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## **Beyond disordered brains and mother blame: Critical issues in autism and mothering**

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# **Beyond disordered brains and mother blame: Critical issues in autism and mothering**

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## **Abstract**

This chapter provides an overview of critical issues in autism and mothering in order to open up a complicated terrain of mother blame, deficit understandings of autism and biomedical regulation of mothers. We first briefly introduce the reader to historical currents in autism and mothering, tracing the emergence of autism as a brain-based difference and mothers' labour as the presumed "fix" for the disorder. Along the way, we meet the "refrigerator mother" – that "cold" mother of the 1950s whose destructive love was thought to cause autism – as well as the "mother therapist" and "mother warrior" of today who must shore up all her resources to wage war against autism in her child. Next, the chapter introduces neurodiversity, feminist disability studies and critical autism studies as academic and activist movements that challenge this fraught terrain and offer new possibilities to understand "autism" more positively and to be in relation with those who have attracted the label of autism. Finally, we recommend future research directions that centre lived experience, embrace difference as fundamental to life, and value interdependence as both an ethics and a politics. The chapter also provides recommendations for further reading.

The Centres for Disease Control and Prevention in the United States have called the sharply rising rates of autism diagnosis worldwide an "urgent public health concern" (27). Media images of so-called warrior mothers who cure their autistic child, or, alternately, mothers who abandon or murder their autistic child have become commonplace. Cultural fascination with the strange otherworldliness of autism has peaked in popular television shows such as *Parenthood* and Hollywood movies such as *Roman J Israel, Esq.* This chapter provides an overview of critical issues in autism and mothering in order to shed some light on this complicated terrain. We lay bare the long histories of mother blame and biomedical regulation of mothers as 'fixers' of autism, understood as a negative difference. We suggest instead that autism is an embodied difference that should be accepted, not cured, and consider how mothers have also been key

supporters and advocates of this alternative view. More supports that accept autism and that support access to life for both mothers and autistic individuals are urgently needed.

## Context and Background

### *By way of a Brief History: Introducing Key Themes and Theories*

The predominant understanding of autism or autism spectrum disorder in our contemporary moment is a biomedical one. Autism is understood as a neurodevelopmental disorder—a genetic condition that affects brain development and functioning. This is thought to result in three key areas of impairment: communication (e.g., impaired language), social interaction (e.g., difficulty making friends, averted eye gaze) and repetitive movements and behaviours (e.g., hand flapping) (“Autism Spectrum Disorder”). Level of impairment is measured along an axis of severity from level 1 “requiring support” to level 3 “requiring very substantial support” (“DSM-5 Criteria”). Within this view, autism is understood to be the result of both heritability and environmental triggers (Rutter). This prevailing biomedical view of autism is partnered with the biomedical imperative to view disorder and mental difference as unnatural and to remedy it (Michalko). Mothers—who carry the bulk of carework globally—are recruited as the primary agents in remedial autism treatments (Douglas, “As if you Have a Choice”). Guided by biomedical practitioners and self-fashioned expertise as “mother warriors,” many mothers access treatments for their child that are intensive and expensive and often have normalization or recovery as their goal (e.g., behavioural therapies). Given today’s biogenetic landscape, mothers are also recruited into particular practices of self-governance to ‘watch’ their own actions. Undergoing expensive testing for the “autism gene,” for example, or engaging in self-care routines that mitigate epigenetic (inherited) risks of having a child with autism (such as maternal nutrition) have become

common routines. Learning to watch for the signs of autism in your developing child, too, has become everyday practice (Douglas, *Autism and Mothering*; McGuire). And yet, things have not always been this way...

Autism emerged as a distinct medical category in the 1940s. Leo Kanner, director of child psychiatry at John Hopkins Hospital and a leader in this new field, called this new disorder “early infantile autism.” He distinguished it from childhood schizophrenia (Nadesan 11) in that the children he observed were impaired from the start in their ability to communicate, unable to engage in reciprocal social interaction and engaged in stereotyped behaviours such as rocking or “twiddling” (Kanner). Given the influence of biological psychiatry and mental hygiene in the 1940s, Kanner thought there must be some biological basis for the disorder. However, he also infamously noted the potential influence of parents, describing those in his study as lacking in warmth and affection. Most parents in the study were college graduates and worked outside of the home, and most families were middle-class and white. These children, said Kanner in an interview for *Time*, were “kept neatly in a refrigerator which didn't defrost” (“Medicine: Frosted Children” 78).

Such notions of refrigerator parents alongside the age-old adage of mother blame, were quickly swept up within gendered post-war efforts to bolster social stability, reinstate middle-class white mothers in the home and replace biological psychiatry with relational approaches such as psychoanalysis in an era reeling from the atrocities of the Nazi holocaust and scientific racism (Nadesan). In the work of University of Chicago psychologist Bruno Bettelheim and others, the “refrigerator mother” was born. This so-called cold mother of the 1950s and 1960s (in some cases, up to the 1980s and 1990s) was overtly blamed for her child’s autistic withdrawal. It was a mother’s innately disordered love and desires—wanting to work outside the home, for

example—where the trigger for autism could be found (Douglas, “Refrigerator Mothers”). The image of the autistic child trapped in a fortress emerged during this time when Bettelheim made the disturbing analogy between refrigerator mothers and guards in concentration camps, a fate so intolerable for the child the only recourse was to withdraw completely. Separation from her child through institutionalization and psychoanalytic treatment for mothers was often prescribed by experts as the solution. Ironically, the refrigerator mother emerged as a privileged identity—other “bad” mothers of this era (i.e., Black, working-class, unwed) and their children were excluded from this elite category and regulated instead through racist and classist hierarchies (Douglas, “Refrigerator Mothers”; Ladd-Taylor and Umansky 12).

Mothers and parents searching for alternatives in the 1960s and 1970s began to champion emerging biological understandings of autism (Rimland). A prominent theory in cognitive neuropsychology, for example, posits that autistic people lack Theory of Mind (ToM), a cognitive structure thought to be locatable within brains as the precondition for empathy, understood as that which makes us human (Baron-Cohen, Leslie and Frith). The alarming implication of this still-popular theory is that without remediation, autistic people do not fully share in humanity and indeed, are thought to be “victim-captives” of their neurology (Yergeau 3). Parents, particularly mothers, formed local and national autism advocacy organizations to educate the public about biological views of autism, raise money for scientific research, advocate for public funding and access to public schools and community living supports (Douglas, *Autism and Mothering*; McGuire). Through their efforts, overt forms of mother blame were debunked, new supports for families and their offspring secured and a nascent form of disability activism forged (O’Toole; Panitch 7; Ryan and Runswick-Cole).

New and intensive behavioural therapies—Applied Behaviour Analysis—emanating from the behaviourist experiments of Ole Ivar Lovaas at University of California Los Angeles on autistic and gender non-conforming children sought to normalize autistic children and their disordered biology/brains through the use of aversives to extinguish autistic behaviours (i.e., shocks from electrified floors) and rewards to shape normative ones (i.e., hugs, food) (Gibson and Douglas; Gruson-Wood). Against the backdrop of neoliberal capitalism and shifting family-state-market relations that pushed care back into the home and community as the primary responsibility of mothers (even as middle-class white mothers entered the workforce in record numbers), the ideology of intensive mothering emerged (Brodie; Hays). It would be “mother therapists” (Douglas, *Autism and Mothering*) under the guidance of new behaviourists who would be tasked with the “critical exigence” (Yergeau 4) to work intensively to remediate and normalize autism. Mothers were taught to ‘watch’ themselves anew—to love and care for their child through practicing intensive, scientifically-guided behavioural techniques. For those mothers who ‘failed’ to take up these new modes of self-governance—working-class, Black and other disadvantaged mothers—or who did not want to care intensively in this way, this was a new form of covert mother blame that concealed unequal gender, class and race relations and individualized a mother’s failure to remedy her child (Douglas, *Autism and Mothering*; Hays 165; Sousa).

Today, ours is a risk society that understands autism as non-viable and hopeless, a threat to a family’s, community’s and nation’s economic and emotional well-being. Today’s “mother warrior” must work ever more intensively to safeguard her family from the proliferating risk of autism, including from her own genes and potentially poor coping and mothering choices (Douglas, “As if you Have a Choice”; McGuire). Within social scientific studies of autism and mothering, for example, research on coping with the stress and stigma of autism as well as

resiliency is predominant (Gray). While vital, possibilities for more autism-accepting and socio-political understandings of autism and mothering are elided in this view. Covert mother blame again cloaks mothers' unequal access to resources and is intensified in our time; mothers become powerful curative forces as "warriors" staving off risk through their own choice and resilience (Douglas, "As if you Have a Choice").

### Central Issues and Debates

In response to the predominance of biomedical approaches to autism, autistic persons, mothers and critical and feminist scholars (not mutually exclusive) have raised a number of important issues and debates: 1) What is autism? Is it a deficit in need of remedy or a human difference? 2) How might mothers care differently, outside a biomedical framework? 3) How do power and privilege shape autism and mothering? 4) What is the role of mothers within disability and autistic self-advocacy movements? (A human rights based movement started in the 1980s by and for autistic people advocating for access and acceptance. See *Autistic Self Advocacy Network*) 5) What should the goal of autism research be? In this section, we introduce alternative frameworks, including feminist disability studies, neurodiversity and critical autism studies, that illuminate these key issues and debates.

Briefly, the interdisciplinary field of disability studies rethinks disability as a socio-political phenomenon and raises questions about how power shapes the meaning we make of human difference. In other words, the field of disability studies is concerned with "not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing, but, more crucially, the meaning we make of those variations" (Linton 2; also see Michalko and Titchkosky). The marginalized standpoints of disabled persons are centered, and

the biomedical view that disability is a *thing* locatable within individual bodies and brains, troubled. As Lennard Davis articulates, “Disability is not an object—a woman with a cane—but a social process that intimately involves everyone” (2). Rather than a personal tragedy, disability studies understands disability as a legitimate, albeit different, way of being in the world with something of value to teach us about our relationships and our life together (Davis). Lived experiences and the fleshy stubbornness of different bodies become sites of cultural production, resistance and new knowledge (Douglas et al.; Rice). Scholars have also signaled the need for disability studies to take up complex histories and intersections between disability, race, class, gender, sexuality and other oppressions and struggles for human freedom (O’Toole 297).

Scholars of mothering, care and disability working at the intersection of feminist and disability studies raise complex questions that attend to such intersections. They point to questions raised by autistic self-advocates, for example, about mothers’ (who may also be disabled) troubling implication in histories of ableist violence, oppression and exclusion toward autistic people such as ABA (Dawson), where care is imagined as a burden on families and mothers in particular. In this view, a mother’s care must recover the autistic body to its presumed normative state, that is, to an independent, productive and contributing body that relies on itself. At the same time, disability studies scholars point out that mothers have, in many instances, been at the forefront of struggles against autistic persons’ oppression (Ryan and Runswick-Cole). Mothers are key support persons and advocates for their autistic offspring, a sometimes-unsettling reality for autistic self-advocacy and disability rights movements that have worked hard to distance themselves from patronizing, dehumanizing and devalued feminized aspects of care (such as dependence) to achieve support and autonomy as their fundamental right (Hughes et al.; Kelly). Beginning from the supposition that care and support are “fundamental to life,”



feminist disability studies recognizes the mother-child relationship not only as political, but also ethical: “caring relationships characteristically carry a jolting, perhaps irresolvable paradox—that of transgressive possibility and coercive constraint, intimate inter-dependence and constraining power, love and violence” (Douglas, Rice and Kelly 4-5). Within the relational tension of loving our ‘different’ child, and against the recruitment of mothers to fix that same child through neoliberal capitalist and biomedical logics (that we suggest do violence to difference), new possibilities for supporting and being-with (versus fixing) our child in relation emerges (Douglas, *Autism and Mothering*; Klar).

Alongside such relational and ethical questions, feminist disability studies scholars trouble the notion of disability as an added care burden for mothers—a common theoretical position in feminist political economy of care. They raise complex questions about interconnections between feminist and disability emancipation within intensive mothering and neoliberal capitalist regimes, for example, pointing out that disability and autistic self-advocates, alongside mothers in positions of privilege, are implicated in transnational capitalist flows of labour given that racialized, disadvantaged and Third World women fill the gap of underpaid carework in Global North neoliberal capitalist economies (Erevelles, Meekosha; Williams). Bridging such ethical, political and economic tensions to achieve deeper understandings of intersecting oppressions and to work toward disability and feminist liberation is vital (Kelly).

A first move toward bridging these tensions is to attend to emerging research that opens different possibilities and questions around autism and mothering. One important approach emanating from autistic communities is neurodiversity, which is the understanding that human neurology is neither static nor fixed (Walker). In other words, embodied difference is part of life, and should be accepted, not cured. This offers an alternative to biomedical views such as Theory

of Mind or behaviour therapies that assume autistic behaviour is the result of a disordered neurology, and therefore that it is meaningless and involuntary (Yergeau). Neurodiversity has been a formative concept within autism self-advocacy organizations organized by and for autistic persons, including the Autistic Self Advocacy Network in the United States (*Autistic Self Advocacy Network*), as well as for many autistic bloggers<sup>1</sup> who argue that autism is a viable way of being, and that parent advocacy should not advance a world without autism as its goal (McGuire 105-7). Neurodiversity perspectives shift the understanding of the human so that neuro-normativity (behaviour that conforms to normative expectations) is no longer the measuring stick of what makes a life worth living, and so that neurodivergent identities (any identity counter to neuro-normativity; see Neurodivergent K) are a viable option for people. A second important alternative to biomedical frameworks and curative therapies comes out of the emerging field of critical autism studies. Runswick-Cole et al., for example, call for a troubling of “any of the current accepted understandings that view autism as a biologically based biomedical disorder or brain difference” (7-9). They include neurodiversity in this challenge. These researchers aim to debunk the science of autism, understand how the diagnosis of autism impacts the lives of those who attract it, critique autism industry and promote alternative ways to provide service and supports to individuals and families beyond that of diagnosis, labelling and remediation (8; also see Davidson and Orsini). Neurodiversity and critical autism studies, in different ways, shift the meaning of autism and the purpose of research, opening up new possibilities for being together beyond biomedical frameworks and normalizing regimes.

<sup>1</sup> See, for example, Amanda Baggs <https://ballastexistenz.wordpress.com/> and Michelle Dawson [http://www.sentex.net/~nexus23/naa\\_02.html](http://www.sentex.net/~nexus23/naa_02.html)

## Controversies and Challenges

We delve more deeply now into two key areas of controversy related to autism and mothering that have particular salience in our contemporary moment. The first controversy is the question of autism treatment, which touches on deeper issues raised above around the meaning of autism, power and privilege (in terms of access to supports as well as whose knowledge about autism counts), and the goal of autism research. We focus our discussion on one recent controversy within parent and autism communities around Applied Behavioral Analysis (also called Intensive Early Behavioural Intervention), however, our comments also apply to a number of other controversial treatments, which we point to along the way. Applied Behavioural Analysis (ABA) is currently the sole funded treatment in most countries (if any), understood as the only evidence-based intervention proven scientifically to be effective in extinguishing autistic behaviours (i.e., flapping or rocking) and increasing normative ones (i.e., making eye contact, using spoken language) (Douglas and Gibson; Ontario Scientific Expert Taskforce). Its goal is independence and normalization. It is prescribed in intensive dosages (up to 30+ hours per week), and thought to be most effective if started early, by age 2. As its founder Ivar Lovaas puts it, the goal is for treated children to become “indistinguishable from their normal friends” (8). ABA is often offered to mothers at the point of diagnosis as a child’s best or only hope for a good life—understood as a life free from autism. Mothers and families have been at the forefront of advocacy efforts for public funding for ABA (Klar, Douglas and McGuire). It is, of course, vital for families and autistic individuals to have access to a variety of supports and therapies to support their well-being and access to life, just as it is for us all. However, when ABA—alongside its goal of independence and normalization—is offered as the only possible hope, this powerfully communicates hopelessness for families who cannot (or do not want to) access ABA

due to long waitlists, limited financial resources or alternative goals for their child (Klar, Douglas and McGuire; also see Gibson and Douglas). It also elides ethical and relational questions about difference (see above), and supports the view that autism is a problem that must be fixed. When ABA fails to recover or produce a ‘normal’ child, which is most often the case, the dire need for support, and alternative approaches to autism is clear.

Within our contemporary moment, the biomedical imperative to remedy difference (Michalko) arising from the prestige of Western science as the utmost authority on health and disability drives normalizing treatments such as ABA. Many families go into substantial debt to access ABA treatment. Other mothers and parents pursue alternative, sometimes risky and usually expensive and intensive treatments to recover or normalize their child including chelation therapy, gluten-free/casein-free diets, hypobaric oxygen treatment, vitamin treatment, anti-vaccination stances, the list goes on (Nadesan). In this way, parents become part of a booming autism industry that commodifies autism (Mallet and Runswick-Cole) and profits from the “critical exigence” (Yergeau 4) to eliminate difference. For over thirty years, autistic self-advocates, activists and academics (not mutually exclusive) have articulated harm as a result of undergoing intensive, normalizing treatments such as ABA that use neuro-normativity as the measuring stick of what is considered human and a worthwhile life (Dawson; Sequenzia; Yergeau). They articulate the need to move beyond dominant biomedical “theories that privilege restrictive notions of what it means to interact and interrelate” (Yergeau 12). The lengthy list of parents who have murdered their autistic child citing hopelessness for their child’s future is an urgent signal that access to supports, different therapeutic goals and positive representations of autistic individuals are urgently needed (McGuire).

This raises a second area of controversy surrounding autism and mothering, namely, mother

advocacy and activism, which again touches on deeper issues raised above about the meaning of autism, power and privilege and the goal of autism research. The most powerful and financially affluent parent advocacy organizations today, such as *Autism Speaks* (McGuire 57), advocate and educate, now globally, from within a dominant Western biomedical framework. This framework, to recap, understands autism as a neurodevelopmental problem in need of a biomedical solution. In this view, behavioral and genetic therapies are interventions that aim to re-shape impairments caused by disordered brain development, and a mother's role becomes that of therapist, fixer and even "warrior". While seemingly a benevolent aim, these efforts export Western culture's understanding of the normative human as non-autistic, white and Western (Douglas "As if You Have a Choice"; Mallet and Runswick-Cole; McGuire; Titchkosky and Aubrecht). Other ways of understanding autism and care beyond that of deficit and remedy are marginalized; scientific research agendas target the cause and cure of autism to the exclusion of research to support a good life for autistic individuals. MSSNG, for example, is a collaboration that brings together corporate America (google) with *Autism Speaks* and over fifty academic and research institutions in thirteen countries to "create one of the world's largest databases on autism," the goal of which is to pinpoint different types of autism and biogenetic treatments ("MSSNG"). One important effect of such efforts has been the generation of vast autism research industries invested in biomedical approaches (McGuire) primarily of financial benefit to non-autistic researchers rather than mothers and autistic individuals (Mallet and Runswick-Cole).

The approach of *Autism Speaks* has been criticized by autistic self-advocates, activists and academics who support a different understanding of autism, autism support and research. These criticisms raise important questions about whose experience and knowledge of autism matters. The Autistic Self Advocacy Network (ASAN), for example, an influential self-advocacy

organization in the United States, points out that most money raised by *Autism Speaks* does not support mothers, families and autistic individuals, but rather, scientists' careers and executive salaries. Further, autistic people's voices are marginalized within the leadership of *Autism Speaks*, and awareness and fundraising campaigns turn on promoting negative, stigmatizing and fearful images of autism ("Before you Donate to Autism Speaks"). ASAN's slogan, "Nothing about us without us!" forwards a vital message that speaks back to dominant approaches and research agendas, suggesting that a different direction for future research is needed.

### New Directions for Future Research

Research that brings autistic voices to the centre and considers the ethical and political dimensions of autism and mothering is crucial. We make the following recommendations. First, future research must aim to more deeply understand the lived experiences of mothers and autistic individuals within current neoliberal and biomedical contexts. This understanding must include both the ethical and political dimensions of care so that the supports and services required for a good life for autistic individuals and those who support them—still predominately mothers—can be identified and implemented. Secondly, research agendas must move away from unquestioned views of autism as disordered neurology in need of a mother's curative labour, and toward understanding difference as fundamental to life. This shift in perspective opens new possibilities to support access to life for *all* people, including autistic individuals and mothers. Finally, a complex interrogation of interdependence as a key goal and value of relationships and relational support should be at the centre of future research agendas. This aligns with recent calls in feminist disability studies research on disability and care to re-centre interdependence:

...in ways that bring the perspective of disabled people and the force of political economy to the fore, taking into account gendered, racialized, and classed aspects of care work while sustaining earlier disability critiques of the realities of violence against disabled persons within care relationships. (Douglas, Rice and Kelly 5)

Key questions to guide future research include: 1) How do mothers support their adult autistic children in a social system that demands independence (Klar; Rooy)? 2) How might we reimagine autistic individuals as agential and relational within the mother/child dyad (Klar; Yergeau)? 3) How might we rethink mothering, care and support vis-à-vis interdependence (Douglas, Rice and Kelly)?

#### Further Reading

##### *Books, Articles and Videos*

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Websites



Amy Sequenzia: <https://ollibean.com/author/amy-sequenzia/>

Aspies for Freedom: <http://www.aspiesforfreedom.com/>

Enacting Autism Inclusion: <http://enactingautisminclusion.ca/>

Neurodiversity.com: [www.Neurodiversity.com](http://www.Neurodiversity.com)

Positively Autistic: <https://positivelyautistic.weebly.com/>

The Autism Acceptance Project: <http://www.taaproject.com/>

The Autism Crisis: <http://autismcrisis.blogspot.ca/>

The Autistic Self Advocacy Network: <http://autisticadvocacy.org/>

Tiny Grace Notes: <https://tinygracenotes.blogspot.ca/>

## Conclusion

The history of autism and mothering is one of regulation, whether the regulation of a mother's love and care within biomedical and neoliberal patriarchal capitalist regimes, or the meaning of being human as exclusive of autistic and other difference within powerful research agendas. This chapter has suggested that embodied difference such as autism, as well as care and support—still predominately performed by women and mothers—are “fundamental to life” (Douglas, Rice and Kelly). Given this, the need for alternatives to biomedical understandings of difference and care is dire if we are to move beyond a landscape of hopelessness and harm for mothers and autistic individuals alike. Within the current research context, social support for autistic people and mothers remains contingent on subscribing to biomedical understandings of autism. Mothers who understand autism differently, or who seek educational and other opportunities for their autistic child beyond ABA, are left on their own without financial support or access to other resources. Indeed, mothers remain vexed figures, either covertly blamed within biomedical

frameworks for failing to normalize their autistic child, or criticized within autism communities for enforcing curative therapies. It is by pursuing a deeper understanding of the ethical and political complexities of mothering and autism that new possibilities for being together beyond biomedical frameworks and normalizing regimes might emerge. It is critical that future research attend to such possibilities.

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