding to capture participant experiences in their own words, emphasising their authentic understandings of their reality) and latent content based on her interpretation of implicit, underlying meaning in the data set. AF grouped codes to develop candidate themes, then refined these to ensure that they were distinct from each other and conveyed a clear narrative. At the end of this stage of the analysis AF re-read the transcripts to confirm whether the data had been summarised accurately. AF's position as an "insider"[39] and the experiential knowledge associated with this influenced her motivation for the study. AF engaged in reflexive writing throughout the research process to further reduce the impact of potential biases arising from insider status. She used reflexive journaling to critically explore emotional responses to participants and her interpretation of the data, and ultimately to maintain an awareness of her power in co-constructing the knowledge alongside the participants.

Results

We developed four main themes: 1) "Depletion"; 2) "You just have to get up and keep going"; 3) "New realisations"; and 4) "We need support too" (see figure 1). We identify all participants using pseudonyms throughout.

Figure 1: Themes and subthemes
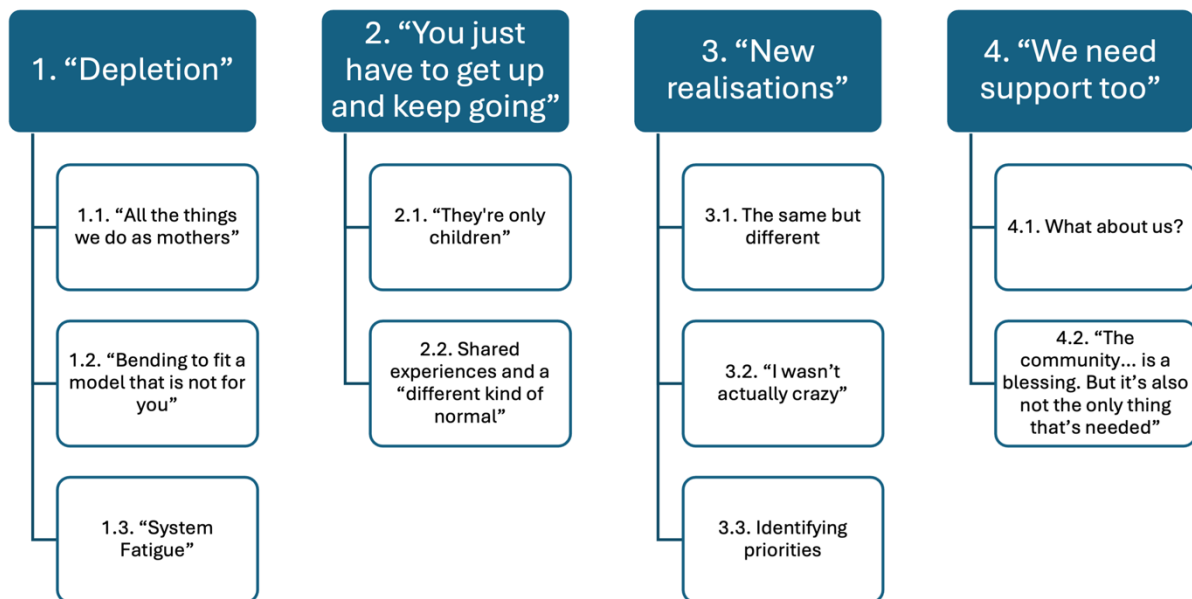
Theme 1. "Depletion"

Participants described how the demands of their mother role impacted on their energy (subtheme 1.1.), which they often conceptualised using the metaphor of a "battery" or "spoons".[40] Participants discussed the exhaustion associated with trying to be the mother that they thought they were expected to be (subtheme 1.2.), as well as that which ensued from interacting with wider systems in relation to their children (subtheme 1.3.).

1.1.   "All the things we do as mothers"

Most participants, whether they lived with a partner or not, described being primarily responsible for doing *"all the things"* (Aspen) related to caring for children and managing the family home. Many reported additional external pressures from studying and employment:

"At the end of the [work] day, I still have about two and a half hours of solid work when I get home... Like the cleaning, the cooking, get them bathed, getting them to bed, laying out stuff for tomorrow" (Sage)

"Caring for my Autistic children and my husband who is physically and mentally disabled... Trying to do a master's degree with a two-year-old and a seven-year-old"
(Hollis)

The demands on autistic mothers were often exacerbated by little to no external support system (e.g. no close family nearby) or finding external assistance *"more draining"* through the social expectation it created.

Several participants reported specific demands related to caring for their autistic children, such as managing their *"meltdowns"* or their *"impulsive"* behaviours. Some further described how their *"intuition"* and unique insight into their autistic children meant that they were *"the only one often that can understand [them]"* (Ash) - as a result, mothers felt they often had to play the role of translator for their child. Almost half (6) of the mothers were also home educating their children because schools were unable to meet their needs. Though there were clear benefits of home-education (such as reduced distress for children), taking on the educator role was cognitively demanding.

The multiplicity of demands described by all participants in their mother role both *"completely, completely drained"* their energy levels and prevented them from recovering. There was little opportunity to *"lay down"* or *"spend time alone"* to *"recharge the social battery"*, let alone engage with personal interests, and the constant presence of their children in the home environment contributed towards an inability to switch off: *"I couldn't go and listen to music, I couldn't go take myself off and draw or paint or like... so I could do nothing because she was there all the time"* (Ash).

This resulted in a *"constant decline"* for participants across *"basically all sides of [their] functioning"* (Sage), though the extent and subsequent impact of this was often overlooked by others. Participants felt they were just expected *"to manage it and go through in ways that they [neurotypical people] would do"* (Willow).

1.2. *"Bending to fit a model that is not for you"*

Societal expectations of *"proper"* motherhood were widely considered to have contributed to participants' autistic burnout. For one participant, the essentialisation of motherhood[41] and reinforcement of this from family members, professionals, and other mothers led them to perceive a lack of reproductive agency. Adair described how becoming pregnant *"with a sense of duty"* had caused them to experience significant distress and isolation:

> *"I didn't want to be pregnant, and I hated my pregnancy... So, I mean you can understand how burnout comes, you know, comes as a result of all that"*

Several participants had internalised extremely high standards of themselves, describing how their energy had been depleted by doing the things they believed that they *"should"* do as mothers, including pushing themselves *"to do activities"* with their child and *"trying to be happy because everybody expects you to be happy as a new mum"* (Juniper). Adair referred to this as *"bending to fit a model that is not for you"*, implying that they perceived an obligation to pursue normative ideals, despite being aware that these were unattainable for them.

Many participants also discussed the cumulative negative impact of masking on burnout, and how it made them feel *"exhausted and stressed"*. They noted how masking supported them to *"tick those boxes"* (Aspen) for what society expects of them, and avoid negative judgement in their mother role, but that ultimately it led to burnout:

> *"So the triggers were all of like the masking kind of behaviours that I had right, of like not really listening to what I needed... It literally was killing me"* (Willow).

However, reflecting the "double bind" of masking[42], unmasking also increased mothers' sense of shame and vulnerability due to the fact they were no longer able to conceal their *"difference"* to appear *"normal"*. This also had a serious impact on physical and mental health, leading to *"burnout that lasts for extended periods"* (Hollis).

1.3. "System fatigue"

Several participants discussed their experiences of advocating for their children in the context of education, health, and social care systems. The cognitive and emotional effort associated with this was reflected in their descriptions of "*fighting a battle*". Laurel recounted having to deal with "*like 50 people, might be more. 100?*" in relation to service involvement. They emphasised the chaos of the systems they had to deal with, saying "*none of them talk to each other*". This was echoed by other participants and meant that they had been required to constantly retell their "*family story to a revolving door of SLTs, OTs, teachers, and adjoining officialdom*" which was "*exhausting and unproductive*" (Adair). Some participants also reported experiences of judgement and discrimination by professionals in response to their attempts to seek support and advocate for their children. Their reflections were suggestive of a systemic lack of autism awareness and acceptance which further contributed to their autistic burnout, leaving them feeling "*judged*" and "*treated unequally*".

One participant also described the cognitive dissonance which arose from their deficit-framing of their autistic child within these systems, which was necessary for them to receive support but "*absolutely not how [I] think about them*" (Laurel).

Theme 2. "You have to just get up and keep going"

Participants maintained their focus on meeting the needs of their children, emphasising that their children were not responsible for their burnout (subtheme 2.1.). Participants also maintained solid relationships with their children and described how they drew on their experiences of autistic burnout to foster a positive, neuro-affirming environment (subtheme 2.2.).

2.1. "They're only children"

Some mothers experienced feelings of doubt and shame that they were unable to model the behaviours that they thought they "*should*" during periods of autistic burnout:

"I'm the adult, I shouldn't be doing this. I'm supposed to be demonstrating emotional regulation, and yet I can't regulate my own emotions at times" (Olive)

Participants described being *"good enough"* mothers during such periods, fulfilling their children's basic needs but often struggling to engage with them as much as they would have liked:

"I'm almost like I can't. So it's like being a bit like a zombie. I'm like, OK, I can do these practical things. I can, you know, I can feed you and I can make sure... But there are days where our kind of basic interaction is very low" (Juniper)

Despite this, participants reported close, positive relationships with their children, with whom they felt a *"sense of belonging"*. They emphasised that burnout *"doesn't mean that I don't love my child"*, with Willow explaining *"my children are like my world"*.

Whilst burnout exacerbated participants' difficulties coping with overwhelming sensory stimuli associated with their children (e.g. *"noisy"* and active play), they did not believe their children had done anything wrong and recognised that they were just *"acting like kids"*. Participants showed an understanding of their children in the context of their individual developmental stages, recognising *"it's difficult for them as children to really like, be mindful of everyone's needs"* (Laurel).

As such, participants were clear that they would not try to prevent their children from being children, and they instead developed strategies and accommodations to manage their own personal responses in situations where they felt overwhelmed. Several participants reported using noise cancelling headphones and removing themselves from the situation where possible, making sure their child *"was somewhere safe"* before finding a quiet space to decompress.

Participants also expressed a desire to protect their children from any negative impacts of their autistic burnout, and discussed how they had actively tried to prevent them from internalising any sense of blame or responsibility for their experiences:

"She is getting used to the idea that yes, it does have an impact on me, but I really emphasise to her it is not your fault, like nobody did anything wrong. This is just the way things are and we have to try to navigate that" (Aspen)

For some participants, experiences in their own childhood meant that the importance of protecting their children was something that they could particularly *"resonate with"*. They wanted their own children to grow up feeling *"emotionally supported"*, recognising the impact that their own parents' behaviour had on them:

"My mum was very probably autistic as well, and she was having these types of behaviours. And that had had an impact on me as well" (Alder)

2.2. Shared experiences and "a different kind of normal"

Across participants' narratives there was a sense that their experiences of burnout had enabled them to validate and connect with their children on an emotional level, *"so, it's like we're kind of going together on this journey"* (Ash). Participants implied that the universality of certain emotions, which were particularly heightened during burnout, supported them and their children to relate to each other in a positive way:

"I sometimes get a little bit like snappy with them, you know? I mean, it doesn't make me feel good when that happens... But I think as well...It's also like a teaching experience for my kids because they can get that way with me as well" (Willow)

Recognising shared energy needs within the home created space for meaningful connection between mothers and children, enabling them to spend quality down-time in parallel with each other:

"Now Saturdays are our day where we don't make any plans. I'm not gonna try and push myself to do anything other than making sure he's kind of hygienic. And that's really positive cause he really looks forward to it" (Juniper)

This in turn strengthened their relationship: *"Our relationship is really strong because of that, 'cause we've got a lot in common"* (Hazel).

Participants also reflected on the importance of open communication with their children during burnout, which enabled them to develop a shared understanding of their needs as individuals, and overcome previous barriers within their relationship:

"I would say, look, I'm really sensory overwhelmed right now and I just need you to not speak to me or not touch me for the next half an hour or whatever it is, because I just need to regulate. And that kind of works. Because before it was... Obviously to him it was perceived as a rejection because he's just got a mum who's stressed, who then doesn't want a hug" (Juniper)

Those who discussed their autistic needs expressed that by doing so they hoped to help their children to be *"more understanding and more knowledgeable"* (Oren), and to reduce any stigma by recognising *"a different type of normal"* (Hazel). Participants also reflected that this could help their autistic children to *"recognise that I understand [them]"* (Juniper), furthering their closeness.

Some participants experienced more frequent periods of being non-speaking due to autistic burnout and used alternative forms of communication to accommodate. These included messaging their children or using tools such as *"emotions thermometers"* to communicate as a family.

Theme 3. New realisations

Participants' experiences of burnout impacted their self-understanding and awareness by precipitating their autistic identification (subtheme 3.1.) and enabling them to contextualise and reframe the difficulties which they had experienced across their lifetime (subtheme 3.2.). Participants' experiences of autistic burnout also supported them to reflect on and adjust their priorities in relation to motherhood, to manage their energy levels, and prevent future burnout (subtheme 3.3.).

3.1.   The same but different

For many participants, the experience of autistic burnout led them to realise that they were, and had always been, autistic. This *"new realisation"* was often followed by a significant period of adjustment as participants negotiated their new and intersecting autistic and mother identities:

"People always say you're the same person you always were before you knew you were autistic. And I'm like, I'm absolutely not the same person. I think because it's coincided with me having a baby. Like, when you have a baby anyway you end up being a completely different person" (Oren)

Some expressed feeling more like their real selves, whereas others experienced grieving for the person that they were *"before"*. Autistic identification was widely considered to be a positive outcome of burnout in that it supported participants to better understand themselves, *"it was really a lifesaver actually"* (Hazel). However, not all participants were positive about their autistic identity in itself:

"It just makes me feel like I can't cope. And like I haven't got the resilience to do what I need to do because I have this thing" (Oren).

For Oren, acceptance of their autistic identity was made more difficult by the lack of post-identification support *("it still blows my brain that you get told this massive thing and then there's nothing"*), and the conflict between societal stereotypes of autistic people and the way that they viewed themselves.

Participants' knowledge of the autistic stereotypes and stigmas also influenced their decision making around whether to disclose their new autistic identity. Whilst certain participants described being "*really open*" about being autistic, others were more *"cautious"* of the potential impact that this could have on the way that people perceive them in their mother role. Participants' narratives around disclosure highlighted the

unique challenges faced by autistic mothers, such as concerns over being perceived as a "*fit parent*" or even "*having their children removed*".

3.2. "*I wasn't actually crazy*"

Participants' experiences of autistic burnout and autistic identification enabled them to contextualise and reframe current and historic difficulties. Many participants recognised that they had experienced autistic burnout at different points throughout their lives, often being misdiagnosed with a specific mental health problem (e.g. depression).

Participants' understanding and insight into autistic burnout as a "*genuine*" and distinct autistic experience meant that they were less likely to perceive their difficulties as "*doing life badly*" (Ayla), which decreased their sense of shame. This shift in perspective also supported participants' acceptance that they could not overcome autistic burnout by trying "*harder*" which for many had compounded their difficulties in the past:

"And when I think about those, what were previously depressive episodes, they have got worse each time. And it's because of that, because each time it's like pushing to get out of them, and then this whole load of masking for however long afterwards, and then another one" (Juniper)

These comments highlight the importance of having fitting terminology to describe and understand one's own experiences, especially when they seem to fall outside of the remit for typical expressions of mental health difficulties (e.g. depression).

3.3. Identifying priorities

Participants discussed how their experiences of autistic burnout had encouraged them to consider what they could *"actually put down"* as mothers, which often involved them adjusting their expectations and standards of themselves in the context of this role. This included shrugging off demands such as *"the mum's book group at school"*

(Ash) or *"pressuring myself to be cooking fresh meals from scratch every day because I don't need to"* (Juniper).

Many participants reported an increased awareness of the importance of recognising and accommodating their own needs, such as *"stimming"* and *"pictures of the steps of the morning so I can make our own social story"* (Ash), which reduced the stress associated with the demands discussed in theme 1.

For some participants, making use of accommodations had also required them to overcome their *"internalised ableism"* (Hollis), for example recognising and accepting that things such as taxis or cleaners *"might be luxuries to other people... actually to us they're necessities, like we can't really function without them"* (Juniper).

Overall participants' reflections on their needs and priorities were emphasised across their accounts of trying to prevent future burnout, stating that they were not *"willing to go back to the place that I was... I'm not"* (Laurel) and as such were *"trying to do everything I can to protect myself"* (Olive).

Participants also described how autistic burnout had supported them to understand that their children *"don't have to take priority all the time"* (Hazel). This was "a massive learning curve" for participants, associated with a significant shift in how they perceived their maternal identity as they came to reject *"idealising",* self-sacrificing notions of motherhood: *"Their needs are always met. I need some of mine to be met."* (Hazel).

Theme 4. We need support too

Participants discussed the accessibility of support, and their positive and negative experiences of this. We developed two subthemes: 4.1. "What about us?" reflects the lack of visibility and representations of autistic mothers; 4.2. "The community... is a blessing, But it's also not the only thing that's needed" considers the benefits and risks of autistic community peer support and establishes how professionals' lack of

knowledge acts as a barrier to services for autistic mothers.

4.1. What about us?

Many participants had accessed information about autistic burnout and how to recover from it through internet searches, books, and podcasts, noting "*there isn't a whole load out there*" (Juniper). Participants emphasised that the advice and support available from these sources often failed to consider the circumstances and needs of autistic people with children. Thus, they found much of it was not "*relevant*" as the pressures identified in theme 1 were not considered:

> *"There's nothing, or very little, geared towards me as a mother... The guidance is always take time for yourself. You know. Do what you love. Well, in my current situation that's just not possible." (Oren)*

It was clear from their accounts that the typical recommendations for recovery from burnout were not realistic given that our participants reported very little real ability to take time for themselves to lessen demands.

4.2. "The community... is a blessing. But it's also not the only thing that's needed"

Most participants discussed the value of advice and peer support from the autistic community and their narratives around this highlighted the significance of autistic mothers' experiential expertise:

> *"And even if they're putting out suggestions, even if they don't work for me, it's like they are slightly more realistic suggestions because these are people with children who are living it" (Oren)*

The predominantly online nature of this support was easily accessible to participants and allowed them to engage flexibly, accounting for their communication preferences and energy levels during burnout because "*it's less pressure than the in person*" (Sage). The online community was also perceived to be a safe place where autistic mothers

could be their authentic selves and not *"worry about being too much or too little"* (Ash). Participants emphasised how the acceptance and validation from those who *"understood"* served to empower them through a sense of collective resistance against normative notions of motherhood:

> *"It takes away a lot of the shame and a lot of what I should be doing as a parent, and these very high standards that I kind of hold for myself of like, oh actually, this is normal for an autistic mum to be going through"* (Juniper)

However, participants also recognised that an over-reliance on other autistic people within the community risks increasing those individuals' own burnout, indicating a need for peer relationships to be boundaried:

> *"I feel like there does need to be more kind of like professional support because you have to also realise that those people are going through their own struggles. They have their own like lifetime of traumas and ableism and stuff… I feel like, you know, they're not your therapist. They're your friends."* (Willow)

This was exemplified by a participant who described their experiences of vicarious burnout from supporting an autistic friend. These accounts highlight the importance of having a strong support network and the opportunity to meet people with similar experiences, but also suggest that peer support alone is not adequate when dealing with serious burnout.

Accordingly, participants stressed the need for professionals who understand autistic people, and *"take it [burnout] seriously"* (Sage). Many had experienced *"stigmatising ignorance"* from professionals. This acted as a barrier to accessing support, citing dismissal, disbelief, and being treated as though they were *"stupid"*, with Hazel recalling a professional who said, *"I'll speak to you very slowly'"* when they disclosed being autistic.

Some participants *had* sought neuro-affirming support privately, describing their experiences of this as *"absolutely night and day"* compared to their previous experiences of support:

> *"I finally have somebody in front of me who understands me. And she definitely did help me through the burnout" (Alder)*

These comments demonstrate the positive impact that professional support can have when it is provided by people with an up-to-date understanding of autistic people and the challenges they might face.

Discussion

Our study aimed to explore autistic mothers' experiences of autistic burnout. We found that the pressures of motherhood were often amplified, with mothers struggling to balance their own needs with those of their children, and the systems they had to navigate to ensure that their child was also supported. However, despite finding certain aspects of motherhood (such as a lack of alone time, or sensory bombardment) stressful, they made a concerted effort not to let burnout impact their children. Recognition that they were autistic gave them the ability to better recognise their own needs and start to remove some of the pressures put on themselves, but they also identified a need for better professional support.

Participants were the primary caregivers for their children and carried out the majority of the domestic duties within the family home, which is consistent with existing literature around the disproportionate burden placed on both non-autistic[43,44] and autistic mothers.[25] Participants were responsible for managing the invisible family load[44] including planning, remembering, and worrying about their children's wellbeing across the multiple dimensions (i.e., managerial, cognitive, and affective).[44] Managing this is associated with psychological distress and exhaustion amongst non-autistic mothers.[43] However, the autistic mothers within our study reported having to manage both their invisible disability and their stigmatised identity, compounding the negative effects of

family load stress. These findings echo Heyworth et al.[25] who found that autistic mothers report acute difficulty managing their demanding everyday family life, ultimately leading to their burnout.

The added complexity of parenting autistic children created additional pressures. Many of these have been reported previously by autistic mothers, such as needing to "translate" their autistic children to others around them.[13,45] Participants reported home-educating primarily due to the negative impacts of mainstream education on their autistic children's health and wellbeing.[46,47] These findings align with existing research, in which non-autistic parents have described home-education as a double-edged sword,[48] and suggests that there needs to be better understanding and accommodation for the experiences of home-educating autistic parents, preventing their autistic burnout.

Autistic mothers continued to be able to meet their children's needs whilst experiencing autistic burnout, showing that whilst autistic mothers face additional challenges and barriers in their role, they are no less capable of caring for their children than non-autistic mothers.[11,13,15] This is particularly significant given recent evidence indicating that only 35.6% of education and social care professionals believed that "Autistic mothers are just as capable of raising healthy, happy children as parents without autism".[49] Recognition of autistic mothers' strengths and caring capacities is crucial in destigmatising narratives which suggest that autistic parents are less able to understand and respond to their children. Such stigma acts as a barrier to accessing support for autistic mothers,[15] and when internalised can lead to poorer psychosocial outcomes.[50]

Participants used their experiences of autistic burnout to facilitate discussions with their children about autism and increase their children's understanding and acceptance.[51] Through these discussions, and by being their authentic autistic selves (for example, by stimming) participants aimed to encourage a positive autistic identity for their children.[10,52] Findings that participants maintained and even strengthened their

relationships with their children during periods of autistic burnout further support a distinction with non-autistic parental burnout.[3]

Participants' narratives around their autistic identification and the period of adjustment following on from this echo those which have been shared previously by late-diagnosed autistic women.[10,53–55] Participants demonstrated varying levels of acceptance of their autistic identity, which may in part be explained by the wide range in their years since identification.[52] A lack of appropriate post-identification support[56] was cited as a barrier to participants' acceptance, thus our findings further endorse the priority for post-identification support . By providing biographical illumination,[57] autistic identification also supported participants in reconceptualising their previous mental health issues, commonly (mis)diagnosed as depression, as periods of autistic burnout. This served to alleviate their shame around their experiences, and around the fact that treatments and approaches had either not reduced their distress or had exacerbated it. These findings are consistent with Kentrou et al.[58] in which 31.7% of autistic women reported at least one perceived psychiatric misdiagnosis prior to their autistic identification. Findings highlight the importance of professionals recognising the clinical presentation of autistic burnout to prevent the diagnostic overshadowing and underdiagnosis of autism.[54] The self-awareness developed because of autistic burnout often promoted participants' use of self-accommodation strategies, which in turn supported them to proactively manage their energy levels. Self-accommodation has previously been associated with increased autonomy and improved quality of life for autistic women.[59] Thus, supporting autistic mothers to identify potential accommodations may be beneficial for the recovery and/or prevention of their autistic burnout.

The impact of stigma was significant for participants navigating their autistic mother identity and deciding whether to disclose. Many reported their anticipation of stigma from professionals and associated fears that they would be perceived as unfit mothers. These findings are supported by existing literature around the negative consequences of stigma for autistic people, [60] and for autistic mothers specifically.[15,19] They reinforce the need for greater understanding, acceptance, and positive representation of autism in

order to challenge this at a systemic level.[50] Challenging stigma can contribute to making disclosure a psychologically safe process for autistic mothers. This can enable them to access the accommodations and support needed to thrive, supporting both the prevention of and recovery from autistic burnout. Perceived stigma is also associated with increased masking[42,61] and masking was identified in this study and existing literature as a key contributory factor to burnout.[28,30,31] Thus reducing stigma may ameliorate autistic mothers' autistic burnout by enabling them to unmask safely.

Participants were reluctant to seek formal support due to fears that they would be dismissed by professionals who lacked knowledge and understanding of autism and autistic burnout. The value of autism training in increasing professionals' knowledge and self-efficacy when working with autistic individuals is essential,[49] as is training that takes a co-production approach.[62] Community knowledge played a crucial part in mothers' support systems, with connection to the online autistic community enabling participants to benefit from peer-support for parenting challenges and autistic burnout. This demonstrates the value of integrating lived experience when improving professional understanding and support, to ensure it acknowledges community-specific needs. These findings also show the value of autistic community connectedness[63] for autistic mothers. Though peer support alone was deemed inadequate and participants were mindful of each other's energy, community connections allowed them to feel accepted and validated by others, in turn facilitating their own self-acceptance and self-compassion.[64]

Limitations and future directions

This study provides valuable insights into the experiences of autistic mothers; however, we encountered several limitations. We did not ask participants about any co-occurring disabilities, though two mothers voluntarily disclosed information relating to these (specifically co-occurring ADHD). Future research would benefit from exploring the influence of any co-occurring conditions on autistic mothers' experiences of autistic burnout, particularly co-occurring intellectual disability (ID). Autistic people

with ID are significantly under-represented in existing research[65] including on autistic motherhood, meaning their experiences and needs remain poorly understood.

Our sample was primarily white, and thus there are likely important intersectional issues that have not been considered. It also consisted of exclusively late-identified autistic mothers, many of whom experienced autistic burnout prior to their identification. Further research is needed to examine any differences in the prevalence rates and subjective experiences of autistic burnout between those who are early and late diagnosed to ensure a more comprehensive understanding of autistic burnout overall.

Conclusion

To our knowledge this is the first study to explicitly examine how autistic mothers experience autistic burnout in relation to their parenting role, and how they can be supported. Our findings highlight the incredible pressure that autistic mothers experience, including expectations to perform normative motherhood, while meeting the needs of their children and the systems meant to support them. Despite this, they parent with compassion underpinned by their own desire to create a safe and accepting space for their child. Our findings have important implications for professionals working with autistic mothers (e.g. healthcare professionals) and highlight the additional need for neuro-affirming support that recognises the unique needs of autistic mothers and the pressures that they face.

Authorship Confirmation Statement

AF and AP designed this study.

AF collected and analysed the data, with feedback from DM and AP.

AF wrote the first draft of the manuscript. AP and DM provided feedback and edited the manuscript.

Author Disclosure Statement

The authors declare the following potential conflicts of interest with respect to the research, authorship, and publication of this article: AP, has accepted speaker fees to discuss her work on autism, neurodiversity, relationships and inclusivity at conferences and training events. She has also received royalties from Pavilion publishing for a book on autistic masking and stigma.

Data availability statement

Data for this project is not openly available

References

1. Copeland DB, Harbaugh BL. "It's Hard Being a Mama": Validation of the Maternal Distress Concept in Becoming a Mother. *J Perinat Educ*. 2019;28(1):28-42. doi:10.1891/1058-1243.28.1.28

2. Modak A, Ronghe V, Gomase KP, Mahakalkar MG, Taksande V. A Comprehensive Review of Motherhood and Mental Health: Postpartum Mood Disorders in Focus. *Cureus*. Published online September 29, 2023. doi:10.7759/cureus.46209

3. Mikolajczak M, Roskam I. A Theoretical and Clinical Framework for Parental Burnout: The Balance Between Risks and Resources (BR2). *Front Psychol*. 2018;9:886. doi:10.3389/fpsyg.2018.00886

4. Benson KJ. Perplexing Presentations: Compulsory Neuronormativity and Cognitive Marginalisation in Social Work Practice with Autistic Mothers of Autistic Children. *Br J Soc Work*. 2023;53(3):1445-1464. doi:10.1093/bjsw/bcac229

5. Daniels JN. Disabled Mothering? Outlawed, Overlooked and Severely Prohibited: Interrogating Ableism in Motherhood. *Soc Incl*. 2019;7(1):114-123. doi:10.17645/si.v7i1.1551

6. Berger M, Asaba E, Fallahpour M, Farias L. The sociocultural shaping of mothers' doing, being, becoming and belonging after returning to work. *J Occup Sci*. 2022;29(1):7-20. doi:10.1080/14427591.2020.1845226

7. Williamson T, Wagstaff DL, Goodwin J, Smith N. Mothering Ideology: A Qualitative Exploration of Mothers' Perceptions of Navigating Motherhood Pressures and Partner Relationships. *Sex Roles*. 2023;88(1-2):101-117. doi:10.1007/s11199-022-01345-7

8. Seers K, Hogg RC. 'You don't look autistic': A qualitative exploration of women's experiences of being the 'autistic other.' *Autism*. 2021;25(6):1553-1564. doi:10.1177/1362361321993722

9. Higgins ET. Self-discrepancy: a theory relating self and affect. *Psychol Rev*. 1987;94(3):319.

10. Lilley R, Lawson W, Hall G, et al. 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*. 2022;26(6):1395-1408. doi:10.1177/13623613211050694

11. Talcer MC, Duffy O, Pedlow K. A Qualitative Exploration into the Sensory Experiences of Autistic Mothers. *J Autism Dev Disord*. 2023;53(2):834-849. doi:10.1007/s10803-021-05188-1

12. Sanchez P. "Against the norm" mothering: A reflexive thematic analysis of autistic motherhood. Published online 2023. doi:10.18744/LSBU.95443

13. Dugdale AS, Thompson AR, Leedham A, Beail N, Freeth M. Intense connection and love: The experiences of autistic mothers. *Autism*. 2021;25(7):1973-1984. doi:10.1177/13623613211005987

14. Griffiths S, Allison C, Kenny R, Holt R, Smith P, Baron-Cohen S. The vulnerability experiences quotient (VEQ): A study of vulnerability, mental health and life satisfaction in autistic adults. *Autism Res*. 2019;12(10):1516-1528.

15. Pohl AL, Crockford SK, Blakemore M, Allison C, Baron-Cohen S. A comparative study of autistic and non-autistic women's experience of motherhood. *Mol Autism*. 2020;11(1):3. doi:10.1186/s13229-019-0304-2

16. Adams D, Stainsby M, Paynter J. Autistic Mothers of Autistic Children: A Preliminary Study in an Under-Researched Area. *Autism Adulthood*. 2021;3(4):339-346. doi:10.1089/aut.2020.0078

17. Bailey DB, Raspa M, Olmsted MG, et al. Development and Psychometric Validation of the Family Outcomes Survey-Revised. *J Early Interv*. 2011;33(1):6-23. doi:10.1177/1053815111399441

18. Hampton S, Man J, Allison C, Aydin E, Baron-Cohen S, Holt R. A qualitative exploration of autistic mothers' experiences II: Childbirth and postnatal experiences. *Autism*. 2022;26(5):1165-1175. doi:10.1177/13623613211043701

19. Winnard R, Roy M, Butler-Coyne H. Motherhood: Female Perspectives and Experiences of Being a Parent with ASC. *J Autism Dev Disord*. 2022;52(5):2314-2324. doi:10.1007/s10803-021-05122-5

20. Grant A, Griffiths C, Williams K, Brown A. "It felt like I had an old fashioned telephone ringing in my breasts": An online survey of UK Autistic birthing parents' experiences of infant feeding. *Matern Child Nutr*. 2024;20(1):e13581. doi:10.1111/mcn.13581

21. MacLennan K, O'Brien S, Tavassoli T. In Our Own Words: The Complex Sensory Experiences of Autistic Adults. *J Autism Dev Disord*. 2022;52(7):3061-3075. doi:10.1007/s10803-021-05186-3

22. Smit S, Hopper J. Love, Joy, and a Lens of Childhood Trauma: Exploring Factors That Impact the Mental Health and Well-Being of Autistic Parents via Iterative Phenomenological Analysis. *Autism Adulthood*. Published online September 21, 2022:aut.2021.0101. doi:10.1089/aut.2021.0101

23. Hume R, Burgess H. "I'm Human After All": Autism, Trauma, and Affective Empathy. *Autism Adulthood*. 2021;3(3):221-229. doi:10.1089/aut.2020.0013

24. Kimber L, Verrier D, Connolly S. Autistic People's Experience of Empathy and the Autistic Empathy Deficit Narrative. *Autism Adulthood*. Published online September 11, 2023:aut.2023.0001. doi:10.1089/aut.2023.0001

25. Heyworth M, Brett S, Den Houting J, et al. "I'm the Family Ringmaster and Juggler": Autistic Parents' Experiences of Parenting During the COVID-19 Pandemic. *Autism Adulthood*. Published online May 12, 2022:aut.2021.0097. doi:10.1089/aut.2021.0097

26. Hull L, Petrides KV, Allison C, et al. "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *J Autism Dev Disord*. Published online 2017. doi:10.1007/s10803-017-3166-5

27. Arnold SR, Higgins JM, Weise J, Desai A, Pellicano E, Trollor JN. Confirming the nature of autistic burnout. *Autism*. Published online 2023:13623613221147410.

28. Mantzalas J, Richdale AL, Dissanayake C. A conceptual model of risk and protective factors for autistic burnout. *Autism Res*. 2022;15(6):976-987.

29. Raymaker DM, Teo AR, Steckler NA, et al. "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": defining autistic burnout. *Autism Adulthood*. 2020;2:2:132-143. doi:10.1089/aut.2019.0079

30. Mantzalas J, Richdale AL, Adikari A, Lowe J, Dissanayake C. What is autistic burnout? A thematic analysis of posts on two online platforms. *Autism Adulthood*. 2022;4(1):52-65.

31. Higgins JM, Arnold SR, Weise J, Pellicano E, Trollor JN. Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating# AutisticBurnout. *Autism*. 2021;25(8):2356-2369.

32. Gore K, Hayward SM, Flower RL, Gilbert M, Barbaro J. "Maybe No One Knows We Need Help": Understanding the Experiences of Autistic Working Mothers in Australia. *Autism Adulthood*. 2024;6(1):47-59. doi:10.1089/aut.2022.0089

33. Phung J, Penner M, Pirlot C, Welch C. What I Wish You Knew: Insights on Burnout, Inertia, Meltdown, and Shutdown From Autistic Youth. *Front Psychol*. 2021;12:741421. doi:10.3389/fpsyg.2021.741421

34. Sturm A, Huang S, Bal V, Schwartzman B. Psychometric exploration of the RAADS-R with autistic adults: Implications for research and clinical practice. *Autism*. Published online February 2, 2024:13623613241228329. doi:10.1177/13623613241228329

35. Overton GL, Marsà-Sambola F, Martin R, Cavenagh P. Understanding the Self-identification of Autism in Adults: a Scoping Review. *Rev J Autism Dev Disord*. Published online March 7, 2023. doi:10.1007/s40489-023-00361-x

36. Hillier A, Gallop N, Mendes E, et al. LGBTQ+ and autism spectrum disorder: Experiences and challenges. *Int J Transgender Health*. 2020;21(1):98-110.

37. Lewis LF, Ward C, Jarvis N, Cawley E. "Straight Sex is Complicated Enough!": The Lived Experiences of Autistics Who are Gay, Lesbian, Bisexual, Asexual, or Other Sexual Orientations. *J Autism Dev Disord*. 2021;51(7):2324-2337. doi:10.1007/s10803-020-04696-w

38. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol*. Published online 2020:1-25.

39. Wilkinson S, Kitzinger C. Representing Our Own Experience: Issues in "Insider" Research. *Psychol Women Q*. 2013;37(2):251-255. doi:10.1177/0361684313483111

40. Miserandino C. The Spoon Theory. But you dont look sick. 2003. Accessed October 17, 2024. https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/

41. Hays S. *The Cultural Contradictions of Motherhood*. Yale University Press; 1996.

42. Miller D, Rees J, Pearson A. "Masking Is Life": Experiences of Masking in Autistic and Nonautistic Adults. *Autism Adulthood*. 2021;3(4):330-338. doi:10.1089/aut.2020.0083

43. Ciciolla L, Luthar SS. Invisible Household Labor and Ramifications for Adjustment: Mothers as Captains of Households. *Sex Roles*. 2019;81(7-8):467-486. doi:10.1007/s11199-018-1001-x

44. Wayne JH, Mills MJ, Wang YR, Matthews RA, Whitman MV. Who's Remembering to Buy the Eggs? The Meaning, Measurement, and Implications of Invisible Family Load. *J Bus Psychol*. 2023;38(6):1159-1184. doi:10.1007/s10869-023-09887-7

45. Radev S, Freeth M, Thompson AR. 'I'm not just being difficult . . . I'm finding it difficult': A qualitative approach to understanding experiences of autistic parents when interacting with statutory services regarding their autistic child. *Autism*. 2024;28(6):1394-1404. doi:10.1177/13623613231212794

46. Goodall C. 'I felt closed in and like I couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people. *Autism Dev Lang Impair*. 2018;3:239694151880440. doi:10.1177/2396941518804407

47. Horgan F, Kenny N, Flynn P. A systematic review of the experiences of autistic young people enrolled in mainstream second-level (post-primary) schools. *Autism*. 2023;27(2):526-538. doi:10.1177/13623613221105089

48. McDonald J, Lopes E. How parents home educate their children with an autism spectrum disorder with the support of the Schools of Isolated and Distance Education. *Int J Incl Educ*. 2014;18(1):1-17. doi:10.1080/13603116.2012.751634

49. Sutcliffe-Khan F, Larkin F, Hamilton L. Parents' and professionals' views on autistic motherhood using a participatory research design. *Curr Psychol*. 2024;43(25):21792-21807. doi:10.1007/s12144-024-05999-2

50. Turnock A, Langley K, Jones CRG. Understanding Stigma in Autism: A Narrative Review and Theoretical Model. *Autism Adulthood*. 2022;4(1):76-91. doi:10.1089/aut.2021.0005

51. Crane L, Lui LM, Davies J, Pellicano E. Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*. 2021;25(4):1161-1167. doi:10.1177/1362361320981317

52. Corden K, Brewer R, Cage E. Personal Identity After an Autism Diagnosis: Relationships With Self-Esteem, Mental Wellbeing, and Diagnostic Timing. *Front Psychol*. 2021;12:699335. doi:10.3389/fpsyg.2021.699335

53. Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *J Autism Dev Disord*. Published online 2016. doi:10.1007/s10803-016-2872-8

54. Harmens M, Sedgewick F, Hobson H. Autistic women's diagnostic experiences: Interactions with identity and impacts on well-being. *Womens Health*. 2022;18:174550572211374. doi:10.1177/17455057221137477

55. Leedham A, Thompson AR, Smith R, Freeth M. 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*. 2020;24(1):135-146.

56. Crowson S, Poole D, Scargill K, Freeth M. Understanding the post-diagnostic support priorities of autistic adults in the United Kingdom: A co-produced modified Delphi study. *Autism*. 2024;28(4):854-865. doi:10.1177/13623613231196805

57. Tan CD. "I'm a normal autistic person, not an abnormal neurotypical": Autism Spectrum Disorder diagnosis as biographical illumination. *Soc Sci Med*. 2018;197:161-167. doi:10.1016/j.socscimed.2017.12.008

58. Kentrou V, Livingston LA, Grove R, Hoekstra RA, Begeer S. Perceived misdiagnosis of psychiatric conditions in autistic adults. *eClinicalMedicine*. 2024;71:102586. doi:10.1016/j.eclinm.2024.102586

59. Paricos A, Sturrock A, Twomey K, Leadbitter K. "I'm not mad, bad, and dangerous … simply wired differently": Exploring factors contributing to good quality of life with autistic women. *Res Autism Spectr Disord*. 2024;112:102338. doi:10.1016/j.rasd.2024.102338

60. Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disabil Soc*. 2022;37(3):427-453. doi:10.1080/09687599.2020.1822782

61. Pearson A, Rose K. A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice. *Autism Adulthood*. Published online 2021. doi:https://doi.org/10.1089/aut.2020.0043

62. Stark E, Ali D, Ayre A, et al. Coproduction with Autistic Adults: Reflections from the Authentistic Research Collective. *Autism Adulthood*. 2021;3(2):195-203. doi:10.1089/aut.2020.0050

63. Botha M, Dibb B, Frost DM. 'It's being a part of a grand tradition, a grand counter-culture which involves communities': A qualitative investigation of autistic community connectedness. *Autism*. 2022;26(8):2151-2164. doi:10.1177/13623613221080248

64. Gillard S, Foster R, Gibson S, Goldsmith L, Marks J, White S. Describing a principles-based approach to developing and evaluating peer worker roles as peer support moves into mainstream mental health services. *Ment Health Soc Incl*. 2017;21(3):133-143. doi:10.1108/MHSI-03-2017-0016

65. Russell G, Mandy W, Elliott D, White R, Pittwood T, Ford T. Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Mol Autism*. 2019;10(1):9. doi:10.1186/s13229-019-0260-x

Table and figure legends

Table 1: Participant demographics

Figure 1: Themes and subthemes