Claire Malcolm and
Melissa Green

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## Black Mothers Raising Autistic Children in the UK

Foreword by
**JASON ARDAY**

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# Abstract

*Mothering at the Margins* combines collective autoethnography with rigorous participant research, creating an authentic, deeply moving narrative grounded in both lived experience and scholarly inquiry. In so doing, it amplifies the voices of an overlooked community: Black mothers raising autistic children in the UK. This project surfaces common experiences of women whose lives sit at the complex intersection of race, gender, and disability – termed by the authors as the 'triad of oppression'. These experiences include those of both co-authors, 26 survey respondents, and 9 participants. Through semi-structured interviews and focus groups, the authors empowered participants to share their journeys in accessing support for, and advocating on behalf of, their autistic children. Research findings revealed patterns of marginalisation and oppression, which the authors distilled into the 'multiplicity of burdens' model. The research highlights the challenges Black mothers of autistic children face, including underdiagnosis, referral bias, deficit-based assumptions of neglect and parental blame, and the impact of systemic racism and discrimination. It informs ongoing debates concerning the importance of cultural competence and anti-racism in autism research and the need for greater equity in access to crucial frontline services for racially minoritised individuals and communities. The book posits changes to both policy and practice in the fields of healthcare, education and social care. Since the researchers are themselves Black mothers of autistic children, this project is uniquely placed to address the paucity of studies that centre the lived experiences of this demographic. As a consequence, *Mothering at the Margins* respects and enhances the agency of those whom it seeks to support and offers a pioneering framework for the development of specific recommendations that will engender meaningful societal change.

## Key words

Blackness, Motherhood, Autism, Neurodiversity, Intersectionality, Marginalisation, Critical Race Theory, Education, Health and Social Care, Policy and Practice

# Acknowledgements

## Claire

Deepest thanks go from the bottom of my heart straight to the following precious souls:

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My parents, my brother, my sister-in-law, and my 'first babies' (my wonderful nephews).

My found family (Catherine, the SWGS and Senghennydd Ladies, and Sarah).

So many kind and supportive colleagues at The Open University.

Mel, who came into my life late and instantly made sense of it, in ways I could never have anticipated and for which I'll always be grateful.

And, of course, to my children, with whom the sun rises and sets. This book exists in service of my boundless love for you. I may have brought you into the world, but it's you who gave me life. Thank you beyond words for the privilege of being your Mama.

Finally, to our research participants – our fellow 'mothers at the margins' – whose voices, generosity and trust made this project possible. We owe you everything.

## Mel

My deepest gratitude is held for Jan Etienne, one of our collection's editors, for keeping me in mind for writing this book after our meeting years ago. Thank you, Jan, for reaching out and believing I could do this topic justice.

Thank you, Claire, for sharing the load and writing this book with me.

To my husband – your role as my rock has helped me become the mother I am today. There is no one I would rather live my life with. Thank you for being the best father to our children.

To my OU mentors, Mimi and Alison, and my sisters from other misters, Suddie and Ann, thank you for your support and unwavering belief in my abilities.

To my beautiful children, thank you for being the source of endless joy and learning, and for teaching me who I am and who I can be. Being your Mummy is an honour and blessing that I hope to always do justice to.

And my final thanks to the 'othered' mothers in this book. I was humbled by you sharing your stories with us and helping us to shine a much-needed light on the experiences of Black mothers raising autistic children.

## Claire and Mel

Heartfelt thanks go to Sonah (Black Mothers Matter) and to Michelle and Reyss (Global Child and Maternal Health) for your time and for your wisdom.

# Foreword

In the quiet corners of society, where voices too often go unheard, this book—*Mothering at the Margins: Black Mothers Raising Autistic Children in the UK*—amplifies the lived realities of Black women whose daily labour, love, and resistance defy both systemic neglect and social invisibility. These are the stories of Black mothers navigating the intersecting terrains of race, disability, gender, and class in a society that has historically overlooked or misunderstood their unique plight. Their experiences are not just personal; they are political. And this work rightly insists we listen.

Autism in the UK is most frequently represented through a singular often white, middle-class lens—a narrative that flattens the complexity of neurodivergence whilst erasing the unique challenges faced by those on the periphery of mainstream visibility. For Black mothers, parenting an autistic child involves far more than access to care or securing a diagnosis. It demands constant advocacy in schools, battles with healthcare systems, and the emotional toll of combating societal assumptions that either criminalize their children or dismiss their mothering as inadequate. Their love, patience, and strategic resilience are acts of radical care in a world that too often denies their full humanity.

This book does not offer easy answers or heroic tropes. Instead, it provides space for nuance, for contradiction, for truth. The exceptional mothers here speak in their own voices, revealing the complexity of their parenting journeys—at times marked by joy, cultural pride, and deep connections, and at other times shaped by exhaustion, bureaucratic obstacles, and racialized disbelief. The intersections of their identities mean they are forced to mother both visibly and invisibly—pushed into hypervigilance while simultaneously being rendered unseen by the very institutions designed to support them.

What is profoundly powerful about *Mothering at the Margins* is that it disrupts the narrative that Black motherhood is singular or monolithic. It resists both deficit-based portrayals and simplistic celebrations. Instead, it invites us to witness mothering as a dynamic, context-bound, and deeply social practice—one that is deeply impacted by structural inequalities yet always striving for dignity and justice.

This work is also a call to action. For policymakers, educators, health professionals, and scholars, it challenges us to reconsider what inclusive support truly means. It urges us to centre Black voices in conversations about neurodiversity and care. And most importantly, it reminds us that knowledge does not only reside in institutions—it lives in the hearts, kitchens, waiting rooms, and WhatsApp chats of Black mothers who have always known how to navigate the margins.

In reading this book, we are offered not just insight, but responsibility. To honour these stories is to commit to transformation. To read closely is to begin listening differently. And to understand these mothers' struggles and triumphs is to glimpse the future of a more just, more caring society. Society at large is eternally indebted to the strength, brilliance, fortitude and advocacy of Claire and Mel. Thank you for this most empowering treatise.

Jason Arday, Professor of Sociology of Education, University of Cambridge, UK

I dream of never being called ‘resilient’ again in my life. I’m exhausted by strength. I want support. I want softness. I want ease. I want to be amongst kin. Not patted on the back for how well I take a hit. Or for how many…

– US writer and director, Zandashé Brown (2021)

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# Learning objectives

1. To **demonstrate** how Intersectionality, Critical Race Theory and Critical Disability Studies illuminate and centre the experiences of marginalised communities.
2. To **amplify** the voices of Black women whose experiences of motherhood sit at the intersection of gender, race, and disability.
3. To **encourage** students to interrogate their own biases in light of these counter-narratives and consider the implications for their professional practice.
4. To **evaluate** how the lived experiences of Black mothers of autistic children inform calls for meaningful reform in education, healthcare, and social care systems.
5. To **provide** students with critical tools to analyse and propose improvements to policies and practices affecting Black mothers and autistic children.

# Introduction

## Our story

### Meet Claire

*"My name's Claire", I began, before racing through my various roles and credentials to a Teams Meeting full of strangers. This was something I was so accustomed to having to do that it almost felt like muscle memory but, today, I decided that I wanted to include one additional detail.*

*"At the moment, I'm working part-time because I have complex caring responsibilities".*

*"Should I stop there?", I wondered to myself, in the pregnant pause that followed. Do I really want to give these people – whom I'm meeting for the first time – a glimpse into the delicate balancing act that almost caused me to be late for this meeting? Do they need to know that, just off-camera, bruises are starting to appear on my forearms from the meltdown my daughter had, only minutes earlier, before she left for school? Can they tell that my eyes are pricking with tears and my forced smile is making my face hurt?*

*Maybe it was something about the almost unprecedented feeling of being in an online space that was exclusively occupied by fellow Black women academics. Maybe it was the sight of the welts and* *scratches, and the intrusive thoughts about the little girl who had given them to me. Maybe it was the guilt of not being able to abandon my professional responsibilities and keep her at home with me where, between us, we could have found ways to manage her anxiety and give her the reassurance she desperately needed. Maybe it was just the exhaustion of masking and the unwillingness to force myself to do so for a moment longer.*

*"My daughter is autistic", I added, as nonchalantly as the morning's traumas would allow.*

*There was no real response. Why would there be? My circumstances at home had no bearing on these women and their pursuit of career development – and neither should they. But, nonetheless, I was pleased to have heard myself say it. Glad that I had named my experience as a Black woman raising a disabled child, while trying to progress in a competitive and unforgiving sector. Proud of myself for shaking off my perception that giving an honest appraisal of the challenges I was facing amounted to making excuses for myself and failing in my duty to live up to the 'Strong Black Woman' trope that usually prevented me from speaking out.*

*Then, in the bottom left-hand corner of the screen, another woman began to introduce herself to the group. "I'm Mel", she said, before detailing her own thoroughly impressive laundry list of academic achievements. "And it's funny you should say that Claire, because I also have an autistic child".*

*Within a few short minutes, and by way of coincidence, we found ourselves in a breakout room for a brief 'icebreaker'. By the end of that five-minute session, I had found in Mel a fellow 'othered mother' – a friend and collaborator who instinctively understood what it was to* *mother at the margins and who, like me wanted to give voice to that experience on behalf of those who could not.*

## Meet Mel

*I couldn't contain my excitement. It's always a boon when you meet another mother – perhaps their kids are the same age as yours, or they live in the same area and are up for regular playdates or they just give off the same parenting-style vibes. Whatever the advantage, I had no expectations of ever meeting a colleague, who was Black, a mother and a fellow mother of an autistic child. For me, this was the equivalent of finding a unicorn. She was funny too. I'd hit the jackpot! I had no shame and asked Claire for her number in the same MS Teams meeting in which we had met.*

*It didn't seem too strange a thing to do as I was conducting a research project at the time, and I knew she would make a perfect candidate for it – so I asked if I could give her a call to discuss what the study entailed. I was comforted immediately as I heard her daughter's echolalic scripting in the background; my own son was also making high-pitched vocalisations as I attempted to introduce myself properly.*

*The conversation swiftly progressed to us talking about our everyday lives and our children. I distinctly remember pacing my bedroom, nodding furiously as Claire described her daughter, the process of gaining a diagnosis for her, and the challenges of finding and registering in an appropriate specialist school. The similarities were so uncanny, I was thrown by them. "This woman is living my life", I thought.*

*I soon found myself telling her about incidents I hadn't told my own family. I confessed my vulnerability in ways I hadn't ever expected to* *with a work colleague. It was both liberating and scary. Throughout the rest of 2023, Claire and I advanced from colleagues who had worked in the same university for six years without being aware of each other's existence to friends who sent multiple daily voice notes to each other on WhatsApp.*

*By the end of the year, we had completed several internal and external research projects together despite only having met face-to-face a total of twice. On 21st November, during Claire's annual Christmas family trip to London, our families met. I felt giddy waiting, standing by my front window looking out for their car. Once we had greeted each other like old friends reunited after years apart, our two autistic children, Sam and Mae, took each other into the garden and swung on swings next to each other, giving each other eye contact and smiles, while their little brothers gleefully tore open their early Christmas presents.*

*The highlight of the evening had to be watching Sam and Mae on the video monitor in my son's room, snuggled up next to each other on his bed like they had known each other from birth rather than a couple of hours. They didn't know that their mothers were sitting close to each other on the sofa downstairs, sobbing as they watched them.*

*It is our babies who have inspired us to translate this personal and professional partnership into a book which can offer support for women whose circumstances reflect our own.*

## Our goals

This book is for Black women and our children. This is not part of the acknowledgements page but is an acknowledgement of the significance of the writing you are about to read. This book is the work of two Black mothers joined together by our careers in academia, bound by our shared motherhood experience – a relationship solidified by the writing of this book.

We contend that a Black woman's experience of mothering is always political. The experiences of Black women, particularly in motherhood, have been and continue to be shaped by a history of slavery, colonialism, and racial oppression. Black women have never been able to own their bodies without the gaze of the policy-making and legal communities undermining their agency (Collins et al., 2021).

In a contemporary context, Black mothers who have autistic children have no choice but to navigate myriad obstacles surrounding disability such as accessing funding, securing support, and managing multiple forms of bureaucracy. While aiming to develop the advocacy strategies needed to fight for their children's rights, these mothers are forced to negotiate barriers generated by intersecting oppressions of race, gender, and (proximity to) disability. It is the aim of this book to highlight and problematise those struggles, and the injustices that perpetuate them.

## Social construction

The language we use throughout this volume requires definition and delineation precisely because the concepts under discussion are **social constructions**. By this we mean that many aspects described in this book are the lived experiences of Black women and are rooted in the multiple, intersecting identities that are imposed on us on the basis of our perceived membership in a socially defined group (Geronimus, 2023).

As noted by Geronimus (2023, p. 129):

> *social identity categories can correspond to society's constructs of race, class, ethnicity, gender, religion, ancestry, language, sexual orientation, immigrant documentation status, place of residence, and other currently or historically salient nodes of racialisation and social classification.*

So it is that the experiences of Black women are not inherent or natural but instead are shaped by the society and cultures in which those women participate. All too often, they are defined *in opposition* to a perceived 'norm', based on the needs, preferences, and experiences of social groups to which Black women do not belong. From the prevalence of certain illnesses to the effects of given medications, to the aims, objectives, and parameters of support services, the experiential baseline embedded into professional training in the fields of healthcare, education, and social care is almost always derived from stories which actively exclude Black women. This is notably the case with respect to the discourse of 'motherhood', in which the experiences of Black women are often either falsely conflated with those of White women or viewed through the prism of negative stereotypes regarding Black women and their family relationships.

Thus, as one of our research participants so powerfully observed:

> *No one tells [our stories]… No one wants to hear our stories… They're not ready to hear our stories. Our voices are so invisible in this space, and that bothers me so much. Because how can we change things if we don't know?*

> *And I want people to genuinely want to know – Survey Respondent, anonymous*

## Counternarrative

In conducting this research, we have been struck by the frequency with which we have been asked, in relation to our chosen participants for the study "Why not White mothers?". This inherent suspicion and hostility toward our conscious decision to amplify the voices of Black women is indicative of a broader issue which frequently derails discussions foregrounding race and racism; specifically, **'colour evasiveness'**. This term refers to behaviours and ideologies which underestimate, or even refuse to acknowledge the impact of race and racism, particularly within educational contexts. We employ it in lieu of the more commonly used term 'colour-blindness' since, as Annamma, Jackson, and Morrison (2016) demonstrate, the metaphor of 'colour-blindness' inadvertently reinforces ableist assumptions by equating visual impairment with ignorance or deficit, when blindness actually provides unique and valuable ways of understanding the world. Not only is such imprecise language at odds with our commitment to inclusion and intersectional awareness, it also obscures the extent to which 'colour evasiveness' is an active choice, rather than a passive state. Denial and obfuscation, particularly in response to attempts by those who are racially minoritised to share their lived experience of discrimination, function to silence marginalised voices and to maintain and reinforce existing power structures. In contrast, acknowledging the impact of racism and sitting in the discomfort that this acknowledgement gives rise to, facilitates empathy, growth and transformation.

As such, throughout this book, we have exposed the problematic nature of the question ‘Why not White women?’ (or, by implication, ‘Why only Black women?) by reclaiming readings of social identity through the use of **counternarrative**, affording the stories of Black women the prominence and respect that they so richly deserve. Our goal is to make a significant contribution to the political, social and structural emancipation of Black women who are raising autistic children, by, not just liberating ourselves through our storytelling but by liberating our communities and our communities’ children.

## Our shared meanings

Throughout this book, we use certain turns of phrase, or embed certain perspectives into our commentary. Since virtually every facet of our identities and experiences as Black mothers of autistic children is contested, we wish to briefly explain some of those choices before sharing our journeys and the journeys of the incredible women who joined us as research participants.

### Being autistic

In the first instance, in discussing our children, we elect to use ‘identity-first’ rather than ‘person-first’ language. That is to say that we describe our children as **‘being autistic’**, rather than as ‘having autism’. We respectfully acknowledge that there are people, both within and beyond the autistic community who may be uncomfortable with this expression. In fact, the book contains some direct quotes from research participants for whom ‘person-first’ language is a preference. However, we explain, at length, why in the case of our eldest children in particular, we feel that it is disingenuous and misleading to separate their autism presentations from their identities and lived experiences. Our children are, of course, more than their autism but their lives are, nonetheless, dictated in large part by their limited capacity for verbal and social communication, their extremely complex sensory challenges, and the struggles they face in navigating their immediate and wider environments. We believe that describing them as 'being autistic' illustrates this reality more accurately than any other alternative turn of phrase.

Further in our bid to use neuro-affirming language, we choose not to use terms such as ASD ('Autism Spectrum Disorder'), ASC ('Autism Spectrum Condition'), or Asperger's, which are either outmoded or which, in our view, place excessive emphasis on perceived deficits.

We use the term **neurodiversity** to describe the broader range of developmental issues which can often affect autistic people (for example, Attention Deficit Hyperactivity Disorder [ADHD] and dyslexia).

We state that we each have two children: one autistic and one **'awaiting assessment'.** We use this language to denote that, while our younger children have not yet been formally diagnosed, this is due in part to the protracted nature of the diagnostic process. The estimated waiting time for the completion of an autism assessment in the UK varies greatly but, on average, it is approximately 2–3 years and is now almost always undertaken in conjunction with education professionals. This ensures that it is rare for a diagnosis to be issued (via the NHS) before a child is already attending school on a full-time basis. At the time of writing, Claire's younger child, Joshua, is not yet old enough to be in full-time education, whereas Mel began the process of engaging staff in her son Daniel's school in 2024, just as he started Reception, in a bid to begin the assessment process. As addressed in the first substantive chapter, the specifics of Daniel's presentation, which Mel suspects is a profile of Pathological Demand Avoidance, further complicate this journey.

Furthermore, to date, our younger children present very differently from their siblings. Specifically, our eldest children have **'high support'** needs, whereas their younger brothers currently have relatively **'low support'** presentations.

The American Psychiatric Association's Diagnostic and Statistical Manual (DSM-5) offers a definition of autism relating to an individual's need for support, as identified during the diagnostic process (American Psychiatric Association, 2013). It is outlined as follows:

Level 1: Requires support
Level 2: Requires substantial support
Level 3: Requires very substantial support

However, to better articulate our children's needs and those of the participants' children, we expand and clarify these definitions. We characterise 'high support' needs as those which result in a complex autism presentation generating some or all of the following issues:

- Significantly reduced capacity for (social) communication, impacting the child's ability to express their needs, or to use spontaneous or purposive language that could be easily recognised by a third party.
- Significant impact on learning, resulting in the need for specialist educational provision.

- Significant behavioural challenges (e.g. frequent meltdowns which cause physical harm to the child and/or their caregivers and peers; lack of awareness of danger necessitating constant supervision, etc.)
- Significantly reduced capacity for self-care (e.g. difficulties with toileting, etc.) which renders the prospect of the child living independently in adulthood, extremely unlikely.

We characterise 'low support' needs as those which may require life-long support and intervention, but which can potentially be met, or at least mitigated, by changes to the individual's environment. This is not intended to underestimate the impact of a low support presentation, but rather to illustrate the breadth of diagnoses to which the word 'autism' can refer.

Our definition of 'low support' applies to presentations in which a child has some, or all, of the following:

- (Relatively) effective expressive, receptive, and mixed language abilities.
- A degree of awareness of, and ability to express and understand, their own identity as an autistic person.
- The capacity to access (and, with appropriate support, to function and flourish in) a mainstream educational environment.
- An awareness of danger and a capacity for self-care, underscoring the potential ability to live independently in adulthood.

While we acknowledge that such a gradation is crude at best, our decision to make use of these descriptive categories (in lieu of outdated or inappropriate expressions such as 'high' or 'low functioning') has been a source of extensive reflection in writing this book. As will be demonstrated in Chapters 3 and

4, several of the women who have shared their experiences with us are raising children who, according to the metrics we deploy above, would be considered to have 'low support' presentations but, as we will go on to demonstrate, this does not diminish the challenges faced by those children, or by their caregivers.

## Models of disability

The use of such gradations also relates to our discussions on the differences between, and respective strengths and limitations of, the medical and social models of disability. The **medical model** is often deficit-focused, defining autism in line with perceptions of what an autistic person *cannot* do and, by implication, positioning 'autistic traits' as a 'failed' or 'deviant' version of a non-disabled 'norm'. In contrast, the **social model** emphasises 'disability' as a social construction. In other words, as an identity category which is the product of mutually agreed upon meanings which are subject to interpretation and change, and which – crucially – should not be dismissed as a 'lesser' version of a non-disabled identity. Disabled people are acknowledged as individuals with a range of capacities, characteristics, aspirations, and experiences that are valid in their own right.

Furthermore, on this interpretation, it is often societal structures that are 'disabling'. To take a simple example, a wheelchair user accessing a public space need not be 'impaired' by their ambulatory disability, provided that the environment has been adapted to guarantee ease of access, by means of ramps, automatic doors, lowered pavements, and other similar adaptations.