AUTISM AND MOTHERING: PURSUING THE MEANING OF CARE

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
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ABSTRACT

This dissertation investigates the cultural production and lived meanings of the identity ‘autism mother’ from its emergence in 1943 to the present day. Drawing on critical and interpretive methods and theories within disability studies, informed by philosophical sociology, poststructuralist and phenomenological philosophies, cultural and maternal studies and feminist philosophies of science, my project explores the shifting emergences, historical traces and cultural meanings of this new mother identity. The analysis addresses psychoanalytic understandings of the ‘cold’ mother thought to cause autism in her child during the 1940s-1960s; the ‘mother therapist’ of the 1970s-1990s who must utilize scientifically guided techniques to achieve a ‘normal’ child; and today’s ‘mother warrior’ who must intensively fight against the so-called rising threat of autism. I take up the identity ‘autism mother’ as a way to explore, and offer an alternative to, Western patriarchal, racist, scientific and capitalist modes of power, knowledge production and subjectivities that are captured by cultural understandings of autism as an undesirable neurodevelopmental difference, non-autistic life as the only life worth living, and mothers as culpable for the remediation of their autistic child. The historical and social significance of everyday text and talk during 1943-2015 by and about autism mothers in the mass media and popular science, as well as focus groups held with autism
mothers in Toronto in the fall of 2013, are analyzed. This work reveals the identity ‘autism mother’ as a key cultural contradiction through which scientific, bourgeois, white understandings of autism, and a contradictory femininity have come to regulate the good/bad mother in new ways, alongside the ever-present complexity and meaning of caring. Emerging from my analysis of everyday texts and focus group dialogues with mothers, I propose pedagogic care as an important alternative that embodies a creative critique of and resistance to exclusionary, and sometimes violent, biomedical and professional regimes. Critically pursuing questions of the meaning of ‘autism’ and ‘autism mother’ as culturally produced, lived identities integrally linked to knowledge production and power opens space for new meanings.
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For Brennan and Jesse
CHAPTER ONE

Introductions and Disruptions

…I remember that was a very scary moment for me when I realized I had sat in the
car for about fifteen minutes and actually contemplated putting Jodi [autistic
daughter] in the car and driving off the George Washington Bridge…

- Solomon, Thierry, & Watkins (2006), *Autism Everyday*

What do you do with that information [prenatal testing]?... “Ryan” is a great kid.
Would I have aborted? It would erase the population.

- Personal communication (November, 2013)

…All those beautiful characteristics that I thought were Evan – the hand flapping,
the toe walking, the playing with door hinges, and lining up toys – weren’t Evan
characteristics at all. Who was my son if he wasn’t all these things? The neurologist
saw the look on my face and said to me, “Hey, this is the same little boy you came in
this room with. He’s not any different. He’s the same boy.” I looked at the doctor
and replied, “No, he’s not. My son is trapped inside this label called autism and I’m
gonna get him out.”

- Jenny McCarthy (2008), *Mother Warriors: A
  Nation of Parents Healing Autism Against All
  Odds*, p. 7

How do we make sense of a world in which such utterances have become *ordinary*,
met by meaningful glances of recognition, sympathy or perhaps shudders of relief by those
who do not suffer this so-called tragic fate, that of being an ‘autism mother’? By autism
mother I mean the historical and cultural production of a new form of subjectivity including
how it has been taken up, resisted, made meaningful and lived in the everyday by mothers.\footnote{I first encountered the term “autism mother” in an online UK based magazine by and for mothers and families of autistic children called \textit{Autism File}. Here, autism mothers includes, often, the commitment to a disease and recovery approach to autism. I use the term differently. I invert it and use it critically, for its many nuances related to my project and the historical and social processes that have constituted the identity autism mother. While fathers may also be primary caregivers, or ‘mothers’ to their autistic child, I study autism mother subjectivity because women remain, overwhelmingly, the primary caregivers of children globally, and regimes of care are gendered historically. Jack (2014) also critically employs the term ‘autism mothers’ in her recent book \textit{Gender and Autism}. I add to this usage how mothers take up, negotiate and resist this identity category.}

How have murderous confessions, the anguish of genetic screening and intensive maternal heroism not only become \textit{thinkable} but “say-able,” part of the “sense” of our everyday world (Titchkosky, 2011, p. 73-6)? How do such utterances reveal not only deep cultural sensibilities about what it means to be human, what it means to mother and care, and which lives are considered worth living in our historical moment, but also accomplish these very sensibilities as \textit{real}, untouched by questions of culture, power and the human activity of meaning-making (Titchkosky, 2011, pp. 73-6; Butler, 2004, p. 20)?

In this dissertation, I explore the meaning and significance of such ordinary talk and texts about ‘mothering’ and ‘autism’\footnote{I employ scare quotes to indicate that I understand ‘autism’, and ‘autism mother’ as culturally produced subjectivities rather than ways of being grounded in the biology of different brains or bodies, for example, or as things in and of themselves. I use scare quotes the first time the terms ‘autism’ and ‘autism mother’ are introduced in each chapter, and intermittently, to remind the reader of my orientation.} as they are socially accomplished in the everyday and deeply entwined with what, and who, is valued in late modern life.\footnote{I use the term “late modernity” not to temporalize or oppose my work to postmodernism, nor to align myself with theorists of modernity (i.e., Giddens), but to suggest that modern forms of power, modes of subjectivity, philosophies (scientific progress, reason, the knowing subject) and social processes (industrialization, rationalization, capitalism) continue to hold sway in our lives side by side with processes of their undoing (difference, skepticism, uncertainty). I am influenced in my thought by Foucault’s work on power (Rabinow & Rose, 2003), Sylvia Wynter’s work on the continued effects of the violent unleashing of colonial Euro-modernity post-1492 (1992, 2003, 2005), as well as Zygmunt Bauman’s work on identity and “liquid modernity” (2000, 2004)} Everyday talk and text means texts from mass media and popular culture in which autism mothers make an appearance, as well as dialogue about everyday text and talk from focus groups held with autism mothers in Toronto in the fall of 2013 (on everyday text, see Titchkosky, 2007, p. 1)
26). The hope is that this project might both reveal new questions about enduring Western modes of power and subjectivity that capture us, and insert new possibilities of critique, resistance, and agency such that everyday life might be transformed to include autistic lives differently – indeed all embodied difference - as lives worth living (Arendt, 1998/1958, pp. 176-7; Titchkosky 2002, p. 236; also see Butler, 2002; Rapp & Ginsberg, 2011).

This chapter introduces the central tensions and philosophical commitments of the thesis. I begin from my experience as an ‘autism mother’ as a way to both familiarize the reader with dominant scientific narratives about autism and mothering already circulating in everyday talk and text, and propose a different way forward. This alternative way forward cares about autism and mothering differently than does science by orienting to an ethic of disruption, or stance of perpetual questioning about the accomplishment of everyday life in talk and text. I work with a key tension throughout this dissertation - constraint/pedagogic possibility – as one that captures the contradictions within the tension between loving a ‘different’ child, and living in a world calling for sameness and identity with non-autistic ways of being. I also spend time in this chapter thinking about the

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4 Though its causes and treatments continue to be contested, autism is predominately understood in Western biomedical terms as a neurodevelopmental disorder (Nadesan, 2005). Current research agendas include a search for the cause of autism (i.e., in genes, gut bacteria), an intensive focus on early detection and prevention (including prenatal), in addition to normalizing or preventative treatments (i.e., behavioural, genetic testing for mothers). Mothers and families have shaped and challenged such dominant research agendas, in part as the moving force behind powerful Western advocacy organizations such as Autism Speaks (critiqued by McGuire, 2011a; forthcoming). Such organizations and understandings of autism are now shaping global health agendas at the World Health Organization, where autism was recently named as part of the growing ‘global burden’ of mental disorders and so-called threat to the well-being and happiness of individuals, families, communities, nations and global populations (World Health Organization, 2013). Alternative environmental or recovery approaches to autism (i.e., biomedical treatments such as gluten-free casein-free diets, vaccination theories, bacterial theories) forwarded by groups such as Generation Rescue in the US and Autism Trust in the UK have also gained the attention of celebrities and the interest of some notable scientists (Symptom, Bender & Gruner, 2011). The neurodiversity movement of autistic self-advocates forward autism as a distinct form of personhood and different way of being-in-the-world, a being in neurodiversity (Broderick & Ne’eman, 2008; Ne’eman, 2010; Sinclair, 1993). I write in solidarity with the aims of the neurodiversity movement – valuing different ways of being and achieving equal rights – while also holding open the meaning of autism as a culturally produced (versus biologically grounded) subjectivity about which we can engage in critical inquiry about the meaning of our life together in late modern times.
meaning and philosophical ground of scientific ways of knowing. While science is not my central object, it saturates everyday talk and text as the preeminent source of knowledge about autism, and autism mothers. Understanding what science means, and what it makes of autism, is important work that opens epistemological and ontological space for the alternative approach I introduce in chapter two. Finally, I outline my main argument: autism mother subjectivity emerged as a key cultural contradiction where a contradictory femininity and Western scientific view of autism have come to regulate the good/bad mother, alongside what it means to be human and to care, in new ways. Emerging from the autism mothers I spoke with in my focus groups and my analyses of everyday text, I propose pedagogic care as an alternative that opens space to critically and creatively pursue questions about the meaning of science, autistic ‘difference’ and mothers’ experience as central to knowledge making and power, and to engage new possibilities of the meaning of care beyond the dominant biomedical sense of care as remedy. I conclude with chapter outlines.

**Beginning from Experience: A Narration of Disruption**

I begin from my own experience as an autism mother. Narrating such experience is nothing new. Since the 1960s at least, autism mothers have been writing their stories of life together with their autistic child (see, for example, Axline, 1964; Junker, 1964; Park, 1967). I attempt to narrate differently, turning to my experience not as an individual story of grief, heroism or defeat, nor as a story about my son, but as an entry point into questions about power and restrictive forms of identity central to mothers’ and autistic person’s lives in our contemporary moment. Narrating in this way is an interpretive, critical and creative task –
how might life with an autistic child not only be a site of struggle and even violence for mothers, as suggested by my opening quotes, but also offer new possibilities to reimagine our ordinary life together outside of such constraints?^5

In the everyday, I have lived the disquieting but very ordinary demand I remedy my son’s autism as a “line of fault,” or space, between the personal and political (Smith, 1987, pp. 49-60). In this contradiction, I am situated between living with and loving my son, and contending with a say-able sensible world that cannot yet imagine forms of social life and identity that integrally include life together with autistic individuals. For my family, this demand has meant public praise when we got the work of advocacy or behavioural therapies right (i.e., my son appeared ‘normal’), and public blame and exclusion when my son’s behaviour appeared to others as alarmingly autistic, or sometimes, not autistic enough. Vaccine activist and autism ‘mother warrior’ Jenny McCarthy articulates her relation to these demands and tensions in quite a different fashion when she says, “My son is trapped inside this label called autism and I’m gonna get him out” (McCarthy, 2008, p. 7). In her description of how an autism “label” reconstituted Evan’s uniqueness as something pathological he is “trapped” inside of, a mother’s love is also reframed as that which might remedy - and rescue - her normal son from this nonconforming autistic

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^5 I include this glimpse of my experience as a mother with the permission of my two sons, Brennan and Jesse. My narrative is not intended to represent who they are, or who my autism-identified son is, his personhood, nor the truth of our family’s journey together. Rather, my experience as a mother is an important starting place from which to theorize subjectivity and its link to Western modes of power, exclusion, and the possibility of something new. Given oppressive histories of care and autism research, I am keenly aware of the ethical dangers involved in my choice. My narrative has the potential not only to participate in histories of disability as a spectacle (for a feminist disability studies critique of spectacle see Thomson, 1997), but also to eclipse my son’s uniqueness through the power of my role as both academic and mother. While it remains an impossible task, I attempt to narrate ethically – to disrupt “my place in the sun” or the innocence of my maternal subjectivity (Levinas, 1989, p. 82; also see Bartley, 2008; Boler 1999; Derrida in Bartley, 2008, p. 61; Simon 2000). In this, I am implicated in power as well as violence. I also maintain that a careful engagement by mothers across and between disability and non-disability is imperative in the project of transforming oppression, a key challenge being taken up by disability studies and feminist scholars alike, a challenge of which this thesis is a part. See, for example, Chapman & Kelly (2015), Kelly (2013), Lewiecki-Wilson & Cellio (2011), McGuire (forthcoming), Titchkosky (2007).
body/mind. McCarthy can be understood as over-conforming to a world that “has almost no interest in, and sometimes would rather kill, alternative ways of being-in-the-world” (Titchkosky, 2002, p. 236). Nonetheless even her over-conformity demonstrates what Bauman describes as the “gap between the ‘is’ and the ‘ought’” (Bauman, 2004b, p. 34; also see Bauman, 2004a, p. 20). I use the notion of a ‘space’ between lived experiences and everyday talk and text to open room for critical and creative inquiry about such exclusions within our life together. Feminist disability studies scholar Rosemarie Garland Thomson (1997) also opens this space of critical inquiry by paying attention to the gap between “disabled people and their representation” (1997, pp. 10-12). Tanya Titchkosky, whose work in disability studies draws from interpretive, phenomenological critical race/Blackness, feminist and cultural studies approaches, opens this critical and creative space to rethink ordinary exclusions within our life together by attending to between-ness in a variety of ways (2007, p. 21), whether as marginality (2002, p. 236), liminality (2007, p. 21) or the gap between “received stories of justified exclusion and the possession of disquiet” (2011, p. 76). In my case, situating my work in this space is my own attempt to reconcile the curative demand of dominant culture to remedy autism, with my love for my sons and our everyday life together (on reconciliation, see Titchkosky, 2002, p. 236; Arendt, 1994, pp. 307-27).

The search to reconcile my contradictory experiences and reach a deeper understanding of them first took place during late night Internet excursions when the labour of mothering had abated. Here, I quickly encountered a clamor of troubling representations of autism and research looking for causes and cures on websites of various autism organizations alongside disconcerting popular media portrayals. Almost always a variation
of the same tale regardless of its location (i.e., mass media, service agencies, advocacy organizations), the story is told of the tragic loss of a normally developing child, disordered brain development, maternal grief, family stress, the need for scientific research and more services, and most important of all, maternal heroism (or defeat) in treating and even recovering her child through her love as framed by biomedical, scientific or professional care (see, for example, Blum, 2007; Clarke, 2012; Connors et al., 2006; Glessner et al., 2009; Jones & Harwood, 2009; Koren-Karie et al., 2009; Nadesan, 2005; Sousa, 2011). A 2008 Redbook magazine article entitled, “What Autism Does to a Mother,” for example, begins this way, “Nicole Kalkowski knows that beyond the stress, fear, and family turmoil that come with learning that your child has this devastating disorder, there is also a devastating aloneness…we follow this mother of three as she struggles to save her son…” (Rones, 2008, n.p.). Here, mother Nicole Kalkowski, her son and family are the devastated, isolated victims of autistic disorder, and being a mother means struggling to “save” your child (yourself and family) from such a fate. The article details how such a rescue might take place. This mom found hope from online advocacy organizations and recovered her son through biomedical interventions (gluten-free, casein-free diet, for example). It is a rare occasion that the seductive “sense” of all this “say-ability” is questioned.

I have found myself both compelled by and angry at such popular as well as scientific narratives of autism and mothering. At times I have been implicated, and these cultural tales became vehicles for expressing love and concern for my son, and for organizing the work of the maternal subjectivity thrust upon my everyday life, that of autism mother. My family and I, too, lived the search for recovery: gluten-free, casein-free diets, supplements, behavioural therapies, alternative therapies (magnetism!), medication,
auditory processing and sensory integration therapy – the list goes on. More often, such narratives pathologized and eclipsed the tenderness, beauty and struggle of our lived experiences (Rich, 1986). Whether the surprise of “the stim” (i.e., flapping hands), interludes of rapture (long periods watching water drip or objects spinning, for example) or the “jarring transition,” our journey exceeded and disrupted any easy way of being together or meaning of care. It is this tension of the say-able/unsay-able, or space between the personal and political that raises the matter of the thesis: paying attention to the ‘quieter questions’ within everyday moments of the disruption and excess of ‘autism’ that gesture both to the unquestioned grounds that constitute subjectivity and the meaning of care, alongside their very undoing. These moments are fleeting, and often difficult, yet they are suggestive of questions not only about the larger contours of Western cultural formations, modes of power and subjectivities that hold us in their grip, but also about disruption and excess as potentially pedagogical, political and ethical moments that are socially produced.

Attending to such questions can offer an alternative human journey, one that holds the promise and hope of being together differently (on transformative hope, see Zournazi, 2003). This alternative journey might be one in which difference identified as autistic (and indeed, all embodied difference) is not rendered a problem to be individualized, normalized or cured, but one of the many possibilities of a richly diverse landscape of our multiple ways of being together. The matter can be put this way: What does it and might it yet mean to pay attention to and care about ‘autism’ – embodied difference marked as abnormal, pathological and in need of biomedical remedy – as a fundamental, even desirable, part of human life together?

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6 I would like to thank autistic scholar Anthony Easton (personal correspondence, February 25, 2015) for his permission to use his descriptions of ‘autistic’ language, which includes “the stim” and “the jarring transition.”
An Ethic of Disruption

I orient to my project with an *ethic of disruption* to work toward opening new possibilities. This means bracketing the question of the ‘real’ meaning of autism and orienting instead to autism as a kind of commotion – a disruption - within the ordinary and expected movements of everyday life (on the “characteristic movements of life” see Foucault, 1976/1980a, p. 25 and Titchkosky, 2007, pp. 64-5). Rather than treat autism as a deviation from “species-typical” functioning, one that requires a normalizing biomedical and social remedy (Silvers, 1998), I attend to the disruption of autism within the everyday as culturally produced and potentially pedagogic moments about the meaning and shape of our life together within a rationalized Western consumer-capitalist world (on disability as teacher, see Davis, 1995; Goodley, 2011; Michalko, 2002; Titchkosky, 2003, p. 233; Titchkosky & Michalko, 2009, p. 6). Today, the predominant understanding of the disruption of autism is a Western scientific one – autism is a tragic, and dangerous, neurodevelopmental disorder on the rise globally (Grinker, 2007; Kim, 2012; McGuire, 2011a; Nadesan, 2005; Osteen, 2008; Wheeler, 2011; also see footnote 3, p. 3). A normal life, presumed to be a social good, excludes the disorder of autism (Silvers, 1998). Within this predominant view, a mother’s care is implicated, steeped in what disability studies’ scholar Rod Michalko calls the “biomedical ethics of remedy (‘curative help’)” (2002, p. 99). Autism needs fixing, and mothers, given their nurturing feminine ‘nature,’ proximity as primary caregivers and close ties to autistic life, are integrally involved.

Re-orientating to autism as a site to learn anew about ways of knowing and being human using an ethic of disruption suggests adopting the philosophical stance of a *space of perpetual questions* that might reveal something new about how different lives have come
to matter, how we have come to practice care and relate to who we have become in our contemporary moment (Rabinow & Rose, 2003, pp. xx-xxi; Butler, 2004). I am influenced by Foucault’s ethic of discomfort as one that learns from Maurice Merleau-Ponty’s formulation of philosophy’s task: “…never to consent to being completely comfortable with one’s own presuppositions” (Foucault, 2000, p. 448). Like Foucault, I do not seek comfortable answers or new facts, but questions that might keep in play a constantly shifting ground, one that is “always unexplored” (Foucault, 2000, p. 448; also see Rabinow & Rose, 2003, pp. xx-xxii). This is a form of critique that, in Foucault’s words, “…is not a matter of saying that things are not right as they are. It is a matter of pointing out on what kinds of assumptions, what kinds of familiar, unchallenged, unconsidered modes of thought the practices that we accept rest” (1988b, p. 154). An ethic of disruption perhaps departs from Foucault’s discomfort in that it is not only a critical, but also a creative philosophical stance. That is, an ethic of disruption engages both the critical work of the skeptic questioning the ground of knowledge, power and subjectivity, and engages these same questions of historical constraint as the creative opportunity for imagining and inserting new possibilities for a different life together. The object of such an ethic is not to moralize, nor to prescribe “better” ways to care about or understand autism (Rabinow & Rose, 2003, p. xxviii). Rather, I aim to question the grounds of a world that includes exclusion and violence toward autistic persons, and mothers’ implication, as normative (on the inclusion of disability as an “exclude-able type” see Titchkosky, 2007, pp. 149-152). This means paying attention to the constant, and disruptive, questions that emerge in the surprise of a mother’s life together with her autistic child as possible other ways of being in the world together that gesture to something beyond dominant regimes of governance.
Orienting to this project using an ethic of disruption means that I attempt to narrate the story of autism and mothering differently, beyond the prevailing scientific view of autism as a tragic disorder. Given the explosion of autism mother memoirs and ‘mommy’ blogs that proceed from this dominant view and leave the ethics of narrating life together with individuals identified as autistic unaddressed, attempting to narrate differently is an urgent task. In this attempt, I risk being implicated in histories of violence by either re-making autism into a ‘thing’, eclipsing my son’s uniqueness or othering difference identified as ‘autistic’. Yet without such ethical risks, the promise of new approaches – and this thesis - to disrupt and offer alternatives to dominant scientific and popular narratives could not proceed (also see footnote 5). Pursuing the central tension of this thesis – constraint/pedagogic possibility – is at the heart of my ethic of disruption, and is central to my aim to open possibilities and tell new stories within a world that desires sameness.⁷

**Disrupting the Preeminence of Science**

In this section, I work to disrupt science as the preeminent source of knowledge about autism and mothering in our time. Scientific views of the human and of knowing constrain what’s possible in terms of who we can imagine ourselves to be, and how we imagine and do our life together. While this dissertation does not take the question of science as its object per se, and while a number of other questions will be important along the way (i.e., neoliberalism, intensive mothering), interrogating the myriad ways that the science of autism appears in everyday talk and text about autism and mothering is central to the work of my thesis. Understanding and questioning the ground of scientific knowledge

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⁷ It is interesting to note that a ‘dash’ of autism is also desirable in our contemporary moment. However, any dash of autism must only be a self-styling and cannot intrude upon the narrow confines of performing the neoliberal consumer subject as autonomous, productive, self-entrepreneurial and rational.
production is thus crucial to this interrogation, as well as to my undertaking to open new approaches to autism and mothering that embrace, rather than expel, questions of difference, disruption and love.8

My work here – through an ethic of disruption and general project of disrupting the prestige of autism science and its valuing of only very particular forms of life - is perhaps a new entry point into the feminist philosophy and history of science, one that stays grounded in interpretive and critical disability studies. Feminist scholars of the philosophy and history of science have only just begun to engage the difference of disability (see, for example, Colligan, 2004, Landsman, 2009, Mitchell, 2001). Like other disability studies scholars, I am somewhat cautious in my engagement of science and technology studies more generally, although I learn from the field’s orientation to science as a complex cultural production rather than a thing in and of itself. Science, particularly biomedicine, has been a dominant approach that casts disabled bodies as Other, abject and pathological, historically subjecting disabled persons to ‘correction’ (i.e., normalization, institutionalization, sterilization) via medicine and technology (Davis, 1995; Stiker, 1999). My work is thus invested in crafting alternatives to scientific views. My main contributions to emerging work at the intersection of feminism, disability studies and the feminist philosophy and history of science is to offer a new entry point from disability studies through which to disrupt the ground that yields autism as an object only of or for science, to bring issues of ethics and politics to the fore, to critically engage and document histories of ‘scientific’ understandings of autism and mothering as they appear in popular media, and to

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8 On feminist challenges to science and the expulsion of affect from knowledge see, for example, Boler (1999), Bordo (1987), Grosz (1993), Haraway (1991), Jaggar (1989).
offer new understandings grounded in the experience of autism mothers about the meaning
of love, relationality, subjectivity, resistance and complicity within scientific regimes.⁹

I first very briefly consider Western philosophical presuppositions about the
meaning of being human and the nature of knowing as the ground of a science that erases
and pathologizes the difference of different embodiments and histories (on the difference of
difference mattering, see Michalko, 2002). This also means taking a closer look at what
science makes of its subject, which I do through an example of mundane autism science. I
do this to both introduce how philosophical presuppositions are at play in autism science,
and to familiarize the reader further with the meaning of autism today as an “undesired
differentness” (Goffman, 1963, p. 5) in need of a scientific remedy, one that implicates a
mother’s love and care, as we shall see. Finally, I consider how my discussion points to the
incompleteness, irrationality and partiality of scientific knowledge and all knowledge
production, suggesting instead that knowledge production is a political and ethical
endeavor. Through this work, I make room for an alternative approach to autism, mothering
and care that not only incorporates the rational and critical, but also the creative surprise of
embodied difference identified as autistic and the possibility of care beyond that of
scientific remedy. This alternative approach orients to care as pedagogic, learning from
how mothers live, negotiate, take up and resist the ethical paradox at the heart of this thesis
- attending to the particularity of the unique person in our everyday, and the dominant
Western ‘scientific’ demand to achieve sameness with a universal understanding of the

⁹ More generally, I have found the following readings on epistemological challenges to Western scientific
(1993), Michalko (2002) and Nielson (1990). I have also found Marx’s materialist and historical conception
of consciousness, Nietzsche’s focus on interpretation, the constructedness of language and perspectivism, as
well as the work of post-colonial and Black scholars very helpful in thinking through standpoint and
human subject as non-autistic. Pedagogic care offers a critical and creative challenge to
dominant conceptions of autism, science, difference, disruption and biomedical care. I
outline my alternative approach and open space for new meanings of care in chapter two.

This section also suggests a methodological direction that will guide my chapters to
come. Like disability historian Stiker, “At most my goal is to enlarge the understanding that
we already have” (1999, p. 18). Everyday talk and text grounded in the prestige and
presuppositions of science already circulates about autism and mothering. My approach
aims to both reveal the ground of such stories and make room to imagine new possibilities
that might begin to gesture to alternative ways of living together with difference beyond
our current regimes of knowledge and care.

What is Science?

Science, suggests Donna Haraway, is a set of practices and technologies caught up
in the “search for translation, convertibility, mobility of meanings and universality – which
I call reductionism, when one language (guess whose) must be enforced as the standard for
all the translations and conversions” (Haraway, 1991, p. 187). Since the philosophy of
Descartes and his followers, instrumental reason has arguably been the “one language” that
has been enforced as the standard for translation in Western knowledge production -
instrumental, impersonal, efficient, exhaustive and relationally detached procedures to be
universally applied through autonomous human consciousness (Descartes, 1985, p. 120;
Llyod, 1993, pp. 39-50). Instrumental reason revolutionized both epistemology and
ontology by separating knower from known, or subject from object, and imbuing a very
particular experience – bourgeois, Western, male, rational, autonomous, nondisabled – with
both necessity and universality (Solomon, 1988, p. 7). In Discourse on the Method,
Descartes writes, “...I was a substance whose whole essence or nature is simply to think, and which does not require any place, or depend on any material thing, in order to exist...” (1985, p. 127). The mind – consciousness and thinking – is substantively separated from the material (the body, location, history, emotion), which becomes a mere extension, a mechanistic and functional realm (Taylor, 1989, p. 145). Haraway calls the resultant “view from nowhere” within modern Western philosophy and science a “god-trick,” “a leap out of the marked body and into a conquering gaze from nowhere... [a gaze] that makes the unmarked category claim the power to see and not be seen, to represent while escaping representation” (1991, p. 188).

Consider, for example, how the “god-trick” is at play in this mundane description of autism science published on vimeo introducing a lecture by research scientist Derrick MacFabe by the advocacy organization *Autism Canada*:

Dr. MacFabe, Director of the Kilee Patchell-Evans Autism Research Group at the University of Western Ontario, has shown in a series of studies that metabolic products from gut bacteria may be potential agents that link abnormalities of the gastrointestinal system with other metabolic and brain abnormalities found in children with ASD [autism spectrum disorder]. His group found that exposing rodents to propionic acid (PPA), a compound produced by ASD associated gut bacteria and elevated in the stools of autistic patients, produced many striking ASD-like effects, such as bouts of repetitive behavior, decreased social interactions, seizures, and immune and metabolic changes in the brain, including specific abnormalities in mitochondrial metabolism. (MacFabe, 2012)
The science of autistic bodies/minds and “brain abnormalities” – the object to be studied - is separated from the seemingly body-less rationality and objective scientific knowledge represented by the Kilee Patchell-Evans Autism Research Group at the University of Western Ontario. We meet director Dr. MacFabe and the products of his research group’s scientific endeavor to explain the causal agents of autistic symptoms. We do not, however, learn of these scientists’ everyday lives working, loving and living as historical bodied beings in our late modern Western capitalist world, what sociologist Dorothy Smith describes as “the actual ongoing practices of actual individuals as they go forward in just the everyday/everynight sites in which they happen and in the time they perdure” (1999, p. 6). Are there children, perhaps even autistic children in these scientists’ lives that they love and leave behind in order to enter this objectifying realm? Is it in a mother’s care such children are left for this work to proceed? What emotional and psychic work is required for this situation of separating love and science to occur? What are the material and cultural conditions surrounding the “personal and local life” (Smith, 1999, p.53) of these scientists that sustain this abstracted realm of scientific knowledge production, including the ways in which mothers are directed by science to care about their child with autism – as ‘abnormalities’?

Rather than the local and contingent, what the viewer ‘sees’ in this description of autism science are ‘signs’ of troubled autistic matter - “metabolic products from gut bacteria” and “metabolic and brain abnormalities” - and a scientific laboratory filled with rats, far removed from everyday/everynight lives together with autistic children. The scientist as knowledge producer, and the endeavor of science to explain and control difference remain unremarked in this scientific ‘view’ as one invested with the power to
“see and not be seen” (Haraway, 1991, p. 188). What we ‘see’, rather, is evidence of autistic abnormalities in autistic stool and rodents injected with propionic acid and their “bouts of repetitive behavior, decreased social interactions, seizures, and immune and metabolic changes in the brain, including specific abnormalities in mitochondrial metabolism.” The leap from stool, and from propionic rats and “striking ASD-like effects” to biological abnormalities that cause disordered symptoms in “autistic patients” is made seamlessly. This an interpretive move that reduces autism to mere matter and distances autism from what is considered human, as well as from social processes of meaning-making, alternative views of autism and the everyday/everynight of autistic children’s lives together with those who love and care for them. In this scientific account, autism becomes little more than a bizarre looking object of and for the Western scientific gaze and its practices. Ethnomethodologists point out that such accounts are not separate from the “socially organized occasions” in which they occur (Garfinkel, 1967, p. 3; also see Gill & Maynard, 1995; Maynard, 2005). In other words, socially organized scientific practices produce accounts of the ‘natural’ and ‘normal’ body as the universal standard of the human, in part, through the identification of autism as abnormal and Other (on the “natural” and “normal” body see Michalko, 2002, pp. 47-8, 56-8). The instrumental aim of all this science is to remedy and normalize autism - identifying the link between autistic gut and brain. While seemingly a benevolent aim, it is one that conceals its implication in science as a project of power and domination that aims to control and vanquish the “body-gone-wrong” (Michalko, 2002, p. 120). The scientific practices described here mark and objectify autistic bodies as Other, elide processes of meaning-making in which such practices occur, erase the local and particular of mother’s and children’s lives, and leave the
gendered and abled Western body of science – and scientists – unmarked. They also depend on a very particular understanding of ‘evidence’ as empirical (Portelli & Konecny, 2013, p. 93; also see p. 42 in this thesis, and footnote 52), or that which can be seen, measured, quantified and gleaned through the senses, an understanding of science I am critiquing here.

The implications of the “god-trick” – explored above in a moment of everyday science and in Descartes’ radical separation of mind from body and the universalizing of the particular of modern Western philosophies of the subject – have been far-reaching. Despite egalitarian Enlightenment sentiments extending universal reason (i.e., subjectivity) to all humankind, enduring ancient associations within Western philosophy between the body, Nature, the irrational, nonwhite peoples and femininity (Wynter, 2003; Lloyd, 1993) meant that the Enlightenment’s Others did not, indeed by very definition could not have an equal share in universal reason and humanity (Fanon, 1952/2008; Foucault 1965/1988a; Mitchell & Snyder, 2003; Stiker, 1999; Wynter 1992, 2003, 2006). Such philosophies linked Reason with instrumental control over the body, the passions and Nature (Taylor,

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10 I note here that philosophical attention to self and subjectivity is by no means new to the modern era. Most notably, between an ancient Greek philosophical concern for “care of the soul” and Descartes’ moment of the cogito, is the “Interiore Homine” of 4th Century philosopher and theologian Augustine (Taylor, 1989, pp. 115-142). In Taylor’s words, Augustine calls for a “radical reflexivity” or turn to the first person standpoint (i.e., the agent’s “experiencing of experience” or “consciousness of consciousness”) as the proper object of philosophical reflection and route to truth: “Do not go outward; return within yourself. In the inward man dwells truth” (Taylor, 1989, p. 129; see also Solomon, 1988, p. 5; Atkins, 2005, p. 7). With Descartes, the source of truth moves inward, too, no longer emanating from – ‘found’ in – the external of Plato’s Ideas or Augustine’s God (Descartes, 1985, p. 115; Solomon, 1988, pp. 2-5; Taylor, 1989, p. 143). The precise ‘nature’ of this inner source – the nature of human nature - of course, would prove to be a point of tension among modern philosophers (whether rationalist or empiricist). Descartes infamously locates this source solely in reason and the “I think” of the cogito (Descartes, 1985, pp. 14-5; also see Lloyd, 1993; Taylor, 1989; Solomon, 1988), while empirical philosopher John Locke, for example, dismisses disembodiment as implausible and foregrounds the necessity of having a body and senses alongside reason and the “same consciousness” over time and space as definitional to personal identity (Atkins, 2005, pp. 24-32). Whether to reason alone, the particularizing, inward turn made by modern philosophers was simultaneously a universalizing one. The experience of the European, bourgeois, abled male philosopher subject came to ‘stand in’ for the transcendental truth about all of humanity not only in philosophical terms, but political, moral, religious and social ones as well. Solomon (1988) describes this radically universalizing inward turn as “…the unwarranted assumption that there is universality and necessity in the fundamental modes of human experience…an aggressive and sometimes arrogant effort to prove that there are no…(valid) possible alternatives” (1988, p. 7).
1989, pp. 149-150). This reshaped age-old binary oppositions in terms of instrumentalizing
Reason that was calculative and efficient - Reason/Nature; mind/body; public/private;
man/female; white/Black - imbuing scientific ways of knowing and versions of the human
as male, white, rational, controlled and certain with value. Such philosophies came to
justify the measurement, dividing, regulation, scientific ‘treatment’, internment and
enslavement of individuals, peoples and territories on a grand scale (Foucault, 1965/1988a;
Solomon, 1987, p. 7; Wynter, 2003, 2006). The “god-trick” in science is not innocent, but
historically implicated in violently expelling the difference of alter embodiments,
locatedness and histories not only from official canons of knowledge, but also from what is
possible in terms of human life (Michalko, 2002). Through Western science, autistic bodies
have come to join the Enlightenment’s Others, and a mother’s care is implicated, as we
shall see in detail in the chapters to come, within the scientific project to expel autistic
difference.

Given this, working toward new stories about autism and mothering cannot simply
be a matter of doing ‘better’ science. If I hope to disrupt the foundations and truths of the
Western philosophical tradition and science, ones that reduce its subject – autism - to mere
matter and care to scientifically controlled remedy that implicates mothers (whether this
remedy is biological, rehabilitative or educational), then an additive process that imbues
historically excluded experiences with value, although an excellent start, is not enough on
its own. Different ways of being have not only been excluded within the conceptual and
practical apparatus of the Western philosophical tradition and science, they have also been
consstituted as different and devalued through these very same processes of domination.
What is normal – Reason, maleness, whiteness, abled-ness, autonomy, order - rests upon
difference for its very sensibility as the valued and the good within an enduring set of deep
gender, race, class and disability inequities (Lloyd, 1993, p. 106). And while it is vital to
challenge binaries and exclusions through centering different autistic and female ways of
being in the world – a task I also engage in here - these ways of being are integrally caught
up with and constituted through such histories. In other words, the very practices through
which we produce knowledge are constitutive of who we are and who we might be together
(Smith, 1999, p. 6). Audre Lorde (2007) puts the point about the vital need for a different
(for Lorde, a poetic) way of knowing that enfolds bodies, histories, experiences and
feelings this way, “The quality of light by which we scrutinize our lives has direct bearing
upon the product which we live, and upon the changes which we hope to bring about
through those lives” (p. 36). I raise these complex conceptual points and challenges not to
attempt to resolve them, but to underscore the passionate belief that guides this thesis: that
a different form of knowledge production about autism and mothering is needed to move us
beyond a scientific approach, its prevailing story of autism and care, and its undergirding
philosophical assumptions as ones that can only yield ‘more of the same’ exclusion and
violence against alter bodies.¹¹ My dissertation thus makes a unique contribution to what
Pamela Block (2015) calls the “emergent landscape” of autistic studies authored by autistic
scholars (and their allies) as the subjects, rather than the objects of knowledge production
(p. 354). These emergent ways to know and care about autism, and autism mothers
differently are crucial within the larger struggles for human freedom by autistic, feminist
and disability activists.

The Partiality of Knowledge: Toward an Embodied ‘View’

The above discussion suggests that what counts as knowledge about autism and autism mothers is not universal at all, but partial, representative of a narrow, non-autistic, gendered and Western experience and scientific approach that is both historical and located. Susan Bordo describes the modern Western search for a philosophy that would yield “truth” and “certainty” to a humanity “naturally” endowed with reason (as exemplified Descartes’ Meditations) as “an aggressive intellectual ‘flight from the feminine’ into the modern scientific universe of purity, clarity and objectivity” (Bordo, 1987, p. 5; also see Descartes, 1985, pp. 111-2). Whether or not we agree that the pre-modern world was more “feminine” than the emerging modern world in Descartes’ time, Bordo’s thesis suggests that ways of knowing more typically associated with the feminine and autistic (and indeed, the human) – the disruptive, loving, sensuous, embodied, practical, situated, ambiguous and relational – are equally deserving of philosophical status. My focus on mothers’ love, care, relationality and the alterity of autism is one way I seek to disrupt the philosophical underpinnings of scientific knowledge production and invite such “enchantment” back into the process of knowledge-making (on disenchantment, see Weber, 1946).

This suggests the need for a new metaphor within knowledge production, to borrow again from Haraway, that disrupts the “view from nowhere” and “embodies vision,” in other words, one that is situated, located, historically contingent and critical (Haraway, 1991, pp. 188-201). While this implies perspectivism, situated knowledge is not an epistemological position that seeks relativism, nor, in my case, one that seeks to imbue the subjugated experience of mothers and autistic persons with unquestioned authority. As an opposite stance to universality or totalization, relativism is its own kind of “god-trick,” one
that tries to be “nowhere while claiming to be everywhere equally” (1999, p. 191; Scott, 1991). Rather, arguing for the insertion of alterity in the process of knowledge production, just as any claim for “objective” or “rational” knowledge, proceeds from the partiality and interpretive nature of all knowledge, as well as from the recognition of knowledge production as a political and ethical endeavor. I agree with Haraway that, “It is not enough to show radical historical contingency and modes of construction for everything” (Haraway, 1991, p. 187). Rather,

We are also bound to seek perspective from those points of view, which can never be known in advance, which promise something quite extraordinary, that is, knowledge potent for constructing worlds less organized by axes of domination. In such a viewpoint, the unmarked category would really disappear…The imaginary and the rational – the visionary and objective vision – hover close together. (1999, p. 192)

The invitation of ways of being marked as autistic, as well as mothers’ knowledge, love and care into knowledge production is a political and ethical act, an insertion of contingency, difference and disruption – bodies, minds, emotions and senses that disrupt and exceed any easy or certain representation or knowing, scientific or otherwise (Michalko, 1999; Titchkosky, 2007). Such ‘disruptive knowledge’ is potentially pedagogical, revealing the meaning of ‘different’ bodies, minds, and senses as contingent, and opening a space of new questions, and perhaps new knowledge, about power, resistance, subjectivity and what it might yet mean to be human together outside of the grip of the Western, scientific ‘non-autistic’ gaze.
‘Autism Mother’ as Cultural Contradiction

So far, I have suggested that within moments of disruption lay both the constraints of our say-able sensible world, as well as pedagogical, political and ethical possibilities. I came to this through the disquiet and contradictions within my own experience, which led me to an ethic of disruption as my philosophical stance. I then turned to disrupt the ground of Western science as the dominant approach to understanding autism, and argued instead for an alternative “view” of knowledge production and difference that is embodied, partial and situated. In this section, I discuss my main argument about the emergence of autism mother subjectivity as a key cultural contradiction. This central argument provides an anchor for the analytic work of this thesis alongside my ethic of disruption, understanding of knowledge production as embodied and political, and central tension of constraint/pedagogic possibility. I begin by briefly returning to the quotes by autism mothers that introduced this chapter.

The quotes by autism mothers from everyday text and talk that appear at the beginning of this chapter speak to the potentially deadly effects of Western scientific understandings of human life and ways of knowing and caring as ones in which certain lives – autistic, disabled and non-normative - are questionable lives (Butler, 2004):

Would I have aborted?...I had sat in the car for about fifteen minutes and actually contemplated putting Jodi [autistic daughter] in the car and driving off the George Washington Bridge...My son is trapped inside this label called autism and I’m gonna get him out... (see page 1)
Here, the unquestioned good of the normal human of Western science and biomedical imperative to remedy difference through care, cure or elimination - even if by violent means - undergird mothers’ everyday text and talk, granting ordinary sense to questions about whether and how their child’s life might, or might not, be worth living. These questions about the viability of some ways of being human and not others are inescapably political and ethical ones, entwined with issues of power, knowledge, difference, identity, care and violence. They are also timely ones within the Canadian landscape.

Consider, for example, the recent re-emergence of public debate about physician-assisted suicide as one in which questionable lives have recently appeared within everyday text and talk. First brought forward in the early 1990s by Sue Rodriguez who had ALS (Lou Gehrig’s disease), physician-assisted suicide re-emerged in 2011 as an issue of human rights in the “Die with Dignity” court case filed by the British Columbia Civil Liberties Association on behalf of a number of families (Council of Canadians with Disabilities, 2009; British Columbia Civil Liberties Union, n.d.). In 2012, the British Columbia Supreme Court ruled that bans on assisted death restrict the right of individuals who cannot complete suicide (which is not illegal in Canada) without assistance and are therefore unconstitutional. However, the federal government appealed this ruling, and the decision was overturned in the B.C. Court of Appeal in October of 2013 (British Columbia Civil Liberties Union, n.d.). In October 2014, the Supreme Court of Canada heard arguments on the case, and in February of 2015 unanimously ruled that the ban on physician-assisted dying entrenches upon an individual person’s liberty, dignity and autonomy, violating Section 7 of the Canadian Charter of Rights and Freedoms (Carter v. Canada, para. 4, 66, 127). If the court’s ruling to void physician-assisted suicide laws goes uncontested, medical
doctors will be empowered to facilitate a planned death with persons who have a “grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition” (Carter v. Canada, para. 4). The intolerable suffering of an “irremediable medical condition” may be personal, social or both, and “irremediable” includes the right to decline unacceptable treatments (Carter v. Canada, para. 127). The individual must be “competent” for such an event to occur (Carter v. Canada, para. 4), but they do not have to be terminally ill in order to “consent” to the “termination of life” (Carter v. Canada, para. 4).

Within this physician-assisted suicide debate, the boundary between which lives are and are not considered worth living gets fuzzy. Disabled, diseased and ill bodies are medicalized suffering bodies excluded from the Western scientific endeavor that inscribes and legally enshrines normative human subjectivity as nondisabled and autonomous through marking disabled bodies as deficient, intolerable and even non-human. Here, Reason (as Western philosophy’s understanding of the human) calculatedly rules the suffering of disordered bodies and disruption of Nature. Death becomes a viable, and rational-legal medical “treatment” that is also considered a kind of good for this nonconformity. Groups such as the Council of Canadians with Disabilities and the Canadian Association for Community Living oppose the legalization of assisted suicide on the grounds that not only does high quality end of life care need to be more available (rather than the option of assisted death), but the assumption that death is preferable to living with a disability requires serious thought and challenge (Council of Canadians with Disabilities, 2014). Despite the Supreme Court’s faith that a “properly administered
regulatory regime is capable of protecting the vulnerable from abuse or error” (Carter v.
Canada, para. 3), histories of murder, sterilization and confinement of disabled persons
suggest a more complex and troubling landscape (see, for example, Levinson, 2010; Stiker,
1999). While a full engagement of the complex ethical and human rights issues surrounding
this debate is beyond the scope of my project, the shocking and lengthy list of parents and
other caregivers who have murdered their autistic child (see McGuire, 2011b, 275-98)
suggests it is not a stretch to ask whether autistic and other questionable disabled lives may
become part of this new landscape of “timely deaths” (Razack, 2013). Everyday text and
talk is a uniquely rich entry point into such deadly questions about the ordinary
accomplishment of subjectivity, whose knowledge matters and which version of the human
counts, as well as a testament to the need to fashion alternatives to Western scientific
knowledge production about what it means to be human, which lives are worth living and
how we might treat them, legally, medically or otherwise.

The above discussion suggests the ways subjectivity is caught up with matters of
life and death through Western understandings of the human, scientific regimes of power
and meaning-making as they are accomplished in an everyday textual register (on
subjectivity see, Atkins, 2005; Foucault, 1982; Mansfield, 2000; Natanson, 1970; Schutz,
1967; 1970). Interrogating how subjectivity appears within everyday text and talk, then,
not only critically examines how we have become who we are in this historical moment,
but also who we might hope to be together, as a human community that cares about some

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12 For further reading, also see http://www.notdeadyet.org/disability-groups-opposed-to-assisted-suicide-laws
13 The terms subjectivity, identity and self, have conflicting interpretations and usages within philosophy as
well as social theory (see Atkins, 2005, for example). Rather than define subjectivity in strict terms, I hold
open its meaning in the tension of the approaches I engage.
lives differently than others (Wynter, 2003, 2006; Zournazi, 2003). The main argument of my thesis is a response to such everyday textual provocations. I argue that autism mother subjectivity emerged as a key *cultural contradiction* through which Western scientific understandings of autism and a contradictory femininity began to regulate the good/bad mother in new ways, shaping what being together means not only for mother and autistic child but *for us all* (Bordo, 2003; Hays, 1996). Sociologist Zygmunt Bauman helps here. He suggests that under modernity, identity has become our most “pressing” “problem” and “task” (2008, pp. 18-9, 20, 32; also see Titchkosky, 2012, p. 128). In our case, and under the guise of mothers’ love and care, the shape of being together paradoxically contains “a duty and an urge” (Bauman, 2004a, p. 21) to achieve a selfsame identity for our different, autistic child. A very narrow identity and selfhood as the only life worth living – as close to a non-autistic, rational, bourgeois, autonomous, western/izing life of self-mastery as possible – is thus extended to autistic life, I suggest, through new contradictory, ‘naturally’ loving and instrumentally calculative mother subjectivities (on the “good life” as exclusive of difference see Taylor, 1989, pp. 22-3; also see Titchkosky & Michalko, 2012; Schutz, 1962, p. 13). What seems new with autism mothers is the intensification of Western culture’s intense desire for sameness – the “god-trick” - to hyperbole, alongside the intensifying affective enlistment of a re-educated mother subject in the shoring up of the borders of the normative human (Ringrose & Walkerdine, 2008). This shapes and intensifies autism mother subjectivity and love into an impossible ethical paradox, an

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14 Sylvia Wynter (2003, 2006) talks about “hope” as a new humanism needed to challenge narrow notions of the human, one that would address itself to the real conditions of human life. The contributors to Zournazi’s *Hope* (2003) take up the challenges facing political movements and intellectuals globally in working toward ways to live together in more humane ways.

15 In a sense, my argument extends the work of disability studies scholars who have written extensively on the enforcement of normacy and the tyranny of systematic assimilation to bodily norms through practices of rehabilitation, special education and biomedicine. See, for example, Davis (1995), Michalko (2002), Stiker (1999), Titchkosky (2007).
irremediable cultural contradiction that must be brokered daily — to mother and to care means to both love our autistic child who appears in their uniqueness within our everyday and to scientifically remedy the difference of autism by simultaneously practicing the ethical violence of making our child identical (on uniqueness see Arendt, 1998/1958, pp. 175-181; on alterity and ethical violence see Levinas, 1969, pp. 33-52, 72-81; on identity see Stiker, 1999; on the meaning of the human see Titchkosky & Michalko, 2012).

The emergence of new (in intensity and scope) Western autism mother subjectivities as a key cultural contradiction post-World War II has also involved a deeply troubling, and shifting re-education of postcolonial femininity and the mother subject, first through psychoanalytic views and natural mothering, and then through behaviourism, cognitive psychology, and most recently, biogenetics and the “working mom” who also mothers intensively (on intensive mothering, see Hays, 1996). This shifting re-education involves an intensification of both intensive mothering and a contradictory femininity, as well as a version of the human that expels the difference of autism and centrally implicates mothers in the remedy of this so-called tragic disorder through her natural, intensive, scientifically composed and instrumental love (Hays, 1996; O’Malley Halley, 2009; Walkerdine & Lucy, 1989). Recent autism mother recruitment campaigns, for example, issue seductive calls to mothers world-wide to join the ‘war on autism’ from Western advocacy organizations that ascribe to scientific and biomedical versions of autism and care (see, for example, “Autism mothers: The final cut,” 2009). This re-education eclipses difference and advances the care of the rational, autonomous, white, bourgeois, non-autistic, Western consumer-subject globally. Indeed, everyday talk and text is “deadly
political,” entangled with life and death questions about power, violence, subjectivity and human possibility (Hall, 1997, p. 290; also see Wynter, 1992; Walcott, 2003).

The emergence of autism mother subjectivity as a key cultural contradiction and mothers’ shifting re-education as they appear in everyday text and talk has everything to do with what – and who - is valued, sought after, hoped for and imagined as possible in late modern life. Tanya Titchkosky says, disabled people “embody alternative ways of being-in-the-world and act as living depictions of the possibility that things could be otherwise” (2003, p. 237). To explore what else might be possible, this dissertation questions, and disrupts, some of our most intimately experienced, felt and sometimes ineffable ways of being together – mother and child - as ones that are not simply personal or natural experiences of love, care and disability, but also political sites of embodied and affectively lived power, knowledge and resistance (Boler 1999, pp. 20-1). This suggests a different way to care about autism and mothering grounded in a kind of pedagogic care or openness to different forms of knowledge that embrace, and learn from, the difference of embodiments marked as alter and maternal care. The hope of this project is to open space that gestures to these new and transformative stories, and for knowledge production to be one such political, pedagogical and ethical site to do so.

**Chapter Outlines**

I organize my dissertation in seven chapters. Chapter two begins with an in-depth exploration of the methodological and theoretical provocations that help me fashion an alternate way forward to understanding autism and mothering. I draw from critical and interpretive approaches, broadly conceived, within disability studies as informed by
philosophical and feminist sociology, poststructuralist and phenomenological thought, maternal and cultural studies and feminist philosophies of science. Through an in-depth exploration of these multiple influences, I learn to use the tensions and bridges between their ‘edges’ as a generative way to engage questions of constraint, power and subjectivity along with questions of disruption and difference as possible gestures toward living otherwise. I also introduce how I composed a unique archive of everyday text and talk by and about ‘autism mothers’ (including two focus groups I conducted with autism mothers in the fall of 2013) as the social location that grounds my analytic work. I explore my archive of everyday text and talk both genealogically and phenomenologically to mine its richness as a site through which both self and world are made, and might be made anew. It is the creative synergies and slippages between the multiple influences and approaches I engage that yield new possibilities for being together under late modernity.

Chapter three, “Autism’s ‘Refrigerator Mothers’: Identity, Power and Resistance,” traces the emergence of autism’s ‘refrigerator mother’ – the so-called cold mother understood to cause autism in her child - in everyday text and talk genealogically, 1943-1969. This was a time when autism was first ‘discovered’ and psychoanalysis rose. I trace the emergence of this mother as she is depicted in everyday text and talk through new forms of knowledge, technologies of blame and forms of visibility that bring her into view in new and contradictory ways, shaping new spaces of governance that turned her gaze inward, toward her own self-governance. I consider how this inwardly directed gaze also, and ironically, became the ground for mothers’ resistance. Working more interpretively, I also pause at points along the way to take a backwards glance at what might be “behind” (Ahmed, 2006, p. 570) the appearance of this mother, and open interpretive space about my
activity of re-reading this mother as its own form of resistance, one that is committed to a
different kind of knowledge about our human life together.

I work similarly for chapters four and five, melding genealogical analysis together
with interpretive moments and my own reading of texts as an activity of resistance. In
chapter four, “Autism’s ‘Mother Therapists’: A New Cultural Hero,” which spans the years
1970-1999, cognitive psychology became dominant, and mothers emerged as cultural
heroes whose skilled techniques were required to normalize their autistic child. For the
years 2000-2015, when genetic views of the human rose, autism’s ‘warrior mothers’
emerged as new mother experts held responsible for shoring up all of this figure’s
contradictory aspects – her ‘masculine’ warring element and her ‘feminine’ softness; her
instrumentality and her love - with which to combat a new landscape of rising rates of
autism diagnosis. I trace the emergence of the mother warrior in chapter five. I also include
an in-depth phenomenological description of the warrior mother in this chapter in order to
take a second ‘look’, from a slightly different and deeper angle, at the cultural ground that
produces this mother at war against autism. Through these chapters, I show the dire need
for something more than the reproduction of a dominant scientific sense of autism as a
problem, and expert sense of the solution that centrally implicates mothers in the
normalization of their child.

Chapter six explores this ‘something more’ through focus groups (set in Toronto)
that I conducted with autism mothers in the fall of 2013. Mothers spoke about forms of care
that both mirrored dominant cultural representations of ‘autism’ and ‘autism mother’ and a
“biomedical ethics of remedy” (Michalko, 2002, p. 99), and at once creatively constructed
something that moved beyond. I call this pedagogic care - a way of being together that
gestures to what else might be possible outside the constraints, violence and exclusions of dominant ‘caring’ regimes that culturally produce, exclude and pathologize embodied ‘difference’ within our late modern life together. My project is an invitation in this way, to attend to the complex histories, social processes, interpretive acts of perception and human suffering that mark our human journey differently (Ahmed 2010, p. 12) – and yet from which we might learn something new about care and the meaning of human flourishing. Chapter seven offers a brief conclusion.
CHAPTER TWO

Methodological & Theoretical Provocations

This chapter attends both theoretically and methodologically to the disruption of autism in everyday life together as it “beckons” us, in poet Eli Clare’s words, to attend to and engage difference differently (Clare, 2007, p. 89). I draw inspiration and guidance from a number of different, even conflicting, interpretive and critical approaches within disability studies that help me hold open a space of questions about disruptive bodies and the extraordinary accomplishment of an ordinary world in everyday talk and text that excludes and devalues ways of being alter. These approaches include, among others, philosophical sociology, phenomenology, feminist maternal and cultural studies, feminist poststructuralism and feminist histories and philosophies of science. My aim is not only to think anew about constraint – understanding the contours of Western neoliberal, capitalist and scientific modes of power and subjectivity that so capture our hearts, bodies and minds in late modern life. I also seek to think anew about disruption and difference as movements and moments within everyday life that point toward what else might be possible for our human life together. I take direction from sociologist Peter Berger who says, “the first wisdom of sociology is this - things are not what they seem” (1963, p. 23). Critical and interpretive approaches help reveal the many “layers of meaning” Berger refers to that compose our social world together, along with its provisional nature. This is a hopeful and even utopic thread in my work that confirms the disruptive and imaginative possibility of
knowledge production, as well as hope for some amount of human freedom (Bauman, 1976; McKay, 2005; Zournazi, 2003).

Within this ‘disruptive’ approach to knowledge production, method and theory intertwine. Tensions and conflicts between underlying philosophical commitments become sites and spaces of generative questions as well as creative edges upon which I ‘slip’, ask questions and disrupt easy answers about knowing or proceeding (Dehli, 2008, pp. 46-7; Ricouer in Titchkosky, 2003, p. 102; Tamboukou & Ball, 2003). Divergent ways of understanding the subject, for example, which slip and slide throughout the pages of my dissertation, as an unstable, non-unitary discursive effect of relations of power within poststructural approaches, and as a meaning-making agent within interpretive sociological approaches (St. Pierre, 2000, pp. 500-05), open up different slants on the disruption of bodies marked autistic as they appear in everyday text and talk. It is within such contradictions and “slippages” in research, Dehli (2008) tells us, that space might be opened to challenge our own governance as researchers within current regimes of knowledge production, even if momentarily, “where we can retrieve creative possibilities for new connections and practices” in research (p. 47). Using what I am calling a ‘disruptive’ approach means that unlike conventional humanist qualitative methodology, there “is no recipe” of how to do “post analyses” (2014, p. 10). Instead, St. Pierre encourages researchers to deeply engage the “posts” (poststructuralism, postmodernism, posthumanism) for direction (and here, I include in the “posts” the work of Foucault, as well strands within disability studies, interpretive and phenomenological approaches) in order that we might “experiment with what is yet to come” (St. Pierre, 2014, p. 15). This chapter is one such deep engagement.
I begin below by outlining my conceptual framework. Aspects of this framework were introduced in chapter one; for example, I introduced the contradictions within my own experience that compel me, personally and philosophically, toward an alternative approach to autism and mothering, I revealed the prevailing approach (whether natural or social science) as grounded in the rationalism and empiricism of Western science, and I argued for the vital importance – at times life or death – of rethinking autism and mothering within our globalizing neoliberal, patriarchal capitalist landscape. My discussion here makes the relationships between my rationale, personal and epistemological commitments, and theoretical framework explicit. This also includes an account of my methodological considerations and commitments - how I came to shape the study and choose the methods and theoretical approaches I did, including the significance of how and why I gathered an ‘autism mother’ archive of everyday text and talk as the ‘data’ for my analysis, and why I include not only everyday texts but also focus groups as part of my project. My aim here is to provide a conceptual ‘roadmap’ of my project for my reader.

The chapter then turns to an in-depth discussion of the key theories and methods used (and here, theory and method interweave). I describe the interpretive approaches I draw from, particularly the sociology of Alfred Schutz and Dorothy Smith and the phenomenological method I use to help me explore my questions: What does it mean to be an autism mother? How is everyday text and talk about autism mothers taken up, lived and possibly resisted? What possibilities for living otherwise might such questioning reveal? I also outline how I engage critical and poststructuralist approaches to power and subjectivity, principally Michel Foucault’s understanding of governmental power and his genealogical method, to historicize my questions: How have mothers and their practices of
care become naturalized as the target of practices of domination and self-governance re-educating and identifying them as both ‘cause’ and ‘cure’ of autism? What disqualified knowledges and forms of resistance can be found within this historical project of making mothers subject that might also instruct us on living otherwise? Next, I provide a detailed discussion of the field of disability studies as one that integrally guides how I shape and attend to all of these questions. Emerging conversations about mothering and care at the intersection of disability studies and feminism are particularly provocative, and my dissertation is itself a contribution to this developing dialogue (see, for example, Kelly, 2013; Rapp & Ginsburg, 2011; Ryan & Runswick Cole, 2008, 2009). In light of all of these discussions, I close the chapter with a brief section that describes how I proceed with, and make sense of, everyday text and talk as the social location for my analyses. I cover substantial ground in some depth in this chapter. As a result, this chapter is somewhat longer than my others. The payoff of this detailed work is the opening of a disruptive and hopeful theoretical and methodological space from which to explore knowledge production about autism and mothering as a creative and pedagogical endeavor about how we have come to care – and how we might care differently - about questions of the meaning of identity, difference, relationships and human alterity.

A Conceptual Framework: Turning to Disruption

I began to critically think through my experiences as the mother of an Asperger’s identified son academically during my graduate coursework. This was why I came to graduate school: I wanted to more deeply understand – even somehow reconcile – our fractured and contradictory experiences (on reconciliation, see Titchkosky, 2003, p. 236;
Arendt, 1994, pp. 307-27). The space between the world Brennan, Jesse and I inhabited together, as a family, and our encounters in public spaces, with professionals and within schools and autism agencies, seemed irreconcilable. Rather than mimic dominant narratives of tragedy or disorder, our rhythm as a family was more often sculpted in unique and lovely ways by the ‘disruption’ of my son’s ways of being identified as ‘autistic’.

While other mothers scooped up their (sometimes screaming) child or shouted, “Time to go!” to leave the park, for example, our transitions were shaped differently. Brennan’s passionate connections to the world around him meant instead that we visited each flowerbed, in turn, together, as an oft-repeated ritual, to slowly make our way out of the park. Along with other such ‘questionable’ behaviours, these untimely transitions and rituals that marked my son’s body autistic disrupted the everyday of parenting, schools and autism agencies, meeting professional concern and even violence. Abuses, bullying, exclusions and negative remarks about my (bad) mothering and my (bad) son by teachers, parents and administrators were commonplace. The day that my younger son Jesse and I walked in on the scene of the principal of then eight-year old Brennan’s school restraining him, spread-eagled and face down on the carpet, the culmination of my son’s forcible removal from a washroom stall, where he had retreated to calm down after an upsetting event in the classroom, was particularly salient. This same principal had also called the police on different occasions to escort our friends’ children in the same class - other ‘unruly’ (disabled) eight-years olds - out of the school in handcuffs. Such ‘everyday’ encounters were impossible for me to turn away from. They became an ethical and political call for reconciliation through cultivating

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16 I employ scare quotes to indicate that I understand ‘autism’, and ‘autism mother’ as culturally produced subjectivities rather than ways of being grounded in the biology of different brains or bodies, for example, or as things in and of themselves. I use scare quotes the first time the terms ‘autism’ and ‘autism mother’ are introduced in each chapter, and intermittently, to remind the reader of my orientation.
a deeper and more complex understanding of how such occurrences could be possible at all, an understanding this thesis pursues, and that I hope might also help to transform the ground of our world as one that includes exclusion (on the inclusion of disability as an “exclude-able type” see Titchkosky, 2007, pp. 149-152) and violence toward autistic persons and mother blame as ordinary.

Before returning to graduate school, the dominant approaches to autism and mothering readily accessible to me in mass media, schools and autism agencies such as those introduced in chapter one grounded in Western science and understandings of autism as disorder and family tragedy, were individualizing, marginalizing and pathologizing. Within such narratives, Brennan, Jesse and I were ‘made over’ – I became the ‘deluded’ (because I embraced my son’s ‘differentness’ as acceptable, pedagogical and even beautiful) possibly dangerous and sometimes heroic mother who must learn to systematically reshape my son’s so-called autistic behaviour (no more hour long sojourns out of the park!). My younger son became the innocent sibling victim. We were a family ‘coping’ with autism. And Brennan’s ‘disordered brain’ was clearly the ‘problem’. One of the first articles I ever read about autism, for example, clipped and saved for me by family who were also trying to understand, appeared in Time magazine (2006) and was entitled “Inside the Autistic Mind.” It rehearsed the now-familiar story: autism is a genetic neurodevelopmental disorder, environmental triggers play a key role, researchers are beginning to find answers, behavioural therapies are key to reshaping autistic behaviour and autistic persons are finding ways to communicate despite their “unusual” and “odd” brains. This is, states the author, ground for hope (Wallis, 2006, p. 46). The certainty and control implied by scientific cause-effect thinking can be enticing. More than once we
found ourselves trying to decipher images of ‘defective’ autistic minds/brains, pondering who might have passed down the autism gene in our family and trying to identify what the possible environmental triggers might have been (The lead paint removal my landlord did when Brennan was a baby? That drink or medicine I took during pregnancy?). However, engaging such ‘views’ seemed only to eclipse and even violate the value and uniqueness of my son and our life together. I started to meet other families in schools and autism programs telling similar stories of marginalization, violence and blame. In stolen moments during break-time at autism service agency seminars or during pick-up/drop-offs at school, other families and I shared quiet questions about our strange sense of fracture as we took part in programs and approaches that somehow missed, and even violated, our knowledge about living well ‘in’ difference, including how to advocate against exclusion, that was of most value in our lives.

Within the equity studies graduate education department that became my intellectual home, I found a number of theoretical and methodological alternatives that helped me understand the layers of our dissonant lived experience, as well as the larger systems of domination that shaped our lives in such ways. Disability studies’ depictions of the experience and politics of alter embodiments, as well as concepts from within Black phenomenology like Du Bois’ (1903/1994) “double-consciousness,” and feminist accounts like Dorothy Smith’s sociology for women (1987), touched something of what my family was experiencing. Yet, something seemed to be missing in these approaches, too. As interdisciplinary or radical as they might be, none of them quite seemed to capture the contradictions we were living or the way in which the mother-child relationship was at the center of such a life, its beauty, contradictions and exclusions. Significant for me, too,
mothers and children rarely appeared within these radical literatures and philosophies or the department itself, much less mothers of disabled children (although, happily, they are showing up!). I needed to seek out or create the conversations that were missing from or marginal within dominant approaches and spaces such as schools, and only just emerging within the radical academic literatures that offered such rich alternatives to scientifically grounded ways of knowing.

It was in this way I first chose to weave together interpretive and critical approaches within disability studies, broadly conceived (and sometimes conflicting), in what I hoped would be a ‘disruptive’ theoretical framework for this project. I wanted an approach that could help me pursue a deeper understanding of the contradictory meanings of the disruption of autism I was experiencing in everyday life as opposed to dominant depictions and approaches. Thus, I incorporate a wide range of interpretive and critical methods and theories to pursue this goal. My aim in developing this framework was, first, critical and emancipatory - to work to reveal the contingent nature of the identity ‘autism mother’ and open space for other possibilities around autism, mothering and care that are more humane and grounded in ways of knowing that move beyond Western scientific ones. I needed to understand how exclusions and violence have become ordinary, and how the identities ‘autism’ and ‘autism mother’ have acquired contemporary meaning such that it seems only ‘natural’ that autism, conceived as a tragic biogenetic problem, is in need of the solution of intensive, scientifically governed maternal care, as opposed to creating new knowledges about alter ways of being together, for example. I engage critical theoretical approaches within disability studies to pursue this work, particularly the work of Michel Foucault on

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17 Here, I use the term critical theory broadly, beyond the work of the Frankfurt school, to include approaches with an emancipatory aim that seek to reveal the contingent nature of all knowledge.
governmental power, forms of knowledge and subjectivity and his genealogical method, as well as feminist poststructuralist philosophy, feminist philosophies of science and feminist maternal theory. Yet, the critical approaches of Foucault and others could not address questions of meaning and the ways in which contradictions are lived, made meaningful and possibly resisted in interactional contexts and maternal consciousness (Hacking, 2004), questions that are very close to me as the mother of an Asperger’s identified son. To address this missing element, I engage interpretive approaches within disability studies as they are influenced by philosophical sociology, phenomenological and poststructuralist philosophies, feminist philosophies of science and feminist maternal studies. My dissertation is at once, then, a disability studies, interpretive sociological, feminist, philosophical and historical project that aims to both critically disrupt and interpretively understand autism mother subjectivity, dominant scientific ways of knowing and systemic modes of late modern power. My ethic of disruption guides my theoretical framework. That is, I turn toward the disruption of maternal and autistic experience as a site of critical and interpretive knowledge that might “subvert” or “turn around” (Portelli & Konecy, 2013, p. 94) exclusive and sometimes violent, dominant ways of knowing and caring. At the end of this section, I return to my ‘disruptive’ theoretical framework and address how I use it to tie the elements of my conceptual framework together in order to seek reconciliation, including my personal and epistemological commitment to a different way of knowing and caring about autism and mothering.

The epistemological commitments arising from my fractured experiences I introduced in chapter one ground my theoretical framework as well as the methodological decisions that shape this project. To briefly reiterate, situated knowledges do not seek
control or certainty, but rather, understanding based on partial and previously excluded ‘views’ from which we might connect with Others and transform systems of domination and exclusion. As Haraway (1991) puts it, “We seek not the knowledges ruled by phallogocentrism (nostalgia for the presence of the one true Word) and disembodied vision, but those ruled by partial sight and limited voice” (p. 196). This alternate feminist approach to knowledge production challenges the separation of knower from known and the denial of particularity within scientific approaches, and instead “embodies vision” (Haraway, 1991, p. 189), recognizing the partiality, historical contingency, ethical dimension and political investments of all knowledge. This challenges the dominant sense of science, as well as disability and maternity, as objects in and of themselves and opens them to historical investigation. I turn below to describe how these epistemological commitments inform the decisions I made methodologically to seek a way to understand autism and mothering beyond current scientific regimes.

Methodologically, I wanted to carefully think through ways - methods – to pursue a layered interpretive and critical understanding of those fleeting but significant moments in which ‘autistic difference’ disrupts the ‘normal’ scene or sense of everyday life in text and talk. Sara Ahmed describes such a methodological move beautifully, stating that her task as philosopher is not to pursue certainty or foundational knowledge, but to “listen to the sound of the ‘what’ that fleets” (2006, p. 565). I needed methods that could help me pursue new arenas of knowledge outside dominant scientific approaches to mothering and autism as stigma, coping, biological disorder or maternal culpability from which alterity “fleets.” The questions I had were less empirical and more exploratory: What other knowledges might dwell within or emerge from disruptive moments? What might this tell us about the shape
of the world in which we live together? How might such a contemplation of disruption and different way of producing knowledge reimagine care and the meaning of being human? To get at these questions, I ‘disable’ and ‘mother’ Sara Ahmed’s (2006) metaphor of the queer sideways or backwards “glance” as a methodological orientation device (also see section on phenomenology below) in order to follow the “what” that “fleets” within everyday moments of disruption. Turning around, taking a backwards ‘glance’ or averting our analytic ‘gaze’ away from dominant approaches and toward disruptive autistic and mothering bodies, helps to critically and interpretively pursue what else might be ‘behind’ - perceptually and historically - the identity ‘autism mother’ as she appears in everyday text and talk. This methodological orientation challenges the dominant metaphor of vision in science and everyday vernacular that equates the physicality of sightedness with universal, certain philosophical and scientific knowledge; and instead, pursues the “partial sight” (Haraway, 1991, p. 196) of the ‘disruptive’ (averted) gaze and alterity of bodies marked autistic, alongside the ‘bad’ mothers who turn toward such aversions as something of value in knowing and being in the world. The ‘evidence’ I gather for my project thus moves outside scientific rationality as well as the empirical – observable, measurable evidence gathered through the senses (particularly vision, which predominates within scientific knowledge production) - to other realms that “evidence-based” science excludes (a science I am critiquing), such as “moral, critical, spiritual, artistic and philosophical” realms (Portelli & Konecny, 2013, p. 93; also see Van Manen, 1990) as well as maternal experience and relationships as rich sites of critical and interpretative knowledge (Scott, 1991).
My methodological orientation is both a disability studies and a feminist one. Maternal and disabled standpoints that are occluded and associated with disorder and pathology within dominant scientific approaches – autistic ‘mindblindess’, or the so-called inability to empathize and thus know others, and the ‘averted’ autistic gaze, for example - become valued sites and ways of producing new and possibly transformative knowledge. This brings together questions from disability studies and feminist studies of science (and, more broadly, science and technology studies) as an emerging conversation of which this thesis is a part (see, for example, Bumiller, 2008, 2009; Landsman, 2009; Rapp, 2011). I discuss how my project is a disability studies one, and how it intersects with feminist work on disability in more detail later in the chapter. Here, I address how my methodology and epistemological commitments constitute my project as a feminist one also.

While there are diverse feminisms, broadly speaking, feminism is the academic and political project that seeks to understand and transform women’s oppression systemically, culturally and psychologically. This includes challenging dominant modes of knowledge production as a key site of oppression, devaluation and exclusion for women. Feminist methodologies share many of the epistemological commitments, methods and aims of interpretive and critical approaches, as well as disability studies and feminist philosophies and social studies of science; namely, the commitment to knowledge production as

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18 North American feminism has typically been described in terms of ‘waves’ associated with feminist political movements, from the (predominately white, middle-class) first wave of ‘maternal’ feminism (women advocated for rights from within their traditional domestic roles as mothers) in the late 1800s and early 1900s, to the emergence of the second wave and (predominately white) liberal (equal opportunity), radical (male/ female differences and sexual politics) and socialist (transforming women’s structural oppression within capitalist systems) feminisms during the 1970s, to the challenge of difference during the 1980s (Black, lesbian, working class feminisms, etc.), the poststructuralist academic challenge of the 1990s, and transnational feminisms of the 2000s. In important ways, this narrative does not capture the long histories of Black, working class and other feminist projects in North America and elsewhere. For further reading on feminism as a political and academic project, see, for example, Adamson, Briskin & McPhail (1988), Collins (1990), hooks (1984), Minh-ha (1989), Mohanty (2003), Nielsen (1990) and Smith (1987).
emancipatory, attention to subjective experience and understanding knowledge as interpretive, contingent and located, and thus knowledge production as political rather than universal and objective (Haraway, 1991; Nielsen, 1990; Smith, 1987). What makes my project specifically feminist is its methodological attention to the “distinctive experience of women” (Nielsen, 1990, p. 19) and mothers within paternalistic scientific regimes as a beginning point for knowledge production, the aim of which is transformative (also see Smith, 1987). This deceptively straightforward shift is layered and complex. Such a shift is, first, about subject matter. My thesis, in part, ‘retells’ histories of autism and mothering from the standpoints of mothers, prioritizing research questions that emerge from, and are relevant to mothers’ lives (see below), including my own. This focus on mothers’ distinctive experience opens a new area of study - pedagogic care – that challenges the exclusion of maternal knowledges about disability within dominant research, and the marginalization of such knowledges within more radical academic literature (see section on disability studies below). A feminist methodology understands women as creative agents of knowledge and makers of history rather than objects of and for scientific study. Attention to the contradictions and dissonances within mothers’ lives thus not only opens new subject matter, but a deeper feminist challenge to the male grounds of scientific knowledge as certain, predictable, universal and objective (Cook & Fonow, 1990; Nielsen, 1990; Westkott, 1990). The above implies an additional element that makes my approach distinctively feminist, that is, I am committed to knowledge production as a political endeavor that seeks new knowledge for the purpose of opening transformative possibilities.

A final element that demarcates my approach as feminist is my understanding of my project – particularly the focus groups I conducted with mothers - as a form of
consciousness-raising, or pedagogical intervention, that revalues the critical exploration of maternal experience as a site of knowledge about dominant, exclusionary and sometimes violent caring regimes. Catherine MacKinnon describes consciousness-raising as a distinctly feminist method, mode of analysis and theory of social change: “the collective critical reconstitution of the meaning of women’s social experience, as women live through it” (1982, p. 543). Its purpose is political. Women’s experiences are centered, and knowledge making becomes a communal, dialogical, critical, emergent process in which subject and object commingle (Nielsen, 1990; Westkott, 1990). When I first began my project, I did not plan to include focus groups, but to perform a genealogy and phenomenology of everyday texts within popular science and representation (I provide a description of these methods later in this chapter) about autism mother identity from its emergence in 1943. I felt that this kind of ‘data’ would be more than sufficient to understand how ‘autism mother’ subjectivity emerged, as well as how this identity becomes meaningful within everyday life. I understood everyday text as a site of identity formation, meaning making, social action and governmental power in mothers’ lives in which I might find a multitude of treasures for sociological analysis and philosophical consideration (Smith, 1999; Titchkosky, 2007). I had been collecting and thinking about everyday texts from newspapers, magazines, television shows and documentaries since 2010. When I began sharing my initial analyses at disability studies and mothering conferences, however, I was asked thoughtful questions that could not be addressed through an emphasis on everyday texts alone. Most depictions of autism mothers rehearsed familiar tropes of tragedy, biological disorder and the sense of mothers as solution. Somehow, the interpretive and critical approaches I was bringing together, though an attempt to speak to the
complexities of my topic and offer an alternative to dominant approaches, had produced rather uniform accounts that could not capture the contradictions of living this identity or mothers’ agency, differences and forms of resistance – elements that I was experiencing in my own life as well (O’Malley, Weir & Shearing, 1997). I was writing myself and other mothers out of the very analysis I hoped might help change such omissions.

Before going any further in gathering and analyzing texts, I needed to talk with mothers about their understandings of everyday depictions of autism and mothering to try and get at the complexities that my analysis of everyday text alone seemed to be eliding. In these focus group discussions, which I describe in detail in chapter six, I began to get a broader sense of the complexity with which mothers negotiate, comply with and resist dominant depictions, as well as a more animated sense of both the contingency and deep lived meanings of autism mother identity. These conversations integrally re-shaped how I gathered texts for my archive as well as my analytic emphasis throughout this dissertation. I spoke with mothers who had experienced extreme forms of regulation under the multiple scientific regimes that have governed autism and mothering since the emergence of autism as a biomedical disorder, from psychoanalysis in the 1940s-60s, to neuropsychology in the 1970s-90s, to biogenetics in the 2000s. Our conversations taught me more about the paradoxes of negotiating autism mother identity, the lived intimacies and technical aspects of everyday text and powerful scientific knowledges, and mothers’ creative resistance within intense regimes of governance. Together, we critically and interpretively produced new communal understandings of our experiences, what I have called pedagogic care, engaging in a form of consciousness-raising in this way. Within such an approach, women’s consciousness – how we make sense of our lives within capitalist patriarchy, the
meanings we attribute to our behaviour (consciousness and behaviour do not necessarily align within regimes of governance), and how we both comply with and resist scientific governance - is taken seriously and valued as a creative, critical and interpretive site of knowledge production that can open space for new, more humane possibilities for being together (Westkott, 1990). The chronological organization of my thesis does not reflect this dialogical process with mothers.\footnote{My decision to place my focus group chapter as the final one does not reflect the dialogical process with mothers that formed the way I worked and that weaves through all my chapters. Without these groups, my emphasis on the complexities of complicity, maternal resistance and consciousness, and imaginative possibilities for alternative ways of living together grounded in ‘bad’ mothering (i.e., finding value in autistic difference) would have been far less prominent. My decision to include this chapter as the final one after a sustained and close analysis of extreme, and in some ways tragic regimes of governance (in the sense of their violence in mothers’ and autistic persons’ lives) included a number of considerations: this chapter ‘fit’ last chronologically; it can be read side by side with the critical work of chapter five as an extended interpretive analysis during our time; and, it addresses the more hopeful question of reconciliation - “What now?” - after a sustained critical engagement (with interpretive ‘glances’ along the way) revealing the radical contingency of autism mother identity. Although often meant negatively, the placement of my focus groups as the last chapter perhaps functions narratively in a positively conceived cathartic sense, one that goes beyond the release of fear and pity (I do not intend to cultivate these emotions in my reader, although this thesis perhaps touches the shared experience of being subject to governance as well as our fundamental existential alterity and vulnerability) to mean the release of a politicized and creative anger that might help to reshape the world (on alterity see Levinas, 1969, pp. 33-52, 72-81; on the uncertainty of communication see McGuire & Michalko, 2011; on politicized anger, see Boler, 1999, p. 114; Pateman, 1989; on catharsis, see, Kaufmann, 1979, pp. 43-51).} After my focus groups, I began to include more diverse texts (such as memoirs and blogs) in the archive I was gathering, and to give analytic attention in all of my chapters not only to the critical analysis of dominant depictions of autism mother identity, but to interpretively understanding mothers’ creative resistance and re-imaginings of ‘care’, ‘difference’ and ‘identity’. In this way, my focus groups helped me write the complexity of mothers’ complicity, agency and resistance back into my critical analyses of autism and mothering that had been too uniform, and to find a way to pay interpretive attention to maternal experience, understanding and resistance throughout my dissertation, elements that compose a strong thread in my thesis.
As a final consideration, I needed a way to organize my work so that I could tie the various aspects of my conceptual framework together and address my aim of reconciliation. I wanted to open space for imaginative alternatives to exclusion and violence by cultivating an understanding of mothering and care grounded in the disruption of autistic and mothering bodies. I also needed my organizational scheme to work specifically for an analysis of everyday text and talk by and about autism mothers, my chosen social location for this project. To meet these requirements, I use my theoretical framework, which incorporates interpretive and critical approaches within disability studies, as an organizing rubric. With varying emphasis, each chapter critically and interpretively addresses everyday ‘autism mother’ text and talk for shifting regimes of scientific governance (psychoanalysis, neuropsychology, biogenetics) along five intersecting axes (on axes of governance, see Dean, 1999; also see the governmentality section in this chapter). These axes were salient, in a lived and meaningful sense, for the mothers in my focus groups as they thought through their understandings of dominant depictions of autism mother identity: forms of knowledge (i.e., psychoanalysis vs. biogenetics), forms of visibility (i.e., encountering case studies or warning signs of autism in everyday text), affective technology (blame made intimate in everyday texts), forms of identity (i.e., the ‘warrior’ mother) and forms of resistance. The exception to this organization is chapters five and six, which can be read together as an extended, in-depth analysis along the five axes for our current time period when biogenetics rose. Entering these axes critically and interpretively for shifting regimes of governance allows me to engage my methodological “backwards glance” both historically and perceptually, revealing not only the radical contingency of autism mother identity but also mothers’ creative resistance and imaginative alternatives.
within paternalistic scientific regimes. This addresses my hope for reconciliation by opening space for new possibilities for understanding the meaning of care outside of dominant science and grounded in maternal and autistic experience. Before proceeding to a detailed discussion of the critical and interpretive theories and methods I employ, I first briefly describe below the meaning of the ‘archive’ of text and talk I gathered for my project.

**Composing an ‘Autism Mother’ Archive**

My archive is composed of a wide variety of everyday text and talk by and about autism mothers gathered for this project over the past four years: daily and weekly newspapers, general interest, women’s and popular science magazines, motion pictures and documentaries, popular books by autism ‘experts’, memoirs by autism mothers (and two fathers), television talk shows, online news sources, e-zines and autism mother blogs, for example. I chose to limit my archive to texts available to a Toronto audience as a way to historically trace shifting interpretations of autism mother subjectivity locally in the midst of a “discursive explosion” – a bringing into discourse - of everyday text and talk about autism, particularly over the past few decades (Foucault, 1976/1980a, pp. 17-8; also see Hacking, 2010). My archive begins in 1943, with the emergence of autism as a new medical disorder in North America, and spans to 2015 and the final draft of this thesis. Rather than a catalogue or quantification of everyday text and talk, my archive represents a tracing of discontinuous interpretive shifts around the meaning of autism and mothering 1943-2015 as they appear in everyday text and talk. This is similar to Foucault’s meaning of the archive as “the general system of the formation and transformation of statements”
(1972, p. 127). In other words, my archive represents the conditions of possibility of shifting truths about autism and autism mothers and their manifold implications in terms of how we have come to practically embody care, particularly mothers’ care, about autistic difference, 1943-2015. I trace shifts beginning with psychoanalytic frames of understanding autism and autism mothers during the years 1943-1969, and move through neurocognitive approaches during 1970-99 to biogenetic views of autism and mothering during the years 2000-2015. I approach the shifts traced by my archive as both interpretive utterances “representative of the cultural grounds of possibility from which they emanate” (Titchkosky, 2011, p. 97), and, as representative of historical struggles of Western modes of power, domination, subordination and resistance (Foucault, 1984, pp. 83-6) that continue to hold us, as late modern subjects, in their midst. I provide technical details about how I gathered everyday text and talk within each individual chapter, since each time period presented its own distinctive challenges and rewards.

As a unique methodological direction, I include focus groups that I conducted with Toronto mothers in the fall of 2013 about everyday text and talk for this project as part of my archive. While conducting focus groups about everyday text and talk has some obvious differences from gathering historical texts from mass media and popular culture, being a participant in research studies (along with attending research seminars) about autism has arguably become an ordinary part of everyday autism mother talk within networks in Toronto, suggesting the relevance and importance of my inclusion of focus groups here. Foucault (1972) identifies the difficulty, perhaps even the impossibility, of identifying the ground of our own archive, one which we inhabit, including the ways we still “speak” from within its rules (Foucault, 1972, p. 130). The inclusion of focus groups about everyday
texts suggests that I proceed from a belief that the critical interrogation of the grounds of our own living archive, and its documentation, are vital activities if we are to imagine different possibilities for being together. While these activities may, indeed, contain yet unknown ways “the present is still unrecognizable to us” (Puar, 2007, p. xix), my choice to include focus groups about everyday texts also provides an “alternative historical record, archive and documentation of our contemporary moments” (p. xv), one that has been very productive as my discussion of my conceptual framework above has shown. I do not engage focus groups as sources of empirical data about autism or mothering as objects of study (to learn about coping or resilience, for example), then, nor did I set out to acquire expertise about the normalization of autistic difference or families (i.e., how to ‘cope better’), an approach more representative of dominant scientific and social scientific research on autism and mothers (Ryan & Runswick-Cole, 2008; St. Pierre, 2014; Titchkosky & Michalko, 2009, 5-6). Rather, I asked mothers in my groups to reflect on ‘autism mother’ identity as it appears in everyday text and talk. I did so by providing a visual display of everyday text and talk from my archive for each group, and by posing two general questions: What are the popular understandings of autism, mothering and care? What is your understanding? This novel approach to composing an archive has been a fruitful means to explore the cultural ground of ‘autism mother’ identity and how it is taken up, lived, negotiated and resisted within the constraints of Western scientific modes of power and within mothers’ lives. It has also yielded new and creative possibilities for understanding practices of care as pedagogic - as grounded in novel interpretive moments within mother’s lives with their autistic child that might begin to speak back to dominant
discourses of the human, care, difference and identity and open new possibilities of being together beyond responding to dominant discourses.

I turn now to a discussion of the interpretive and critical approaches that I draw inspiration from to compose an approach to everyday text and talk that can engage questions of power as well as meaning and lived identity. Like the work of the chapters to come, theory and method interweave as I make my way through this discussion, gesturing to the inextricability of practice and thought in terms of the way I proceed throughout my dissertation. This is an approach that acknowledges the partiality of knowledge production, and as such, is politically and ethically invested in including previously excluded and disruptive standpoints. I begin below with a brief introduction to interpretive sociology.

**A Brief Introduction to Interpretive Sociology**

Although born of the same socio-political upheaval and scientific turn to certainty as Enlightenment philosophies of the subject (Natanson, 1970; Smith, 1987), interpretive approaches, particularly recent ones concerned with questions of power, are a radical edge in sociology that challenge the Western philosophical underpinnings of the discipline’s positivist beginnings (see, for example, Adler & Adler, 1987; Callero, 2003; Cerulo, 1997; Hochschild, 1983; Hughes & Paterson, 1997, 1999; Smith, 1987, 1999; Titchkosky, 2003, 2007). These approaches, which draw from phenomenology, ethnomethodology, symbolic interactionism and more, turn on the vitality of interpretive acts of consciousness, the openness of language and processes of meaning-making to understand identity, embodiment and world as tied to everyday social practices (see, for example, Blumer, 1969; Garfinkel, 1967; Goodley & Tregaskis, 2006; Mead, 1934; Natanson, 1970; Schutz, 1967; Titchkosky & Michalko, 2012; Weber, 1947). Interpretive approaches are potentially
transformative in terms of how they might attend to the practical ways more enduring forms of power come into being over and over again in the here and now of the everyday, and thus how we might attend to disruption anew. Disability theorists working in an interpretive vein, for example, have shown how ‘clear’ norms of communication are socially accomplished (thereby producing autism as a communication deficit), the result of everyday talk and member’s methods of establishing meanings that rely on insider, scientific and non-autistic knowledge (Garfinkel, 1967; Gill & Maynard, 1995; Maynard, 2005; McGuire & Michalko, 2011). Interpretive approaches engage Berger’s invitation to the “fascination” of sociology, “It is not the excitement of coming upon the totally unfamiliar, but rather the excitement of finding the familiar becoming transformed in its meaning” (Berger, 1963, p. 21). In our case, autism mother subjectivity is not somehow a natural corollary of having a disordered autistic child but is an identity that comes into being materially and actually in the crucible of social practices and ready-made meanings that are lived out in the everyday, ones that could be made otherwise. Below, I re-read two of Erving Goffman’s much read and provocative works on identity and difference as an entry point into new questions from interpretive sociology about the ordinariness of disruption within everyday life. Goffman ‘sets the stage’, so to speak, for my discussion of how the disruption of disability might be figured anew.

Reading Goffman Against Himself: Rethinking the Disruption of the Ordinary

In Presentation of the Self in Everyday Life (1959), Goffman articulates a dramaturgical approach focused on impression management of identity within highly defined situations like institutions (for further reading on the dramaturgical approach see, for example, Brisset & Edgely, 1990). His notion of the self is one of a socially negotiated
performance within stable yet tenuous social situations always replete with the potential for
disruption (and therefore, according to Goffman, for embarrassment and shame). The
performance of selves is not only verbal but includes non-verbal gestures, bodily
movements, facial expressions and emotions all to “impress” others and manage potential
disruptions to one’s desired effect (i.e., to achieve or perform identity). Thinking autism
and mother together, I am interested in disruption in the course of ordinary life for reasons
other than Goffman’s. While disruption, including embarrassment and shame, may indeed
be a part of ordinary life, normative, non-autistic modes of the “management” of disruption
are social processes need not be, despite Goffman’s statements otherwise, “It can be
assumed that a necessary condition for social life is the sharing of a single set of normative
expectations…” (1963, p. 127). Indeed, disruption “can be reconfigured into a place where
the ordinary of ordinary life can be thought about in a new way” (Titchkosky, 2003, p. 19).
Goffman reconceives the subject in aesthetic terms but stops short of reconfiguring
disruption as a space of questions about living together with difference differently.\textsuperscript{20}

Paying attention to the ways we are, and are not, paying attention to disruption as a
way to rethink the ordinary is perhaps one way to read Goffman’s much engaged \textit{Stigma:}
\textit{Notes on the management of spoiled identity} (1969) in a critical yet generative way for my
project. Goffman’s account of the process of stigmatization is, of course, filled with the
problematic language of “the normals” and their “not quite human” counterparts (Goffman,
1969, p. 5).\textsuperscript{21} Goffman, however, emphasizes stigma as a social \textit{process} of identity

\textsuperscript{20} The apparent link between Judith Butler’s notion of gender performativity (1997a) and Goffman’s
dramaturgical approach is notable, though Butler aligns her subject with Nietzsche and views performativity
as the effect of discourse and power, one that has absented the meaning-making subject. Indeed, agency, for
Butler, is located within a small margin of error within an otherwise iterative process of identity and
difference, as well as in the political act of theorizing (Butler, 1997a; Atkins, 2005, pp. 257-265).
\textsuperscript{21} Goffman includes “abominations of the body,” “blemishes of individual character,” and “the tribal stigma
of race, nation and religion” as types of stigma (1969, p. 4).
construction that occurs in interactional contexts that involve an “undesired” attribute and stereotypes (norms and ideals) he himself identifies as fictions rather than somehow natural attributes of individual bodies (p. 128). Goffman’s concept of stigma has been highly influential within the sociology of health and illness, medical sociology and the study of deviance. However, when sociologists take up Goffman’s work to study disability, attributes often have a way of slipping back into individual bodies, leaving the normative order or context unnoticed. Goffman himself placed limits on how his work on stigma might contribute to the study of deviance. He argued that the management of deviance (as for impression management and disruption above) in social interaction is an ordinary part of social life. Efforts should be focused on studying processes of the ordinary (1963, pp. 126-47). Sociologists concerned with disability, however, do not typically study the ordinary processes of social interaction that accomplish the meaning of autism, for example, as a ‘fact’ and a sense-making device (for important counter-examples, see Gill & Maynard, 1995; Maynard, 2005; McGuire & Michalko, 2011; Michalko, 2002; Titchkosky, 2003; Titchkosky & Michalko, 2012). David Gray’s work in medical sociology, for example, departs from the unremarked “view from nowhere” (Haraway, 1991, p. 188) of Asperger’s Syndrome as a set of problematic and undesired attributes caused by an (medically) objective problem-body. By not asking about the ordinary social processes that compose these ‘facts’ of Asperger’s as sensible and say-able in the first place, Gray is freed to describe coping within families, “felt” and “enacted” stigma and gender differences in coping styles (albeit, these are also important topics, yet ones that are overrepresented in research on disability). Such work then proceeds onto the measurement and management of parental levels of stress, lay conceptions of autism or correlations between severity of
autism and stigma (see Gray, 1993, 2002, 2003). At no point is the composition of the ordinary facts of autism, or the ordinariness of “restorative measures” (Goffman, 1963, p. 128) such as biomedical treatment or coping queried. Rather than attending to the “undesired differentness” (Goffman, 1963, p. 5) of stigma as a disruption that might speak back to and possibly transform normative and exclusionary modes of sociality, disruption settles back into individual autistic bodies as a mother’s problem and worry (Titchkosky & Michalko, 2012).

**Paying Attention to Disruption Anew: Phenomenological Sociology**

Phenomenological sociology helps me reconfigure disruption as a space of questions about the everyday accomplishment of an ordinary that excludes alter ways of being and knowing. Edmund Husserl’s (1859-1938) writings have been highly influential in the development of phenomenological sociology. Writing against a climate of radical skepticism, historicism, empiricism and relativism in the wake of Nietzsche and others, Husserl turned to Descartes’ *Meditations* and subjectivity to re-establish self-reflective consciousness as the ground for truth. As such, his is a transcendental phenomenology. One of Husserl’s major concerns was to establish phenomenology as a science of the lifeworld. His “epoche,” or method of reduction, was central to this task as it offers, in Husserl’s view, direct access to the realm of conscious experience as one of “pure meanings” independent of the existence of “things in themselves” (Solomon, 1988, pp. 129-134; Husserl, 1954/1970). The writings of W.E.B. Du Bois (1868-1963) and Franz Fanon (1925-1961) also make crucial and under-recognized contributions to phenomenology that bring alive the everyday ways – through a white girl’s glance toward Du Bois, or the composition of a black bodies through white space for Fanon, for example - in which whiteness and
racial exclusion inhere in the ground of a post-colonial everyday of which European phenomenology is a part (Du Bois, 1903/1994; Fanon, 1952/2008). Du Bois articulates this experience as a “double-consciousness, this sense of always looking at oneself through the eyes of others” (1903/1994, p. 2; also see Henry, 2006 on Africana phenomenology). Fanon vividly describes the myriad psychological, bodily and social ways that white colonial ways of being have bodily inhabited blackness. He describes a project “aiming at nothing less than to liberate the black man from himself” (1952/2008, p. xii). These provocations help me articulate the whiteness of the ground of autism, and autism mother identities along the way.

In this section, I pay particular attention to the work of Alfred Schutz (1899-1959) within phenomenological sociology to fashion my approach. I also address Dorothy Smith’s work on women’s standpoint as a way to begin inquiry in order to attend to practices of knowing within sociology as ones that are also situated and gendered ones (Smith, 1999, p. 62). I engage an interpretive reading of both Schutz and Smith. Schutz draws on Husserl’s phenomenology to take up the problem of subjective and objective meaning (the culture/science debate) in the social sciences (Schutz, 1967; Etzrodt, 2008). One of Schutz’s major undertakings was the substantive clarification of Max Weber’s definition of the subject matter of sociology as the “interpretive understanding of social action” (Weber, 1947, p. 88; Schutz, 1967). Rather than a complete phenomenological reduction to pure meaning, “essences” and the realm of the transcendental ego, Schutz (1967; 1970) relocates Descartes’ cogito in the realm of the social, and begins by accepting the existence of mundane social reality and other selves (also see Butler, 1998; Natanson, 1970). In this way he makes the question of structures of meaning and the everyday realm
of sociality, or intersubjectivity, a central problematic for sociology. In my reading of it, within this approach to phenomenological sociology interpretation is key (Schutz, 1970).

Husserl tells us that our world of everyday life comes to us as an “always already developed and further developing meaning-configuration” (Husserl, 1954/1970, p. 104; also see Schutz, 1967, 1970). Inherited from our predecessors, ours is a meaningful world, the existence of which is “intuitively given” as an “inarticulate” background or horizon for all of our understandings, perceptions, actions and experience (Husserl, 1954/1970, p. 104, p. 133, p. 142; Schutz, 1970, p. 73). Husserl calls this taken for granted realm of existence and meaning the “lifeworld” (Husserl, 1954/1970, p. 133, 142). We belong to this world together (Husserl, 1954/1970, p. 104; Natanson, 1970, p. 48), yet the interpretive acts and social processes which configure meaning in which we are an ongoing part are “concealed” from us (Husserl, p. 1954/1970, p. 104) within already accomplished and taken for granted “interpretive schemes” that nevertheless direct our attention, understanding and action in some ways and not others (Schutz, 1970, p. 74). In the “natural attitude” of the lifeworld, we proceed as if the world is “simply given” (Schutz, 1970, p. 111). The disruption and discord we saw so tidily, faithfully and readily remedied in Goffman and Gray “hangs together” in the lifeworld without much ado (Husserl as cited in Schutz, 1967, p. 82), as the recognition of disruption presumes and is configured through the same horizon of meanings, the same interpretive schemes (Husserl, 1954/1970, p. 110; Schutz, 1967, pp. 82-3; Natanson, 1970, p. 63). How might we direct our attention and wonder about disruption and the everyday differently, as matters in need (rather than not) “of further analysis” (Schutz, 1967, p. 74)?

22 Though I make my own study of it here, I am indebted to the work of Titchkosky & Michalko in phenomenological disability studies (2012) for my approach to this section.
The lifeworld is both the “scene and also the object of our actions and interactions,” Schutz tells us (1970, p. 73). We “gear into” this world of everyday life in a bodily sense, both shaped by and shaping our surroundings (p. 73). In a sense, this means that we also “gear in” socially, and, as we saw above, work together to ‘smooth out’ the disruption of our socially accomplished ‘real’ when gears don’t ‘mesh’. Schutz elucidates this mystifying process in helpful ways. Within the lifeworld each of us occupies a particular standpoint, a particular here and now from which we ‘view’ the ‘there’ of others. Our past experiences compile a “stock of knowledge” that is socially derived, and each here and now engages this stock in what Schutz calls a “system of relevances.” This system establishes the “borderlines” of relevance vis-à-vis our standpoint and acts as interpretive schemes of recognition for the known and unknown. Relevances change along with us as we move in and through the world (Schutz, 1970, pp. 73-4). Smith (1987) and Haraway (1991) also led us to this possibility of multiple realities and perspectives through situated knowledges. Indeed, beginning in the difference of social identity gives us a standpoint in the world (Titchkosky & Michalko 2012, p. 130). At the same time, and remarkably, we proceed together as if the meaning of the social world and the existence of other selves are experienced in common, despite individuality, disruption and difference (Natanson, 1970, p. 58; Titchkosky & Michalko, 2012). This is the problematic of sociality, and Schutz again helps me here.

Schutz argues that within the world of everyday life, we take for granted that standpoints are interchangeable (i.e., you would experience my ‘there’ if you were ‘here’). In this way, systems of relevance are themselves assumed congruent. Schutz calls this the “general thesis of reciprocal perspectives” (1962, p. 12). Most crucially, “What is supposed
to be known in common by everyone who shares our system of relevances is the way of life considered to be the natural, the good, the right one by the members of the ‘in-group’” (Schutz, 1962, p. 13; also see Titchkosky & Michalko, 2012, p. 132). This is one way to think about how power inheres unnoticed in the very ground of the everyday (i.e., congruence and reciprocity) out of which we conduct the ordinariness of sociality. Another way to think about this, Schutz’s thesis suggests, is through language as a typifying medium: “idealizations” about belonging in the world together – interpretive schemes that define who and what is ‘in’ (non-autistic, white bodies, for example) - supersede individual standpoints and therefore difference (Schutz, 1962, p. 13).

Dorothy Smith (1999) addresses the problematic of exclusion and difference within Schutz’s sociology, whose subject, writes Smith, must “neglect her particular local existence” (p. 49) to take part in objectifying practices that “forget” the gendered material relations and practices of textuality that organize social domains such as sociology (p. 54). Instead, Smith begins from women’s lived “actualities” – the felt, embodied and particular of a local here and now in social relations with others – as previously excluded “standpoints” in and beyond sociology. Beginning in women’s standpoint dislodges any transcendent, essentialized or privileged knower, or assumption of reciprocal perspectives within phenomenological sociology. Rather, women’s standpoint “…does something rather different. It shifts the ground of knowing, the place where inquiry begins” (Smith, 1992, p. 91). For my project, this shifts the ground of knowing from dominant sociology and science, and the disembodied Cartesian “view from nowhere” of autism as disordered body-object and mother-as-remedy, and places it practically and actually within the realm of mothers’ lived experiences of the disruption and difference of their autistic child. In this
view, experience is not ‘knowledge’ (Scott, 1991), but a place – a standpoint - from which we might seek knowledge and understanding. Smith’s interpretive and phenomenological leanings in sociology also incorporate a way to understand how the everyday is linked to systems of power. In Smith’s language, everyday, located actualities are linked through text to abstract, “extralocal” and “organized practices” that constitute “relations of rule” and organize consciousness both within and beyond sites of knowledge production like sociology (Smith, 1999). For Smith, the social is an accomplishment of “the ongoing concerting and coordinating of individuals’ activities” (Smith, 1999, p. 6) In other words, Smith’s introduction of actual, embodied, and situated practices of previously excluded knowers into knowledge production and the thesis of “reciprocal perspectives” is a ‘way in’ to understanding, bringing into ‘view’ and possibly disrupting, both the everyday composition of the ordinary (including how we produce knowledge) and enduring systems of power - what Dorothy Smith calls abstract relations of ruling - that extend beyond local contexts.

Paying attention anew to the disruption of autism in everyday text and talk, then, is paying attention to the ordinary accomplishment of the ‘real’ in courses of social action, to how we ‘know’ the existence of other selves, and to how dominant systems of relevance – a socially derived stock of knowledge that excludes some standpoints – come to inhere within and beyond knowledge production. What does the thesis of “reciprocal perspectives” make of autism and mothers within dominant science and social science? Not only is autism considered the bad, the wrong and the unnatural, it is considered incongruent, non-reciprocal and even a non-standpoint. As McRuer puts it for the matter of disability, “we were never identified” (2006, p. 151). Autistic life cannot, indeed does not,
“gear into” the world in any sense of the term. Autism introduces the uncertain and disruptive within a shared cultural horizon that values certainty and sameness. As such, mothers must “gear in” as bearers of sameness whose very subjectivity consumes and contains the difference of autism as a matter of individual disordered bodies, thus reducing uncertainty and difference to sameness and leaving the ground of the everyday both undetected and undisturbed (Titchkosky & Michalko, 2012). It will be the work of my analyses of everyday text and talk in the chapters to come to reveal the ground of the everyday and reorient to the disruption of autism as a space of questions about how we might live together with difference differently. I do so, in part, by adopting a phenomenological method.

A Phenomenological Method

I offer a very selective reading of the phenomenological method. Rather than proceed from the “natural attitude,” phenomenology “brackets” taken for granted assumptions about the world of everyday life and instead takes the hopeful and wonder-filled stance of a “perpetual beginner” (Merleau-Ponty, 1962, p. xv; also see Husserl, 1954/1970, p. 133, 142; Titchkosky & Michalko, 2012; Van Manen, 1990). A phenomenology of the social world seeks to reveal the ground of the everyday as it appears in acts of interpretive consciousness (Merleau-Ponty, 1962, p. vii). This is a commitment to a rigorous kind of description rather than explanation. Through phenomenological description, the philosopher attempts to get close to the “essence” (Butler, 1998, p. xi) of

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23 Rather than employ Husserl’s transcendental notion of bracketing as unmediated access to ‘pre-reflective’ consciousness (a stance that seems to maintain the scientific separation of subject and object, and contradict Husserl’s thesis of intentionality “to be conscious of something” (Husserl. 1913/1982, p. 200) that intimately ties consciousness to the world of which we are a part), I employ the method interpretively, learning from Merleau-Ponty (1962), and use bracketing as a kind of open curiosity about the ordinary of everyday life, “a kind of astonishment before the world that disrupts habitual patterns of thinking” (LeVasseur, 2003, p. 417)
phomena – the tie that binds mother and child - even as she acknowledges an excess of meaning that shimmers in an always-open horizon of phenomenal experience (Gerwitsch, 1966, pp. 89-96; Schutz, 1970, p. 96; Butler, 1998, p. xi). Description then, is less a matter of “mental-image making,” though it may include this, than it is a creative act of interpretive consciousness intimately tied to a world of which it is a part (Merleau-Ponty, 1962, p. xv; Butler, 1998, p. x). It is this spirit of description I bring to bear as I ‘read’ everyday text and talk from popular culture and the mass media 1943-2015, and attempt to weave a new story about autism and mothering. I also bring this spirit of rigorous description to bear on my analysis of focus group conversations with mothers, which I describe in detail in chapter six. I use phenomenological description and identify key thematic structures of meaning (Van Manen, 1990) that emerged in our conversations together, as well as the deeper existential theme of pedagogic care.

A phenomenological method also involves “bracketing” taken for granted assumptions and meanings in the natural attitude that surround autism mother appearances. This is difficult work. Autism and mothering, and how they appear in everyday text and talk, are lived and experienced in a deeply affective register. Yet biomedical understandings saturate the sense of the life-world. In today’s context, it appears beyond question (and almost cruel to suggest otherwise) that because of her loss (the loss of her child’s normal and healthy development), a mother is grieving. Similarly, stories about mothers fighting against autism make sense to us – mothers must do so, and do so out of love, in order to give their child future happiness and success. Here, in the pragmatic use of because-of and in-order-to motives (Schutz, 1967, pp. 86-96), the totalizing frame of the biomedical - animated by the unquestioned prestige of scientific sensibilities in the natural
attitude – remains concealed. Bracketing the natural attitude reveals how our understanding of autism and a mother’s grief are possible at all, and exposes the apparatus of the “sayable” and “sensible” world (Titchkosky, 2011, pp. 73-6) within objectivizing biomedical terms that regimes of knowledge and power govern. Revealing the processes and ground of interpretation that govern how meanings are produced will be the ‘pay-off’ of this method.

To do the work of bracketing, I use the idea of the “backward glance” or “the behind” as a methodological orientation device. Ahmed writes:

To see what the “natural attitude” has in its sight we need to face an object’s background, redefined as not only the conditions for the emergence of the object (we might ask: how did it arrive?) but also the act of perceiving the object, which depends on the arrival of the body that perceives. (2006, p. 549)

Thinking with Ahmed, my own mother body figures as I turn and take a “backward glance” (2006, p. 570) to get at this mother’s background. Looking backward disrupts typical standpoints or responses to disruption in the everyday. The “backward glance” I use is not the temporal backward glance of everyday because-of motives, nor the future-oriented glance of in-order-to motives (Schutz, 1967, pp. 86-96). It is instead a ‘peek’ behind the increasingly familiar everyday text and talk about autism and mothering. It is a ‘glance’ that follows Ahmed’s “queer connection” between Husserl’s thesis of intentionality (i.e., only the object remains the same in acts of perception, a “changing same” that is at once there and intended), which I can not do justice to here, and the question of “the behind” or an object’s background – that which we must “conjure” (perceptually and in its historicity)
in order for an object to appear (Ahmed, 2006, pp. 548-9). The question of the ‘real’ meaning of autism will remain both unasked, and unanswered here. By uncoupling the ‘real link’ between autism as biomedical, and experiences of meaning, histories of interpretation and possibilities for new interpretations might emerge. Autism returns only at the end of my journey, one that has given me a new “slant” (Ahmed, 2006, p. 562) on autism, as it were: Western framings of autism may in part be an accumulating effect of a re-educated mother subject and contradictory feminine subjectivities that are also acts of interpretive consciousness tying the “good life” to the achievement of a self-same identity for us all.

Phenomenology is a hopeful way to turn. As a philosophy of the everyday it opens space both theoretically and methodologically to pay attention to how we pay attention to disruption and the configuration of the ordinary – to interpretive and potentially creative acts of consciousness that have everything to do with power, meaning and possibility. Schutz suggests that interpretative acts of consciousness turn on “…the referral of the unknown to the known as that which is apprehended in the glance of attention to the schemes of experience…” (1967, p. 84). In the space of the referral of a “glance of attention,” worlds and lives are made. This is a relation between self and world, between self and other that is so close it is both “constitutive” and “binding” (Butler, 1998, p. x; also see Natanson, pp. 2-6). Yet even within such binding terms, Schutz tells us, the glance of attention is not completely determined. There remains an element of uncertainty, of the novel. What’s more, “the schemes have their horizons and perspectives, their lights and shadows” (Schutz, 1967, p. 83). Megan Boler’s thinking on attention within her study of the social inscription of emotions within educational contexts is helpful here. Boler uses the concept of “inscribed habits of (in)attention” to capture how the selectivity of attention –

24 For further reading on the thesis of intentionality, see Husserl 1913/1982, pp. 199-201.
emotional and otherwise – is socially inscribed, politically enlisted and pedagogically (bodily) habituated in ways that are aimed toward a particular “good” (1999, pp. 180-1). Here, there is room for hope and creativity. We might pay attention to disruption anew rather than as a repetition of the same restrictive “good” (Husserl, 1954/1970; Schutz, 1967; Smith, 1987; Titchkosky & Michalko, 2012).

**Poststructuralist Approaches to Subjectivity and Power**

Interpretive and phenomenological approaches are helpful in my project to understand disruption in the lifeworld anew, and to release new possibilities of knowing our human life together beyond Western scientific and social scientific ones. These alter ways of knowing, as I have explored them, embrace previously excluded standpoints, and pursue an understanding of the intimate ways everyday life comes into being, and might be resisted, between us. I turn now to poststructuralist approaches to power to disrupt phenomenology and interpretive sociology a little more, and understand an additional element of the lifeworld not adequately addressed by these approaches alone – how modes of power and restrictive understandings of subjectivity that hold sway have come to be possible at all (Hacking, 2004, p. 278). Foucault describes his project to historicize the present this way, “to create a history of the different modes by which, in our culture, human beings are made subjects” (1982, p. 208). This means subjecting Western culture’s most evident truths to historical investigation and the philosophical stance of radical skepticism; in other words, it means employing an ethic of disruption. This is a critical approach in the sense that its aim to expose the contingency of self-evident ‘truths’ is an emancipatory aim. These truths include the autonomous, self-reflective meaning-making subject, for example,
as an “effect” and “target” of modern forms of power rather than a source of truth or knowledge (Foucault, 1982). Below, I describe governmental power and the genealogical method as aspects of Foucault’s project that are particularly salient for my purpose. Through genealogy and an attention to governmental power, I attempt to understand the links between everyday text and talk, subjectivities, embodied practices, and more enduring forms of knowledge and systems of power, adding a critical dimension to my phenomenology.

**Governmentality**

Governmentality is a strategic form of modern power involved in ordering the “conduct of conduct,” or structuring “the possible field of actions of others” (Foucault, 1982, p. 221). Significantly, governmental power also includes the work of self-governance, or “techniques of the self…the procedures…suggested or prescribed to individuals in order to determine their identity, maintain or transform it in terms of a certain number of ends, through relations of self-mastery or self-knowledge” (Foucault, 1994, p. 87), in addition to “putting in order” the conduct of others (Foucault, 1982, p. 221). Governmental power is “both an individualizing and a totalizing form of power” (Foucault, 1982, p. 221) in this way, not only constituting subjects as self-governing, but also as objects of dominant forms of knowledge (psychology, biology, genetics, psychiatry) at the level of populations (also see Foucault, 1991a, pp. 99-100). The technical language of developmental psychology and biomedicine enters mother’s lives, for example, through “warning signs of autism” features in parenting magazines or news reports (see, for example, “10 Early Warning Signs of Autism,” 2013). Features like these mark the autistic body, or standpoint, as deviant and disordered, part of a targeted population. Through
seductive images and alarming language, they suggest that ‘good’ mothers will align their self-conduct with psychological views of development and adopt a wariness and watchfulness for anything ‘out of the ordinary’. Any disruption to normal development is subject to interventions that invite mothers’ intimate participation in remedying this troublesome population. In this way, governmental power enters our lives in both intimate and technical ways, operating practically through our “freedom,” inviting our participation by extending its reach to bodies, hearts and minds: “…it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action” (Foucault, 1982, p. 220). Thus, governmentality is a productive rather than coercive form of power, constitutive of opportunities for acting and imagining ourselves within our everyday, making some ways of being possible, and others unimaginable, and at times, forbidden (Foucault, 1976/1980a, pp. 94-5; Foucault, 1982, p. 220-1; Rose, 1996; also see Douglas, 2010b).

Although governmental power enters our lives in intimate, embodied and practical ways, it is a distantiated form of rule linked to larger, even global systems of power (Dean, 1999; Rose, 1996). It operates technically and practically through specific targets like mothering and disabled bodies to naturalize prevailing forms of thought (i.e., liberalisms and the autonomous individual, ideas of progress, science, reason) and knowledge (i.e., genetics, psychoanalysis) through “innumerable” and divergent points in the larger social body (Foucault, 1976/1980a, p. 94; Dean, 1999; Rose, 1996). Everyday text and talk is one such point. Foucault’s analytics of governmentality can be entered along four axes:
The first of these dimensions concerns the forms of visibility necessary to the operation of particular regimes...[they] make it possible to ‘picture’ who and what is to be governed...A second dimension concerns the technical aspect of government...by what means, mechanisms procedures, instruments, tactics, techniques, technologies and vocabularies is authority constituted and rule accomplished?...The third dimension...concerns the forms of knowledge that arise from and inform the activity of governing...The final dimension is concerned with the forms of individual and collective identity through which governing operates and which specific practices and programmes of government try to form. (Dean, 1999, pp. 30-32)

Attending to these four dimensions of governmental power within my genealogies of everyday text and talk is helpful as I work to understand how autism mothers are governed, and govern themselves. I organize my genealogies along these four axes in order to trace autism, and autism mother subjectivities, and their discontinuities and complex linkages to predominant forms of thought, visibility, knowledge, practices and technologies. Governmental power offers an entry point into understanding and historicizing how the material and institutional constraints of our late modern world – transnational, patriarchal, ableist capitalism – are intimately and practically tied to subjectivity and the ordering of conduct. As my conceptual framework described, I also work along a fifth axis of analysis - forms of resistance. This adds an interpretive dimension and ‘edge’ to my genealogies that I use to open new possibilities about the meaning of mothering and care. Finally, it is important to note the significant contribution to our understanding of the governance of bodies marked disabled by Foucault and disability studies scholar Shelley Tremain (2005,
Tremain is particularly interested in understanding the myriad ways the governance of disabled bodies proceeds within the realm of prenatal testing and selective abortion, as well as stem cell research (see, for example, Tremain, 2010). My dissertation further extends this critical work in disability studies and governmentality by disrupting any notion that Western understandings of autism and autism mother are somehow ‘natural’. Through this approach, I also invite attention to the disqualified knowledges at the edges of autism mother discourse that might also work to disrupt the very foundations of who we have come to imagine ourselves to be (Foucault, 1980b, pp. 81-2).

**Genealogy as Method: Linking Text, Talk, Subjectivity, Power & Possibility**

Alongside rigorous phenomenological description, I adopt a genealogical approach to everyday text and talk. This is an historiographical method that traces the emergence of truth claims and identities as they are produced and naturalized through modern forms of power (disciplinary power, biopower and governmentality) and knowledge that target the body (Foucault, 1984, p. 76; also see Foucault, 1991b; Bordo, 2003, pp. 165-6; Tamboukou, 1999). Genealogy is unlike the pursuit of “anthropological universals” - Western forms of instrumental reason as the pathway to truth and meaning of humanness, for example - within metaphysical and scientific approaches. Instead, genealogy proceeds along a different path, and traces the emergence of ‘truths’ as integrally caught up with histories of struggle, power and forces of domination and subordination. Foucault states that the “development of humanity is a series of interpretations” and the “role of genealogy is to record its history: the history of morals, ideals and metaphysical concepts, the history of the concept of liberty or of the ascetic life; as they stand for the emergence of different interpretations…” (1984, p. 86). This means that rather than “writing a history of the past in
terms of the present,” a genealogy performs instead a “history of the present” (Foucault, 1975/1995, p. 31; also see Bordo, 1987, p. 5; Tamboukou, 1999, p. 205). In my case, this means tracing the historical emergence of today’s truth of the human as autonomous and non-autistic, as well as understandings of mother-love as ‘naturally’ tied to intensive biomedical efforts to remedy her ‘disruptive’ child. Genealogy seeks to answer questions such as, “Why this version of the human? Why now?” and to reveal the “conditions of possibility” of the emergence of such interpretations, truths and identities.

Like the phenomenological shift to begin inquiry in the lived actualities of excluded standpoints, genealogy proceeds differently than the “god-trick” involved in dominant Western scientific and social scientific studies of autism and mothering. Rather than seek “lofty” origins, “immobile” causes or static essences as accounts of the history of interpretations, genealogy descends to “cultivate the details and accidents that accompany every beginning” (Foucault, 1971, p. 80) along a variety of axes (i.e., forms of thought, techniques, practices, forms of visibility, forms of identity; see Dean, 1999). The use of the technology of the case study in magazines and popular science, for example, not only popularized meanings of autism as non-human, bizarre and tragic. It also had the effect of implicating a mother’s love and so-called nature in the biomedical impulse to remedy by bringing mothers’ everyday practices increasingly into ‘view’ (see Chapter 3). Interestingly, in seeking the beginnings of shifting and divergent truths, Foucault points us to “the most unpromising of places, in what we tend to feel is without history – in sentiments, love, conscience, instincts” (1984, p. 76). This means disrupting some of Western culture’s most cherished, deeply felt and taken for granted “truths,” including that
of progress, reason, autonomy and a mother’s love, for example (Foucault, 1965/1988a, 1991a), opening room for other possible truths to emerge.

With genealogy I take another “backward glance” (Ahmed, 2006, p. 506), this time to historicize the very possibility of autism, and autism mother, within Western culture. My aim, which is exploratory and partial, is also transformative, “Let us give the term genealogy to the union of erudite knowledge and local memories which allows us to establish a historical knowledge of struggles and to make use of this knowledge tactically today” (Foucault, 1980b, p. 83). For my project, a genealogy of everyday talk and text by and about autism mothers makes room for the possibility that “things could be otherwise” (Titchkosky, 2003, p. 237). It is the effectiveness of genealogy in tracing the links between taken for granted truths, embodied practices and sentiments on the one hand, and larger social forces and systems of power on the other, as they are articulated in everyday text and talk, that makes it so interesting and useful for my study.

The Disruption of Disability Studies

Disability studies is the final source of scholarship upon which I draw to fashion my approach, particularly as the field has been influenced and challenged by feminist, phenomenological and poststructuralist approaches. As an interdisciplinary field of critical scholarship and activism, disability studies interrogates disability as a socio-political phenomenon from a wide variety of angles, raising critical questions about the transnational, historical, economic and social processes that marginalize and devalue alter
embodiments and disabled persons’ lives. As its own force of activist and scholarly disruption, this profuse field of study shapes my philosophical commitment to disruption, methodological approach of attending to the difference of disability differently (see Michalko, 2002) and critical analyses of ‘normative’ embodiment, exclusionary versions of the ‘good’ life, and violent modes of inclusion and exclusion, to name just a few key contributions. I also draw from, pose new questions within and thus make a unique contribution to emerging conversations about mothering and care at the intersection of feminist and disability studies. Until recently, such conversations have been marginal, although not absent, within both feminist and disability studies (on such marginalization see Lewiecki-Wilson & Cellio, 2014, pp. 3-10; Ryan & Runswick-Cole, 2008). They raise complex and contradictory issues about dependency, autonomy and care, as well as questions about histories of oppression and emancipatory struggles for mothers and disabled persons alike. In this section, and in the chapters to come, I explore the tension-filled ‘edges’ between feminist and disability studies about mothering and care, and approach the relation between mother (who may also be disabled) and autistic child as a “space between” where we have “the chance to read and write disability differently” (Titchkosky, 2007, p. 39; also see Kelly, 2013). This disability studies approach disrupts dominant understandings of what it means to care and be human together in late modern

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times, and helps point to the spaces in which we might generate, imagine and create new possibilities inclusive of the difference of disability (Thomson, 2013).

I begin below with a brief description of the emergence of disability studies as a distinctive field, including some of the ways disability studies has been challenged to grow beyond its beginnings in the politics and experiences of predominately white, Western physically disabled men’s lives. I then tease out some of the different threads of emerging conversations between disability studies and feminism about motherhood most salient to the work and contributions of my project. It is my hope that this narration of disability studies will both help orient the reader to the ways disability studies anchors my interpretive and critical approaches, and helps me to attend to the “tug and beckon” (Clare, 2007, p. 89) of stories about the disruption of autism in everyday talk and text in not only critical, but creative and new ways.

The Field of Disability Studies: Emergence

In her article, Disability Studies: A Field Emerged (2013), feminist disability studies scholar Rosemarie Garland-Thomson comments that recent major works in the field “mark the full emergence of a distinctive interdisciplinary field that has come to be called critical disability studies” (p. 915). Here, I describe some of the key features of disability studies as a distinctive interdisciplinary field even as it embodies vastly diverse critical scholarship and activism that is reflective, too, of the divergent array of alter human embodiments (Davis, 2006, p. xii; Goodley, 2011; McGuire, 2011b; Snyder & Mitchell, 2006b, pp. 194-99). It is the attention to the social significance of disability that is perhaps the first feature to notice about disability studies as a distinctive field. In other words, the “subject matter” of disability studies is “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, 1998, p. 2; also see Kudlick, 2003). This means the subject matter of disability studies is both diverse, yet focused on similar questions about how the difference of disability acquires meaning, and how we might make these meanings anew within transnational, socio-political, historical and interactional landscapes.

As a field of scholarly work and activism, disability studies also poses a significant epistemological challenge to the ground of Western science, most particularly to biomedicine, as the preeminent way of knowing and responding to the difference of disability in late modern times. Titchkosky (2007) says, “A defining feature of disability studies scholarship…is that it is establishing a tradition of inquiry that problematizes the ways in which disability is figured against an ahistorical, apolitical and even asocial background” (p. 38). Like Haraway (1991) and Smith (1999) who call for a new metaphor in feminist knowledge production that situates knowledge, “embodies vision,” and shifts the ground of knowing, disability studies scholars shift the ground of knowing away from the scientific “view from nowhere” (Haraway, 1991), and instead historicize and analyze the unmarked body of normalcy by beginning in disabled persons’ experience, or standpoints (also see Thomson, 2001). This means a rejection of the still prevalent notion in the health, natural and social sciences that disability is an object in and of itself. As Lenard Davis articulates, “Disability is not an object – a woman with a cane – but a social process that intimately involves everyone” (1995, p. 2; also see Thomson, 2013). Indeed, like feminist epistemologies, disability studies politicizes knowledge, and shifts the ground of knowing to the historical, economic, cultural and interactional processes in which disability appears and becomes meaningful in everyday life. As my conceptual framework described,
this means my methodology, or way of proceeding, is both a feminist and disability studies one.

Another feature of this field is its ontological challenge to normative conceptions of the human that exclude alter embodiments. Disability studies scholars and activists understand disability as a legitimate, albeit different, way of being-in-the-world with something of value to teach us about our human life together (Davis, 1995; Goodley, 2011; Titchkosky, 2003, 2007; Titchkosky & Michalko, 2009). The corollary of the preeminence of the scientific study of disability as an object in and of itself, however, is the ubiquitous understanding of disability as a situation of exceptional personal tragedy (Barnes, 1998, p. 65; Davis, 1995, p. 2; Titchkosky & Michalko, 2009, p. 2). Rather than understanding disability as an integral part of the diversity of human life, this view holds that the tragedy of disability is individual, “wrought with problems for which solutions must be sought” (Titchkosky & Michalko, 2009, p. 2; on disability as a problem, also see Abberley, 1998, p. 93; Mitchell, 2002, p. 15). Since the Enlightenment, the predominant solution has been that of biomedical remedy, which has been practiced in a variety of ways including advocacy (McGuire, 2013), confinement (Ben-Moshe, Chapman & Carey, 2014), maternal care (Douglas, 2014), and, as Mitchell and Snyder (1997) describe, “numerous professional and academic disciplines that concentrate upon the management, repair and maintenance of physical and cognitive incapacity” (p. 1). Disability studies represents what Dan Goodley calls a “paradigm shift,” from writing and thinking about disability as a problem-object or “personal predicament” - how individuals cope, adapt to or overcome such bodily tragedy – and towards the study of disability as a “social pathology” (Goodley, 2011, p. xi) which
includes the shift toward understanding disability as a different, and viable, way-of-being-in the-world.

Understanding disability as a social rather than individual pathology has its legacy within disability activism and the forging of the social model of disability in the work of scholars and activists such as Mike Oliver (1990, 1996), Colin Barnes (1998), Vik Finkelstein (1998) and from a feminist standpoint, Jenny Morris (1991). Forty years ago, this more radical understanding of disability erupted on the political scene as the rallying call of the disabled people’s movement during the re-organization of the Union of the Physically Impaired Against Segregation (UPIAS) in the UK. In contrast to the Disability Alliance, and its exclusion of disabled people from positions of leadership, UPIAS states:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.

For proponents of the social model, it is society, and not impairment, that disables people. Disabled people are isolated and excluded due to social organization that bars them from participating in social life, and thus disabled persons constitute a socially oppressed group. Such oppression and disadvantage is “neither natural nor inevitable” (Abberley, 1987, p. 7; also see McGuire, 2011b, p. 40) as if a corollary of individual impairment. Rather, as for other socially oppressed groups, the social model of disability understands exclusion and oppression as the result of ongoing oppressive social and economic arrangements and dominant ideologies that devalue and exclude disabled people from everyday life (Abberley, 1987; also see Hunt, 1998; McGuire, 2011b, p. 40). Indeed, the field of disability studies itself and its activist beginnings owe much to the radical political movements of the 1960s and the work of feminist, queer, anti-racist and working class scholars (Davis 2006; Goodley, 2011, p. xii, 2).

If, as the above suggests, disability is not simply an object to be known, a problem to be solved, or a personal tragedy to cope with, but is instead a socio-political phenomenon and form of oppression that unfolds in relation to non-disability and dominant culture, then, in Rod Michalko’s words, the disruption of disability becomes “something to think with” (2002, p. 168; also see Titchkosky & Michalko, 2009, p. 6). Attending to the difference of disability as it appears in relation with others and dominant values means reorienting to disability as a teacher. That is, disability studies opens a “space” from which to disrupt the normal and ordinary and to ask critical questions about alterity and our shared life together, possibly even inserting something new:

How can the ways in which a disabled existence interacts with the culture that surrounds it and organizes it be listened to for the whisper of that seemingly
unsayable that resonates with new content, new meaning, inserting itself into our understanding of the social significance of the situation of disability? (Titchkosky, 2003, p. 36)

With similar hope, Rod Michalko likens disability to a mirror, that when held up to society can be revelatory of unquestioned assumptions, values and practices that continue to marginalize and devalue alter forms of embodiment (2002, p. 168). Snyder and Mitchell, too, speak of the disruptive potential of the field of disability studies: “the field of disability studies situates itself as a force of destabilization...displacing the object of change onto unaccommodating environments, beliefs, disciplines, or research methods” (2006b, p. 192).

It is this hope of disability studies and the disruption it promises (on the hope and promise of disability studies, see Titchkosky, 2003, p. 36-7, 2007, p. 39) that I draw inspiration from as I attempt to engage an ethic of disruption that might attend to the difference of autism in the shape of mother/child differently, and begin to imagine a different version of knowledge production, care and the “good” life that integrally include autistic ways of being.

**The Field of Disability Studies: Divergences**

Diverging voices within disability studies promise to extend its disruptive hopes. Here, I describe the significance of two key divergences for my project: the move to trouble the impairment/disability binary and the call for disability studies activists and scholars to attend to difference from feminist, queer and anti-racist scholars and activists. First, as described above, the social model of disability articulated by UPIAS (similar to early feminist distinctions between sex and gender) makes a clear distinction between
impairment and disability to foreground disability as a social pathology and not an individual, tragic problem of disordered bodies (Goodley, 2011, p. xi; Titchkosky & Michalko, 2011, p. 9-10; also see Barnes, 1998; Oliver, 1996). This has been a strategic political stance to gain citizenship rights for disabled people. And yet, despite the success with which the social model dislodges the problem of disability as an individual and bodily one, as Iris Marion Young (2001) points out, the social model “continues to presume a certain fixity to these bodies” (p. xiii). In some ways, the social model leaves the difference of disabled bodies (understood as impairment) unremarked, as a matter for medicine, one that is somehow outside of history and everyday relations between bodies and culture. Poet, essayist and activist Eli Clare, writing about reclaiming our different bodies – queer, shaky and unsteady bodies - in relation to material and violent oppressions makes this recommendation,

I am asking that we pay attention to our bodies—our stolen bodies and our reclaimed bodies. To the wisdom that tells us the causes of the injustice we face lie outside our bodies, and also to the profound relationships our bodies have to that injustice, to the ways our identities are inextricably linked to our bodies. (2001, p. 364)

Bodies taken as autistic– flapping hands, stiffened bodies, rocking bodies, fixated bodies - are never fixed in this way but slip, disrupt and exceed any easy distinction between impairment/disability, power/subjectivity, oppression/identity, self/other and disability/non-disability. As Titchkosky and Michalko (2011) put it, “our bodies are not asocial since the social organizes even what can be understood as impairment, lack, deficit or bodily function” (p. 10; also see Corker, 1998; McGuire, 2011b; Michalko, 2002). For my
approach, this means incorporating these poststructuralist insights about difference and 
caring about the bodily disruption of autism not as an individual problem in need of 
biomedical remedy, nor as solely a “social pathology,” nor again as an essential identity 
grounded in bodily difference, but a space of perpetual questions about power, identity, 
difference, embodiment, meaning-making and possibility, one, following an ethic of 
disruption and pedagogic care, where the ground is always slipping (Butler, 1993; Corker, 
1998; Corker & Shakespeare, 2002). This includes the hope that there may be a different 
way of being together, one that might even begin to celebrate, rather than seek to remedy, 
the ‘difference’ of embodiments socially produced as autistic.

Secondly, divergent voices within and beyond disability studies have challenged the 
field to take up the complex histories and linkages between disability, race, class, gender, 
vulnerability and other oppressions and struggles for human freedom (see, for example, Bell, 
Not only does the diversity of disabled bodies, minds and senses far exceed that of the 
UPIAS version of disability as “physical disability,” the field of disability studies has 
produced its own version of a “normative body” in its “body” of work (McGuire, 2011b, p. 
50). As Corbett Joan O’Toole (2004) describes this exclusion in her article “The Sexist 
Inheritance of the Disability Movement,” the “…myth of the white, straight man in a 
wheelchair is evident in personal accounts, essays, and in the professional literature of 
disability scholars” (2004, p. 295). Among others, feminist disability studies scholars have 
articulated, as Rosemarie Garland Thomson puts it, the myriad ways “disability can be 
included as a category of analysis that parallels and intersects gender, race, ethnicity and 
class” (Thomson as cited in O’Toole, 2004, p. 297). My work joins in the endeavor to
enlarge our understanding about these intersections between the “axes of difference” (Erevelles, 2011, p. 6). For this project, this means a complex attention to intersecting histories of difference and oppression in the spaces between mothers, mother and autistic child and non-disability and dominant culture as I attempt to shift the ground, and begin from mothers’ lived actualities (Razack & Fellows, 1997-98).

Emerging Conversations about Mothering at the Intersection of Feminist & Disability Studies: Divergent Convergences

I turn now to a discussion of the emerging conversations about the complex oppressions surrounding mothering, care, gender and disability at the intersection of feminist and disability studies. These conversations are complex and layered, yet generative. They raise difficult questions about mothers’ (who may also be disabled) implication in histories of ableist violence, oppression and exclusion, as well as biomedical ‘views’ of autism, even while mothers have, in other instances, been at the forefront of struggles against disabled persons’ oppression (Panitch, 2008). These conversations also challenge disability studies scholars and activists to rethink conceptions of care and values such as autonomy; and feminist scholars to more fully incorporate disability studies into their work on mothering and care (Hughes et al., 2005; Kelly, 2013; Kröger, 2009; Morris, 2001; Shakespeare, 2006; Williams, 2001). I trace partial threads of these conversations as divergent convergences that form, at best, a torn, fragmented and tension-filled fabric. Nevertheless, working the ‘edges’ between feminist and disability studies scholarship and activism on mothering, gender and care and their conflicting views opens a space of

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27 Also see Bell (2006); Doucette (1990); Erevelles (2002); Connor & Ferri (2005); Fine & Asch (1988); Hall (2011); Garland-Thomson (1997); McGuire (forthcoming); McRuer (2007); Meekosha (2011); Morris (1991, 1993); O’Toole (2004); Quayson (2007); Thomas (1999, 2006); Thomson (1997); Titchkosky & Aubrecht (2009, 2015); Wendell (1989).
important questions about intertwining histories of oppression and struggle, as well as the possibility of releasing new, and potentially transformative stories.

Conversations about gender, disability and mothering are nothing new within either disability or feminist studies. Feminist disability studies scholars, for example, have articulated the myriad ways gender and disability operate both materially and symbolically as intertwined systems of oppression, ascribing inferiority, passivity, deviance, material exclusion, medical control and Otherness to both female and disabled bodies (see, for example, Fine & Asch, 1988; Thomson, 1991, 2001, 2005, Hall, 2011; Morris, 1991, 1993; O’Toole, 2004; Wendell, 1989, 1996). Examples of how disability and femaleness are historically and bodily equated in Western culture as “too-much” (Bordo, 2003, pp. 160-1), or, alternatively, as lack, abound – as deformed monsters or witches, castrated males, rejecting, disordered mothers, genetic disability, or madwomen, for example (Thomson, 2001, pp. 6-9). Indeed, beginning in 1949 with the publication of Simone de Beauvoir’s *The Second Sex*, disability and feminist scholars have demonstrated how women and disabled people are understood in Western culture as “immanence” alone and not transcendence, “being pure body, unredeemed by mind or spirit” (de Beauvoir as cited in Thomson, 2001, p. 8; also see de Beauvoir, 2011/1949, p. 16-7). For disabled women, however, there is a further denial and devaluation, “Whereas motherhood is often seen as compulsory for women and therefore potentially oppressive, the opposite is true for disabled women, who are denied or discouraged from this reproductive role” (Thomson, 2001, p. 5). The issue of genetic screening and selective abortion of disabled fetuses is another complex convergence between these two fields as well as feminist studies of
science, one that is generating rich dialogue (see, for example, Keller, 1995; Landsman, 2009; Mitchell, 2001; Tremain, 2010).

Despite this rich history of feminist and disability studies engagement, until very recently, mothers of disabled children have been a marginalized presence within both disability studies and feminist discourse. When mothers of disabled children have appeared at all, it is often the tragic or oppressive aspects of the experience that have been emphasized - whether for mothers or disabled people - as if a ‘natural’ corollary. As Ryan and Runswick-Cole (2008) reveal, the conversation within disability studies about the contributions of mothers is in need of more consideration, given that mothers often share aspects of disability oppression with their child, and make significant contributions toward disability justice. Historic possibilities for strategic alliance (i.e., mothers were a moving force in the de-institutionalization and educational inclusion movements) have instead often found disability studies and mothering scholars and activists at cross-purposes with one another. As a vocation to care, mothering embodies intimate, emotional and dependent aspects of care that represent much of what disability activists fought against to forge the social model – associations between disability and the feminine realm of dependency, passivity, emotions and bodily need (Morris, 2001; Hughes et al., 2005). Equally troubling for disability activists and scholars is mothers’ association and at times complicity with undeniably oppressive and discriminatory systems of care, such as institutional care, and medicalized understandings of disability (Hughes et al., 2005; Kröger, 2009; Ryan & Runswick-Cole, 2008). As a political alternative, social model activists and scholars emphasize a Western, masculine ethic of equality and justice, forwarding empowerment and equal citizenship rights (Hughes et al., 2005). This has led to important gains toward
inclusion for many disabled people, forging a social and consumer-led model of care that
distances itself from emotional, bodily or dependency aspects. Instead, independent living,
choice, control and autonomy in terms of “help,” “support” or “assistance” (i.e., through
personal assistants; see Shakespeare, 2006, p. 139) are emphasized. Care, for the social
model, has been disaggregated from love, mothers, and the “feminine” realm of
dependency, passivity and emotion, despite many mothers’ often life-long involvement in
their disabled offspring’s lives as advocates, activists and carers (Hughes et al., 2005;
Kelly, 2013; Kröger, 2009; Morris, 2001; Williams, 2001). As Wood articulated for the
disability rights movement, “disabled people have never demanded or asked for care!” (as

Disability studies critiques of care, including those that move beyond the social
model to incorporate divergent voices and issues outside of personal assistance, are vitally
important. Indeed, bio-medical forms of care that seek to normalize, contain or ‘cure’
disability, and mothers’ implication in them, have exclusionary, even violent,
consequences. Anne McGuire’s (2011a, 2011b, 2013, forthcoming) pioneering work on
autism advocacy and the cultural production of autism, for example, is a powerful
attestation of both the force of parental advocacy that colludes with bio-medical versions of
disability and care, and the need for alternatives. Against a backdrop of Western(izing)
scientific versions of autism and normalized violence against autistic people, McGuire
traces the “productive force” of contemporary advocacy (where mothers are the primary
movers). She says, “…far from being, simply, a response to a disorderly autism, advocacy
has become a productive force that has and continues to govern what autism is and can be”
(2011b, p. 36). Autism Speaks, what McGuire calls “the largest, the richest, and, so, the
most influential autism advocacy organization in operation today” (2011b, p. 103), is, for example, spearheaded by families, and forwards an understanding of autism as an undesirable neurodevelopmental disorder – one that threatens us all - and is committed to ‘care’ about autism through seeking its elimination globally via the promotion of this version of autism as well as research into its ‘cure’. McGuire’s work demonstrates the vital need for a disability studies critique of the many aspects of parenting and care, including mothers’ activism and advocacy. For my project, McGuire’s work is a provocation to work the ‘edges’ of critical and interpretive feminist and disability studies as informed by feminist philosophies of science, phenomenology, philosophical sociology and phenomenology to learn how their often-diverging emancipatory goals are constraints in a dialogue that might also converge in new sets of possible questions about care, advocacy and activism in generative ways (for examples of this approach see, Hughes et al., 2005; Kelly, 2013; Kröger, 2009; Morris, 2001; Shakespeare, 2006, p. 139; Thomas, 2007; Williams, 2001).

Feminist scholarship in political economy, for example, diverges sharply from care as a right or form of disability oppression, and understands care instead as a form of gender, race and class oppression. While its focus in not limited to mothering, feminist political economy demonstrates how informal and formal carework is linked to the restructuring of social, economic and political relations post-welfare state (Brodie, 1995; Walkerdine & Lucy, 1989). Beginning in the 1980s, when middle-class white women were entering the work force in record numbers, neoliberal economic shifts saw the return of care to the realm of the private family and the withdrawal of public supports from the community, resulting in a “double burden” of care for women as both paid workers and
primary caregivers in the home (Armstrong & Armstrong, 1984; Brodie, 1995). The ideology and practice of “intensive mothering” - what Sharon Hays (1996) describes as “child-centred, expert-guided, emotionally absorbing, labor-intensive and financially expensive” (p. 8) – also emerged during this time, alongside the contradictory figure of the “working mother” committed to her career. It would be Western women of colour, together with racialized women from Third World countries that would fill the gap of underpaid carework in these new economies, including the social model of care (Meekosha, 2011; Williams, 2001; 2011). Facing these complex economic and ideological contradictions, feminist scholars and activists often cast disabled family members as an added “burden” of care for mothers (Hughes et al., 2005; Kelly, 2013; Kröger, 2009; Morris, 2001; Williams, 2001). While a feminist political economy dislodges straightforward notions of equality within the social model of care, disability studies critiques the ableist view of disability as nothing more than a problem that is evident within feminist political economy. Bridging the edges between a feminist and disability studies critique of care is difficult.

Recently, disability studies scholars have begun to address these complex and intertwining oppressions by “building bridges” (Kelly, 2013), tenuous ones that might also easily slip, across and between feminist and disability studies critiques of gender and care, feminist political economy and a feminist ethic of care, which I touch on briefly below (also see, for example, Hughes et al., 2005; Kröger, 2009; Morris, 2001; Shakespeare, 2006; Williams, 2001, 2011). Within complex situations of constraint, mothers often simultaneously resist and comply with ableist formulations of care and gender ideologies, as well as learn from the alterity of their disabled offspring (Ryan & Runswick-Cole, 2008). Disabled persons and assistants, too, often transgress boundaries between “personal
assistant” and “consumer” (Kelly, 2013). These messy realities of care blur any easy lines between self/other, autonomy/dependence, emotion/reason or private/public. Such slippages suggest that the devalued “feminine” realm of emotion, embodiment and love that the social model of care wished to circumvent cannot be so easily left behind, and may have something of value to add to conversations about care. Feminist philosophers of an ethics of care have worked to empower and imbue the practical, relational, embodied and affective aspects of the typically feminine domestic realm with philosophical status, linking women’s experiences of care to different modes of thinking, reasoning and being as distinct from “male” ones. This counters views of feminine moral reasoning – the relational, contextual, located and embodied - as deviant from and lesser than a male “ethic of justice” based on universal Kantian ethics (Held, 2006). Such approaches argue that an ethic of care is a radical political challenge to Western rationalized modes of knowledge, identity and social organization (Gilligan, 1993; Kittay, 1998; Noddings, 2003; Ruddick, 1995; Tronto, 1993). My decision to begin inquiry in women’s standpoints and to include the ‘difference’ of autistic bodies, the realm of emotion and pedagogic care in my work is indebted to the work of Nel Noddings, Carol Gilligan and others in the feminist ethics of care.28

This is tricky territory, however. As feminist philosopher Anita Silvers (1995) cautions, a feminist ethics of care has the potential to lead to “an even more oppressive paternalism” (p. 40). Indeed, a feminist ethics of care can romanticize not only women’s domestic roles, relationships with our children and disability experience, but also

28 Carol Gilligan’s *In a Different Voice* (1993), a psychology of the differential development of female morality, and Sara Ruddick’s *Maternal Thinking* (1995), an argument for a distinct mode of maternal thinking and politic of peace, one that follows from the practical reasoning work of care, are foundational in the feminist ethic of care. Other feminist works of this ilk include, among others, Nel Noddings *Caring: A feminine approach to ethics & moral education* (2003), Joan Tronto *Moral boundaries: A political argument for an ethic of care* (1993) and Eva Feder Kittay *Love’s labor: Essays on women, equality and dependency* (1998). For a thoughtful and comprehensive approach to the feminist ethic of care as a radical challenge to liberal individualism that attempts to address criticisms of essentialism, see Held (2006).
essentialize/universalize them as well, thus subtly erasing differences between us. Rather than try to resolve conflicts between diverging approaches, I engage them as ones that might generate new questions about mothering and disability. Recent work of this ilk, for example, is yielding new work about mothering and disability as potentially transformative forms of advocacy, activism, pedagogy, care, relational ethics and even disability experience (see, for example, Chapman & Kelly, 2014; Charles & Berman, 2009; Filax & Taylor, 2014; Fisher & Goodley, 2007; Goodley & Tregaskis, 2006; Hughes et al., 2005; Lewiecki-Wilson & Cellio, 2011; Ryan & Runswick-Cole, 2009). This work at the intersection of intertwining oppressions presents an occasion to question, disrupt and think anew about care and our intimacies as mother and child as ones that are not a straightforward matter of disability or maternal oppression, but interpretive and political sites replete with lessons about human alterity, power, resistance, difference and possibility. Given all that I have considered about how I draw from interpretive and critical approaches within disability studies as influenced by philosophical sociology, feminist maternal theory, phenomenological and poststructuralist philosophies, as well as feminist philosophies of science (see Chapter 1), I turn now to a discussion about how I formulate everyday text and talk as a richly generative site from which to disrupt, and rethink, autism and mothering.

**Everyday Talk and Text**

I turn to *text* as the key social location through which I investigate the accomplishment of everyday life and shift the ground of knowing about autism and mothering. Text has assumed a central and proliferating place within late modern Western consumer capitalist societies where spoken and written language and literacy are key values
and demands (Smith, 1999, p. 135; Titchkosky, 2007, pp. 26-8). Newspaper reports, magazine articles, public service announcements, agency websites and workshops, motion pictures, documentaries, television talk show appearances, Ted talks, autism mother blogs and memoirs, Facebook groups, prenatal genetic screening, developmental checklists, individual education plans, research surveys, disability tax credit forms – the sites through which text enters and shapes our lives and identities as autism mothers, including how we take them up, and possibly speak back, are many. Indeed, being the mother of an autistic child means sharing encounters with texts and the meanings, constraints and possibilities they impart for our human life together within what might be thought of as autism mother networks - similar (though not identical) movements through the pathways of a social world organized and coordinated by text. While text has often seemed to refer to anything that can be ‘read’ for meaning (see, for example, Barthes, 1977), for this project, as we have seen, text means everyday text and talk by or about autism mothers drawn from popular culture and the mass media during the years 1943-2015 in Toronto, Ontario, as well as dialogue about such everyday talk and text with Toronto mothers of autistic children from focus groups I conducted in the fall of 2013. The everyday text and talk I gathered for my archive is part of a larger social/intertextual organization of autism mother discourse that includes many other sites within the social such as autism service agencies or encounters with health practitioners (Smith, 1999, p. 134; Foucault, 1972). My choice to focus on mass media, popular science and social media (during 2000-15), aims to acknowledge their wide reach through a shared social life, as well as their intimate and lived salience in the lives of autism mothers.
Understanding the significance of everyday text and talk as it enters our lives within the complex space between everyday interpretive consciousness – or embodied subjectivity – and abstract ruling relations, or power, is the knot I am pursuing in this dissertation. Dorothy Smith’s (1999) exploration of how text co-ordinates and organizes the social, and consciousness, as well as how the social is modified through our actual everyday/everynight interpretive practices producing and interacting with texts - reading, writing, interpreting, feeling, resisting, disrupting, speaking back or complying – is helpful. Her work describes, in part, how text is a generative site within the co-ordination and reproduction of power relations. Smith writes, “In coordinating particular local sequences of activity among participants, utterances [speech and writing] reaffirm, regenerate and modify social organization as it is projected toward the next occasion of action together” (Smith, 1999, p. 145). Reading Smith with an interpretive ‘slant’, however, also suggests that texts enter our lives in practical and lived ways within the everyday. We come to conduct ourselves, and our relations with others, through text. Text is identity forming in this way, an identity that is also lived bodily. This also implies, secondly, that texts carry with them the cultural ground of the world from which they emanate. Indeed, each utterance, Merleau-Ponty tells us, contains just this world of unarticulated yet “ready-made meanings.” He says, a “…word is a gesture, and its meaning a world” (1958, pp. 213-4). Everyday text and talk is a rich site that ‘utters’ shared (and often exclusionary) meanings within our social world. Following from this, and third, text orients us to a shared social world and thus to one another. It is a site of social action that is both constrained by the ground of the social world in which we find ourselves, and that is open to “modification” through our everyday actions and interpretive activity. This is to say with Titchkosky
(2007) that, “Text is a social location and organizer for the accomplishment of meaning, making text count as a form of social action” (p. 27). Finally, it is through the open horizon and interpretive nature of language (Schutz, 1970, p. 96) that text enters our lives and meaning is accomplished. Language is open to the “dialogic” in this sense, to the ongoing interaction between the “taste” words have acquired from other contexts and usages, and the insertion of the new, “language, for the individual consciousness, lies on the borderline between oneself and the other. The word in language is half someone else’s. It becomes ‘one’s own’ only when the speaker populates it with his own intention, his own accent…” (Bakhtin, 1981, p. 294; also see Smith, 1999, p. 136). Everyday text and talk is thus a rich site to explore the knot of power and subjectivity as a complex, multi-directional and lived space of meaning making. Text is a social location through which power inheres, identity comes to be lived and resisted practically and actually, interpretive social action accomplishes meaning and the social, and through which, therefore, we might begin to insert something new (Arendt, 1998/1958, p. 176-7) into the ground of a world that currently excludes autism as a viable way of being-in-the-world and implicates mothers in its elimination.

Drawing on the methods and theories of interpretive and critical approaches within disability studies as influenced by feminist, philosophical sociology, phenomenology, post-structuralism and maternal theory, helps me shift the ground of knowing about autism and mothering, and my understanding of everyday text and talk, beyond that of Western science and its “god-trick.” This is an approach that dares to imagine possible worlds outside of the constraints of our own as one that excludes and devalues alter ways of being and caring. Conflicts and edges between the multiple approaches I draw from converge in generative
questions about the ways in which power, difference and possibility are embodied, resisted and lived complexly and ambiguously through everyday text and talk in mothers’ and autistic person’s lives (Boler, 1999, pp. 20-1; Ricouer in Titchkosky, 2003, p. 21). My approach pays attention to the disruption of autism in everyday text and talk as moments in which I might work to reveal, and possibly reconfigure the ground of an ordinary, sensible and “sayable” world that articulates autistic lives as a problem to be solved, and mothers as the solution. Through my analysis of everyday talk and text as both an interactive scene of social action and site of power, the text that I weave here offers new understandings.

Chapter 3 begins this work with a ‘look back’ at the emergence of refrigerator mothers as a key cultural contradiction – those ‘bad’ mothers of the 1940s, 1950s and 1960s thought to cause autism in their child through their cold and disordered love.
CHAPTER THREE

Autism’s ‘Refrigerator Mothers’ – Identity, Power & Resistance

Adding a new element to an age-old adage - that mothers are to blame for their child’s as well as society’s ills - this chapter traces the emergence of the refrigerator mother. This particular historical narrative is situated in Toronto. I attend to ‘popular’ science and women’s magazines, motion pictures and books that offer renderings of these so-called ‘bad’ mothers identified through regulatory scientific regimes who would paradoxically birth ‘autism’ and mothering in both dominant scientific as well as radical terms. To do this work, I turn my analytic attention to the unarticulated background – both historically and perceptually - of the scene of everyday talk and text by and about ‘autism mothers’ in terms of power, resistance and interpretive possibility for the years 1943-69 (on scenography see Butler, 1993, p. 28 and Michalko, 2010, p. 71; on everyday text see Smith, 1999 and Titchkosky, 2007). I begin in medias res – in the middle of an already unfolding story of mother-blame, shifting meanings of motherhood, expertise and childhood disorder on the Toronto scene. Autism mothers were not the only bad mothers during the post-World War II years. Various popular renderings of both the so-called rejecting and overprotective mother circulated in everyday text, including the ‘suffocating’ Jewish mother, deficient working-class mother, pathological Black mother and absent working mother (Caplan, 1998; Ehrenreich & English, 2005, p. 4251; Ladd-Taylor & Umansky, 29 I employ scare quotes to indicate that I understand ‘autism’, and ‘autism mother’ as culturally produced subjectivities rather than ways of being grounded in the biology of different brains or bodies, for example, or as things in and of themselves. I use scare quotes the first time the terms ‘autism’ and ‘autism mother’ are introduced in each chapter, and intermittently, to remind the reader of my orientation.

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1998). However, I argue that the refrigerator mother emerged as an extreme, a key cultural contradiction through which scientific understandings of autism and a contradictory femininity began to regulate the good/bad mother in new ways for all mothers (Bordo, 2003; Hays, 1996). I also work to reveal the radical potential of the emergence of autism mothers within disqualified knowledges about human difference, relationality and love that dwell at the edges of ‘official’ scientific discourse, but at the centre of these mothers’ lives (Foucault, 1980b).

Creating an ‘Autism Mother’ Archive, 1943-69

My interest in autism mother history was ignited some years ago while reading Majia Holmer Nadesan’s (2005) *Constructing Autism: Unravelling the ‘truth’ and understanding the social*. In this groundbreaking book on the social construction of autism through scientific discourse, Nadesan notes the popular reach of psychoanalytic literature through Dr. Bruno Bettelheim’s work in the 1950s and 60s. Bettelheim was renowned as an expert on child psychopathology in the United States. He wrote regularly for the *Ladies Home Journal* and appeared on television talk shows, speaking, among other things, about his refrigerator mother theory – the cold, rejecting mother responsible for the autistic withdrawal of her child (Nadesan, 2005, p. 87; also see Hanley, 2002; Pollak, 1997). Given my own intimate, present-day relationship to understandings of autism and mothering in everyday talk and text, my discovery of Bettelheim unfolded into a lengthy pursuit of him. I began searching for his *Ladies Home Journal* columns about autism and mothers (which I

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30 The reach of expert knowledge through popular women’s magazines, child-raising books, government pamphlets and medical offices is also noted by Ehrenreich & English (2005), who argue that by the 1920s in the United States at least, a “nation-wide apparatus for diffusing expert advice on child raising to the working class, as well as to the educated and wealthy, to the small towns as well as to the cosmopolitan centres” had been well established (p. 3923).
was not able to retrieve). This search led to recovering a number of books, articles and one documentary on autism that include different fragments of autism mother history, and to an enduring interest in autism mother history that has culminated in a rich and unique archive of autism mother talk and text. Here, I describe how I went about collecting texts for my archive for the years 1943-1969, the time period that saw both the rise and fall of psychoanalytic approaches to autism within North America.

Everyday talk and text in which autism mothers make an appearance during the post-World War II years in Toronto is in some instances readily available and in others quite difficult to locate or retrieve. My research has included, first, extensive searches through online databases. I found the EBSCO Reader’s Guide Retrospective and Proquest Historical Newspapers databases particularly helpful for these years, and located numerous newspaper and magazine articles this way, some of which were available as full text, and others that had to be ordered from other university libraries, purchased from online archives, or that could ultimately not be retrieved. Because autism is also often referred to as ‘childhood schizophrenia’ or ‘psychosis’ during this time of its emergence, I used combinations of the broadest search terms possible, as well as each term separately: ‘autism’ ‘schizophrenia’ ‘psychosis’ and ‘mother.’ I also spent many hours in the Robart’s Library at the University of Toronto in the microfilm room, where I searched archived issues of magazine and newspaper articles identified through my database searches. This was slow and methodical work, and a minimally successful way to retrieve hard copies of items (there is a Maclean’s magazine article about Warrandale, a Toronto treatment facility during the 1960s, that I still have not been able to retrieve!).

To ensure I included all relevant periodicals in my archive, I scoured the Reader's Guide to Periodical Literature (1945, 1950, 1955, 1960, 1965), the Canadian Index to Periodicals and Documentary Films (1945-1963), and Canadian Periodical Index: An Author and Subject Index (available for the years 1930-47). I used the guides’ cross-referenced subject headings related to ‘autism’ ‘mothers’ ‘psychosis’ and ‘schizophrenia’ to complete my searches, including the phrases ‘problem children,’ ‘child psychiatry,’ ‘child psychology,’ ‘mentally handicapped,’ and ‘children, abnormal.’ To determine which magazines and newspapers were circulating in large numbers in Toronto between 1943 and 1969 (> 100 000), I consulted individual volumes of N.W. Ayer & Son's directory, newspapers and periodicals (1945-69). I also read Mary Vipond’s (2011) work on the mass media in Canada to make educated decisions about the circulation of American publications in Toronto during these years I could not verify elsewhere. Vipond suggests that major American newspapers, magazines and publications were widely available to a Toronto audience since the early days of the print industry (1800s) either through circulation or subscription, along with most major American television shows. While I highlight Canadian periodicals and newspapers, I also include some major American periodicals (Time and Scientific American, for example), popular psychology (see, for example Bettelheim, 1950, 1959, 1967; Park, 1967) and one television show (The Dick Cavett Show) circulating in Toronto through the years 1945-69, as well as secondary sources that round out the picture (see, for example, Pollak, 1997). This means my story features some of the typical actors who make a regular appearance within autism mother history – Bruno Bettelheim and Leo Kanner for example – in addition to mothers’ voices
and Canadian storylines together, something that does not appear to have been done within autism history in quite this way before.

I draw from a robust and unique archive that begins to sketch a new story about autism mothers in Toronto. Given some inconsistency with which materials during the years 1943-1969 were archived as well as the aim of my project, my collection is not meant as a catalogue of every appearance of autism mothers in everyday talk and text. The point is not so much a complete survey of popular renderings as it is an interpretive and genealogical engagement with the historical emergence of a particular meaning of autism mother the traces and powers of which we live with today (as the following chapters will show). It is the refrigerator mother and her meanings I am after, not an exhaustive survey of the number of times she appears in everyday text. My in-depth searches for archival materials, alongside the divergent storylines, rewritings and multiple beginnings of autism mother history and identities they trace, certainly echo Foucault’s (1984) description of genealogical research: “Genealogy is gray, meticulous, and patiently documentary. It operates on a field of tangled and confused documents that have been scratched over and recopied many times” (p. 76). This chapter performs a genealogical analysis of how emerging forms of governmental power post-World War II, specifically forms of knowledge, visibility, technologies and identities, drew new lines between the normal and abnormal by directing mothers’ gaze ever more deeply inward, toward her inner emotional and bodily life (Dean, 1999; Rose, 1996, 1999). I consider how this inwardly directed gaze also, and ironically, became the ground for mothers’ resistance. As such, this chapter ‘looks back’ to historicize the very possibility of autism, and autism mother, within Western culture today, as well as to rethink forms of resistance. Working more interpretively, I also
pause at points along the way to take a backwards glance at what might be “behind” (Ahmed, 2006, p. 570) the appearance of this mother, and open interpretive space about my activity of re-reading this mother as its own form of resistance, one that is committed to a different kind of knowledge about our human life together.

The ‘Birth’ of Autism Mothers

In 1943 Dr. Leo Kanner, an Austrian psychiatrist who emigrated to the United States in 1924 where he directed the child psychiatry unit at John Hopkins Hospital, published eleven case studies of children whom he had observed over some years in his hospital clinic (Kanner, 1943; also see Pollak, 1997, pp. 249-50). Here, he described children whose characteristics he thought presented a new disorder distinct from other diagnoses such as childhood schizophrenia. He called this new disorder “early infantile autism.” Unlike childhood schizophrenia, Kanner wrote, which involved an initial relationship of self to world, these children never forged a social relationship with their parents, families or social world around them. They were impaired in their ability to communicate, unable to engage in reciprocal social interaction and engaged in stereotyped behaviours such as rocking or “twiddling.” These children were, according to Kanner (1943) and the parents he interviewed, in a world of their own from the start.

Writing under the influence of biological psychiatry and the mental hygiene movements of the early twentieth century (psychoanalysis, though dominant in these years, did not completely eclipse alternate views), Kanner felt there must be some biological basis for the disorder. Interestingly, however, he also noted the potential influence of parents, who seemed to form their own unique group, and would go on to study them in more depth.
as well as offer his views publically (Kanner & Eisenberg, 1955; Park, 1967, pp. 126-28; Pollak, 1997, pp. 249-51). In a Time Magazine medical feature (“Medicine: Frosted Children,” 1948), for example, Kanner, as a leading figure in the emerging field of child psychiatry, is quoted as observing that these parents display a “mechanization of human relationships” (n. p.). In another medical feature twelve years later summarizing Kanner’s pivotal contributions to the new field of child psychiatry, his view seems to have solidified: these were the type of parents “just happening to defrost enough to produce a child” (as cited in Thomas, 1960). Highly intellectual as well as successful in their careers, predominantly Anglo-Saxon or Jewish, oriented to abstraction rather than people and even cold, Kanner noted, “In the whole group, there are very few really warmhearted fathers and mothers” (as cited in Thomas, 1960, p. 250). Most mothers, it was noted, were college graduates and many worked outside the home.  

It would be a short distance to travel, one facilitated by the work of psychoanalyst Bruno Bettelheim (see below) and new forms of visibility already apparent in Kanner’s work, for this emerging understanding of autism and a contradictory feminine (loving/destructive; masculine/feminine) to begin to regulate the good/bad mother in new ways. I turn below to address these new forms of visibility, as they appear in everyday talk and text by and about autism mothers in the post-World War II years in Toronto.

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33 It is interesting to note that Austrian psychiatrist Hans Asperger, who worked independently of Kanner in Vienna, made a parallel “discovery” he called “autistic psychopathology” (Asperger, 1991), which he thought had some biological basis. Asperger noted similar patterns of behaviour and drew similar conclusions about a group of children in his care, with the difference that the children he observed acquired language more readily than those observed by Kanner and typically became “successful” if “egocentric” adults (Pollak, 1997, pp. 249-50). Asperger’s work did not become known in North America (and presumably was not known to Kanner) until the 1980s, and as such, I do not include it in my archive for this chapter (Nadesan, 2005; McGuire, forthcoming). Despite similarities between Kanner and Asperger, this divergent beginning for
Turning the Gaze Ever-Inward: Governing Mothers’ Inner Lives

The emerging terrain of child psychiatry and psychology as distinct disciplines during the first half of the twentieth century in North America brought certain – and new - aspects of middle-class mothering and child development into view within everyday talk and text. Walkerdine’s work on developmental psychology and child-centred pedagogy (1984) suggests that child psychology depended for its ‘object’ – the ‘normal’ child – on particular child-centred pedagogic practices in homes and schools that made some aspects of children’s (and by implication mothers’) emotional and psychic life visible as ‘natural’ and not others, producing new ‘truths’ about normal child development through these same practices (also see Dehli, 1994a, p. 90; Rose, 1999). The production of such truths, “make possible both what can be said and what can be done” (Walkerdine, 1984, p. 149). In a climate of heightening concern for social stability and governance of the family and child (Rose, 1999, pp. 123-9), new truths about development recast the lines between normal and abnormal, with “early infantile autism” often forming the extreme pole of an emerging category of “emotionally disturbed children” in Ontario (other examples include delinquency, psychosis and shyness), now considered distinct from both adult “disturbance” as well as childhood “feeblemindedness” or “mental retardation” (Nadesan, 2005, pp. 53-79; Kirkwood, 1967, p. W1; Landsberg, 1965a, p. W1; Landsberg, 1965b, p. 18; Schill, 1957a, p. 13). Alongside these new knowledges and categories of childhood disorder, as well as new forms of visibility (see below), new understandings of normal development also meant new treatment facilities for emotionally disturbed children

autism does point to both the historical convergences and divergences of what is now considered a unitary disorder – autism spectrum disorder - despite continued divergences across time and space (Grinker, 2007; Kim, 2012; McGuire, 2011b).
emerged, like the program for autistic children at Thistletown in Toronto for example, which re-occupied older custodial institutional space ("A Fine Start," 1958, p. 29; "Thistletown Plans Expansion," 1960). Rather than a custodial emphasis, however, their focus was on rehabilitation through early, short-term and often residential treatment for children. As Stiker (1999) says of rehabilitation in general, it “marks the appearance of a culture that attempts to complete the act of identification, of making identical” (p. 128). In other words, unlike the “mentally retarded,” the newly emerged autistic population was thought to not only be “improvable” but also curable or at least capable of achieving some degree of normalization (on the historical separation of the “improvable” from the “unimprovable” see Rose, 1985, p. 37, pp. 39-89). It would be the intimate involvement of mothers within these newly emerging forms of treatment, an involvement that invited mothers to turn their gaze toward the governance of their own inner emotional and psychic life rather than their child’s, that would most strikingly bring mothers’ domestic, emotional and embodied practices into view in new ways.

**Forms of Visibility: Maternal Treatment**

Bruno Bettelheim’s work as the director of Chicago’s Orthogenic School was influential in popularizing the emergence of new forms of visibility for autistic individuals and their families in Toronto, including the symbolic and literal psychoanalytic treatment of mothers. Bettelheim’s influence in North America as a leading child expert during this time was considerable. Although he was a clinician and researcher, Bettleheim wrote several popular books about autism and emotional disturbance in children that held wide sway. He had an accessible style, and was featured regularly in American newspapers, popular magazines (*Scientific American* and *Time Magazine*), women’s magazines (*Ladies Home
Journal) and television talk shows (Dick Cavett Show), many of which were available to Toronto audiences. His work at the Chicago school was even popularized in a made for television movie (Bettelheim, 1950, 1967; Nadesan, 2005, pp. 97-8; Pollak, 1997, pp. 249-285; Hanley, 2002). Bettelheim secured a Ford Foundation grant (1956-62) to study and treat autistic children at this school in Chicago. He believed, following psychoanalytic theory more generally (Ehrenreich & English, 2005, p. 4110, 4121), that it was by giving autistic children the love and proper nurturance for each stage of development damaged by their disordered parents, predominately by the mother’s failure as a naturally loving maternal figure, that recovery from emotional disturbance might be found (Bettelheim, 1967, p. 7). This meant that mothers, too, required treatment.

Bettelheim’s influence found its way to Toronto. Warrandale, a residential treatment school committed to providing the “love and essential nourishment for growth” for “emotionally disturbed” children, was influenced by Bettelheim’s psychoanalytic approach (“Centre’s Controversial Director has 90% Success With Patients,” 1965). The school was directed by social worker John Brown who studied at the University of Chicago and worked with others influenced by Bettelheim’s approach. Amidst much controversy surrounding his psychogenic approach, Brown implemented the holding method, one layered with Freudian symbolism aimed at correcting the damage of a mother’s disordered love. In one scene from the Cannes Festival award winning Allan King documentary of everyday life at the school entitled Warrandale (King, 1967), two female staff members are featured in what appears to be an example of such ‘maternal treatment’. The film shows them forcibly holding - restraining - a boy of approximately ten years of age who is

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physically struggling against them and telling them to “fuck off.” When he asks one of them to get her breasts out of his face, this female staff repeatedly asks him (while continuing to shove her breasts in his face), “Why don’t you like my breasts in your face?”

As the boy spits and struggles, a second female staff member takes over. She straddles him, pinning his hands above his head and yelling, “I don’t care what you think about my breasts! I want to know what you’re really feeling!” At length, the boy collapses in tears as Brown himself enters, adjusts the holding technique of his female staff members, strokes the boy’s face and reassures him that he is being helped. The viewer is invited to wonder what kind of breakthrough or help they may have just witnessed in Brown’s male, scientific adjustment of the forceful care and treatment by these female staff, and the boy’s tears that fall at the end of this ‘primal scene’. Has the boy’s damaged development vis-à-vis his mother’s damaging love been forcefully corrected by being held to the female breast (regressed) and guided by the male hand of science? Here, the causal link between a mother’s disordered female nature and the deficit of autism (Thomson, 2001) is made bodily, through a symbolic mother’s breast, which also becomes, naturally, what might recover this damaged autistic child as guided by the careful and authoritative hand of a science symbolized as male grounds of knowing human life.

While autistic children were identified within new scientific regimes and moved into residential or day treatment, mothers and families were also being worked on and

35 It is troubling to note the way in which Warrandale (King, 1967) played a key role as the first of a series in a new form of cinéma vérité King introduced - “actuality drama.” It was considered a pioneering piece of art, and King himself an artist of great depth. King’s aim was to “capture life as it happened” and chronicle “unadorned reality” in the form of “passionate stories.” This form of cinema was understood as showing great compassion for those who suffered the extremes of the human condition (see Koresky, n.d.). However, the effect of Warrandale seems more to confirm dominant conceptions of autism as a tragic and bizarre condition that must be remedied, even if by violent means, than it does pioneering art. And it is interesting to note that the chronicling of histories of normalized violence against autistic individuals, alongside their exploitation as objects of innovative cinematic documentation, was deemed appropriate knowledge and practice, and not evidence of human rights violations, for example.
brought into view anew. In addition to the symbolic maternal treatment described above, Brown also included “disturbed” mothers and families directly in their children’s treatment through recreation and support groups (Stapleton, 1965, p. 57). Other treatment centres with a rehabilitative goal also emerged in Toronto during this time. The Crèche, a day treatment program for autistic children in Toronto, operated with a pedagogic and therapeutic emphasis for mothers and children. Mothers were invited to observe social workers as they worked with their so-called disturbed child (“Crèche Hears Praise of Welfare Work,” 1961; “Crèche Will Continue Treatment at Centre,” 1961, p. 52; “Taught to Be Children at This Day Nursery,” 1962, p. 5). In addition, Thistletown, a traditional residential therapeutic hospital program for autistic children involved mothers in counseling (“A Fine Start,” 1958, p. 29; Landsberg, 1965b, p. 18). Such treatment also moved into the home through therapist’s visits, where mothers’ domestic practices - cleanliness and domestic routines, for example - could be directly observed and scrutinized for signs of compulsivity or disorder (Park, 1967, pp. 164-5). Ironically, while mothers’ love was considered “natural” and mothers were urged to “trust their instincts” during this time, scientific guidance about what these so-called natural instincts looked like – brought into view through the touch of Brown’s hand or mothers’ observations of professionals - was also required (Ehrenreich & English, 2005, p. 4144; also see O’Malley Halley, 2009, p. 52).

The inclusion of mothers, families, and indeed, the wider public in treatment, whether symbolical or practical, represents a key shift and new form of visibility emerging alongside new treatment facilities, regardless of approach. Indeed, it was very often the mother, instead of or in addition to the autistic child, who was prescribed treatment in order
to properly interact with her child, and whose domestic and emotional life was thus brought into view and governed in new ways. In *The Siege*, one of the first widely published autism mother narratives, Clara Claiborne Park (1967) describes her initiation into psychoanalytic treatment for her autistic daughter, Elly, through Anna Freud’s Hampstead clinic in England. While the experience differed markedly from the “chilly” reception in other clinics the family had tried in the United States, Park recounts,

The sessions, to my initial surprise, centred not on Elly but on me. It was not until much later that my husband told me the one thing that the Clinic had withheld; that they had thought that it was less with Elly’s emotions I would need help than with my own. (Park, 1967, pp. 158; also see Hanley, 2002)

The guidance, intervention and expertise of scientifically grounded approaches was needed to put in order mothers’ disordered inner emotional life for the benefit of her disordered child by turning her own gaze ever-inward. Psychoanalysis’ instinctually loving mother was to be guided by the “insidiously paternalistic” advice of professionals (Ehrenreich, 2005, p. 4153, 4158, 4191). According to this clinic, however, Park was an “unusual” mother. She had already demonstrated that disordered love could be corrected with her “persistence and energy” (p. 155). Because of Park’s attention and proximity in mothering Elly, one now bolstered by professional guidance, “Regressions had been kept temporary. A massive regression now appears unlikely” (1967, p. 155).

Through new forms of visibility like maternal treatment the value and prestige of professionalism and scientifically grounded conceptions of autism now bodily inhabited conceptions of mothering. This accomplished a remarkable, contradictory yet ordinary
understanding of mothers as both the cause of and the cure for autism in an historical moment where disability and femininity intertwine as deviance and disorder (Thomson, 2001). While this linkage between autism and mother brings to mind Goffman’s courtesy stigma, it also exceeds his conception of disabled-nondisabled relations. Goffman describes a courtesy stigma as the “discredit” that is extended to “the ‘wise,’ namely, persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it” (1963, p. 28). Yet mothers were obliged to “share some of the discredit of the stigmatized person to whom they are related” (p. 30) and more, since mothers’ disordered nature caused the discredit. As such, mothers were compelled to open their domestic, bodily and emotional lives to scientific and professional scrutiny (on the scientific regulation of motherhood see Ehrenreich & English, 2005; Walkerdine, 1984; Walkerdine & Lucy, 1989; on professional scrutiny see Gibson, forthcoming), and to turn their own gaze ever inward toward the scientific reordering of their disordered emotional and psychic life. In this, mothers were invited to fashion and negotiate their identity as a contradiction, as one both guided and shaped by the paternalistic hand of science and driven by maternal love, itself presumably shaped by both science and nature (on paternalistic science, autism and mothering see McGuire, 2011b, p. 78). The practices, vocabularies and techniques of what Nikolas Rose (1999) calls the “psy” disciplines – psychology and psychiatry – both constituted the identity of mothers anew in this historical moment, and enticed mothers into their own self-governance through these same regimes. This social process not only exalts mothers like Park, who love their child with “persistence and energy” as they broker their own scientific governance. It also
puts in order what being a good mother can mean for all mothers in their intimate ordering their emotional and psychic life.

**Forms of Visibility: Case Studies**

A second form of visibility already operating in Kanner’s (1943) article above, and further developed in Bettleheim’s work on autism – the case study - brought the newly captive autistic population, as well as their mothers and families into view in new ways, and within the ascendant scientific vocabularies of psychoanalysis. Case studies depend on the expertise and interpretive frames of their narrator for direction. They include the collection, viewing and interpretation of in-depth information – often viewed as the facts about a case - about an individual’s so-called exceptional life in all of its “peculiar and exotic” 36 history, along with that of the individual’s family context. They have recently been used, sometimes in liberatory ways, in a variety of disciplines, including the social sciences (ethnography, autoethnography), social work, education and journalism. They differ from other narrative forms, such as scripture, myth or folklore, and seem linked to the emergence of other modern European colonialist practices of chronicling the fine distinctions between the normal and abnormal, such as the medical case history, the cabinet of curiosities or the freak show (Thomson, 1996, 1997, 2001). Among others, the sixteenth century book, *On Monsters and Marvels* by surgeon Ambroise Paré (1982) is an example of how the case study as a form of medical visibility has long-captured the intimate movements of mothers in Western culture and linked them to the production of disability. The myriad case studies in this volume documenting mothers’ implication in childhood

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36 I wish to thank my colleague and friend Margaret F. Gibson for her permission to use our personal correspondence (May 18, 2014) in emails about case studies as a form of Western medical and colonialist visibility. Also see Silverman (2012, pp. 72-3) for further reading on Bettleheim’s case studies.
deformity include the following: “narrowness, or smallness of the womb,” “the imagination,” “having remained seated too long, having had her legs crossed, or having bound her belly too tight when she was pregnant,” “having received some blow or fall,” and “hereditary diseases” (Paré, 1982, pp. vii-viii). Here, the supernatural weaves together with emerging scientific understandings of biology and heredity to blame mothers and explain the abnormal. In psychoanalytic vocabularies, the case study brought mothers’ psychic lives into view, subjecting the devalued feminine realm – the emotional, embodied and domestic – to scientific governance in new ways.37

Bruno Bettelheim forged his psychoanalytic theory of the cold, refrigerator mother, for example, from case studies he describes in his popular book, The empty fortress: Infantile autism and the birth of the self (1967), as well as in popular science features like Joey: A “Mechanical Boy,” which appeared in Scientific American (Bettelheim, 1959). In The Empty Fortress, Bettleheim lays out his theory of the rejecting mother as one who initiates an autistic withdrawal in her child through her own chilling emotional disorder. While also taking pains not to directly blame mothers by stressing that it is the infant who ultimately responds to these chilling mothers, Bettleheim is also now infamous for such statements as, the “mother’s pathology is often severe,” (1967, p. 69), and the “figure of the destructive mother…has its source in reality, namely the destructive intents of the mothering person” (p. 71). As support for his theory, Bettelheim draws both from sympathizers in psychoanalysis (see, for example, Mahler as cited in Bettelheim 1967, p. 43), as well as from detailed and lengthy symptomatic and family case studies for three autistic children. He took particular aim at the mother:

37 See also Sigmund Freud’s (1990) use of the case study as with “Little Hans” and “Dora,” for example.
...the mother felt trapped in her marriage, resented husband and child...both to earn enough to keep the family going and to forget it all, she went back to nursing...she chose to work in a setting that matched her own feelings of hopelessness: a hospital dealing mainly with terminal cases. The infant’s total care was left to miscellaneous baby sitters, some of whom seemed to inspire Marcia with great fear. What little the mother did do for Marcia “I did in a hurry. I’m a bossy person.” (Bettelheim, 1967, p. 158)

Here, Bettelheim takes us far afield from the autistic child, implying that the mother’s disordered feelings, desires, intentions and wishes - indicated by her resentment and choice to return to “work in a setting that matched her own feelings of hopelessness” - and her subsequent careless inattention to Marcia, were damaging and initiating factors in her daughter’s autism. Bettleheim’s conclusion reflects the popularity of psychoanalytic sentiments during the post-World War II years that mothers naturally belonged in the domestic realm. Their absence through work, rejection or unconscious “aggression” toward their child was catastrophic, resulting in a host of emotional ills including infantile autism (Ehrenreich & English, 2005, pp. 4265-4291). Case studies bring a mother’s bodily and psychic movements within this unnatural relationship with her child into stark view (on the “characteristic movements of life” see Bordo, 2003, pp. 165-6; Foucault, 1976/1980a, p. 25; Titchkosky, 2007, p. 171). This new form of visibility created new and intimate spaces of governance for mothers that enticed them to turn their gaze inward, toward the affective investment in domestic roles and scientific governance of their love and maternal instinct.

Bettelheim’s signature inclusion of strange photographs, paintings and drawings by autistic children in his case studies were another “diagram of power” (Dean, 1999)
associated with autism popularized during this time. They provided further evidence of so-called harm by mothers and illustrated an emerging scientific understanding of autism as the withdrawal of self from the world, as well as a nascent discourse about the “recovery” of children from autistic withdrawal (Bettelheim, 1967, pp. 89-339). In Joey: A “Mechanical Boy,” for example, we meet Joey, a “schizophrenic” (autistic) child who “had been robbed of his humanity” (Bettleheim, 1959, p. 117) by cold, rejecting and emotionally neglectful parents who treated him like a machine. The mother was particularly targeted:

How did Joey become a human machine? We learned that the process had begun even before birth. Schizophrenia often results from parental rejection, sometimes combined ambivalently with love. Joey, on the other hand, had been completely ignored...“I never knew I was pregnant,” his mother said, meaning that she had already excluded Joey from her consciousness...“I did not want to see or nurse him,” his mother declared. “I had no feeling of actual dislike. I simply did not want to take care of him.”...We were struck especially by her total indifference as she talked about Joey. This seemed much more remarkable than the actual mistakes she made in handling him. (Bettleheim, 1959, pp. 117-8)

This mother was clearly “out of order” and lacking. As Ehrenreich and English (2005) describe the mother-child relationship during this time, “If anything should go awry in the mother and child relationship or in the child’s development the finger of blame would no longer point at the mother’s faulty technique, but at her defective instincts” (p. 4232). Here, natural motherhood, grounded in a female biology that necessarily harbors a desire to care for her infant, was deficient and “remarkably” missing. “This mother was “indifferent” to
her infant. Her bodily “not-enough-ness” (Bordo, 2003, pp. 160-1) as a mother that “excluded Joey from her consciousness” invaded her child as an autistic withdrawal.

Bettleheim documented how, with the school’s help, “Joey at last broke through his prison…and became a human child” (1959, p. 127), a humanity that excludes the alterity of autism and the “not-enough-ness” (Bordo, 2003, pp. 160-1) of different indifferent mothers, standpoints that are not a part of the “in-group” or “the good” (Schutz, 1962, p. 13).

Bettleheim documents Joey’s journey back from autistic withdrawal through drawings. The earliest, a line drawing self-portrait, shows Joey as a robot formed from coiled wires. This “symbolizes the child’s rejection of human feelings” (1959, p. 116) as a result of parental rejection, says Bettleheim. A series of drawings follow with more complex configurations of robots and machines, which demonstrate, for Bettleheim, Joey’s growing self-esteem and efficacy “since he has acquired hands with which he can manipulate his immediate environment” (p. 119). Joey’s “intense anxieties,” a result of “rigid but also completely impersonal” (p. 122) toilet training by his mother led to a series of pictures about sewage and Joey’s damaged anal stage of psychosexual development. A final picture in the series shows a “gentle landscape,” which, according to Bettleheim, “symbolizes that human emotions had been regained. At 12, having learned to express his feelings, he was no longer a machine” (p. 126). New forms of visibility such as maternal treatment and the case study turned a mothers’ gaze inward toward her bodily practices and psychic life in new and contradictory ways – mothers became essential to normal development yet destructive, scientifically guided yet necessarily proximate and naturally loving. In this way, important new links were made between a contradictory feminine, the emerging category of autism, and the moral and scientific governance of the good/bad mother.
A Technology of Affect

Indeed, it was in some measure through the psychoanalytic blame of mothers for autism – what might be considered a technology of affect – that mothers were invited to turn their own gaze ever-inward, toward the scientific guidance of the conduct of their inner life. During the 1950s and ‘60s, psychoanalytic approaches eclipsed, although not entirely, the influence of alternate understandings of autism. Drs. Ilg and Ames of the Gesell Institute, for example, two female doctors who appeared regularly in the 1960s in a child behavior column in the Toronto Daily Star, offered a biological understanding of autism and reassurances for mothers,

The viewpoint which lays the blame for neurosis, emotional upset, autism or other differences in children at the doorstep of the parents (especially the mother), has many adherents. And it has its encouraging side as well as its discouraging one...Most parents would feel more relaxed if they shared our belief that most cases of brain injury, and even such extreme emotional disturbance deviations as autism are largely determined by genetic factors. (Ilg & Ames, 1961, p. 65)

These “more relaxing” biological paradigms represent an alternative birth for autism within North America, one that arose alongside psychoanalytic views. Both Kanner and Asperger felt there was some biological aspect to autism, for example (Kanner, 1943; Asperger, 1991). And in 1964, at the same time Bettelheim’s refrigerator mother was enjoying

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38 My approach to the affect as a technology of governance, is indebted to the work of Derek Hook (2005) on racism as affective technology, and Sara Ahmed (2004) on economies of affect. In this dissertation, I critically interrogate the ways in which affect operated intimately as a technology of self-governance within shifting scientific regimes that were linked to distantiated programmes of rule.

39 It is interesting to note that today’s biogenetic approaches, while dominant, have not dispelled psychoanalysis nor its version of mother blame from the world stage – it remains the dominant approach in both France and South Korea for autism treatment and research, for example (Grinker, 2007; Kim, 2012).
popularity, Bernard Rimland, a psychologist and father of an autistic son in the United States, put forward a counter-theory of autism as a genetic and neurocognitive disorder (Rimland, 1964; also see Nadesan, 2005, pp. 148-9). It was not quite yet the time for the rise of biological understandings (cognitive psychologies and biogenetics) of being human, at least not for autism, however. Indeed, this moment is one in which the emergence of the ‘truth’ about autism, and autism mothers, can be grasped in Foucault’s (1984) genealogical sense, as linked to historical struggles of power, knowledge, domination and subordination.

In the 1950s and 1960s in Toronto, it was the scene of the mother-child relationship, particularly that of the nursing infant and a mother’s intimate responses, through which normal development proceeded or was arrested as the case may be (Nadesan, 2005, pp. 97-9; also see McDonnell, 1998). Much psychological research during these years agreed that normal development now depended upon a mother’s proximity: “The studies of Bowlby, Ainsworth and others fueled the claim that children’s mental health depended on mother-love – and that mother-love meant being at home with your child” (Ladd-Taylor, 1998, p. 14; also see Ehrenreich & English, 2005, p. 4297). As Bettelheim put it for the case of autism, and in psychoanalytic terms:

Because while the infant can make it clear, through the way he holds his body, whether or not he feels comfortably held, he cannot ensure that this active expression of his feelings will meet with a positive response. That will depend on how the mother reacts. (Bettelheim, 1967, p. 17)

Here, the mother-infant relationship is imagined to be naturally symbiotic. The infant’s actions “make it clear” to the mother what her response should be. A mother’s negative
emotions, her “too-muchness” (Bordo, 2003, pp. 161) or not quite right love, as responses to the stimulus of her infant’s “active expression of feelings” cumulates in a “negative” result in her infant – its eventual autistic withdrawal. A mother’s love, or natural adjustment to her infant’s “active expression of feelings” garners a ‘positive’ result – normal development. According to Bettelheim, maternal reactions could range from the most subtle – a grip that is slightly too firm – to the most extreme: “I believe that the initial cause of withdrawal is rather the child’s correct interpretation of the negative emotions with which the most significant figures in his environment approach him” (1967, p. 66).

Bettelheim, among others, even went so far as to assert, “the precipitating factor in infantile autism is the parent’s wish that his child should not exist” (1967, pp. 125-6; also see Mahler as cited in Bettelheim, 1967, p. 43; Hanley, 2002). Bettelheim’s theory was echoed in mass media and popular science circulating in Toronto at the time, “Thwarted or ignored in early childhood by hostile or indifferent parents, victims of autism sense during infancy that their own action cannot shape their lives” (“Psychiatry: Chicago’s Dr. Yes,” 1968). The “parent” referred to, of course, was predominately the mother, who harbored “murderous impulses” (Mahler as cited in Bettelheim 1967, p. 70) that her child should not exist, and through her subtle and extreme bodily and psychic responses, extinguished her infant’s humanity – a humanity in the shape of particular stimulus-response patterns and not others - and initiated autistic withdrawal. This deterministic psychological view of being human ties disordered femininity to disability (Thomson, 2001), and has no room for autistic difference, interpretive ambiguity within the mother-child relationship (which might include both love and aggression!), nor creative agency on the part of the mother or child. This extreme scientific regulation of mothers’ so-called natural love as potentially disordered (unnatural)
and toxic diminishes their humanity and attests to what feminist Adrienne Rich describes as the “invisible violence of the institution of motherhood” (Rich, 1986, p. 277), a violence that operates through blame, fear and guilt.

Accomplished through the psychoanalytic scrutiny of a mother’s emotional, psychic and bodily life – a technology of affect - these subtle and extreme forms of scientific blame that simultaneously required a mother’s proximity were invitational, urging mothers to follow psychoanalysis’s gaze inward:

I could not say that Elly [autistic daughter], in the give and take of a family…was getting far more of what she needed than she could in a residential school…I could not speak these heretical thoughts; I could do no more than allow them to hover at the edges of my mind…I feared that as soon as a real psychiatrist learned about our games he would recognize them for what they were – a mother fooling around, lucky if in her inexperience and deep involvement she merely escaped doing harm.

For how likely was it that she could escape it? Alone, without professional guidance, what possible qualifications could a mother have with her psychotic child herself? (Park, p. 121)

Here, to be a mother has come to mean being “alone, without professional guidance.” While science would eventually confirm to Park she had indeed helped her child, here, she describes her fear of harming her child through “fooling around” and “deep involvement” in her own mothering practices as “games” outside of the gaze of science. As another mother asks in the documentary Refrigerator Mothers, “What have we done that is so awful that would drive a child into such a regression? I was told that I had not connected or
bonded with the child because of inability to properly relate to the child” (Hanley, 2002).
The esteem of science in the natural attitude had psychically and bodily inhabited
conceptions of natural mothering, alongside mothers’ interpretive processes. The idea that
the paternalistic “input of experts” was tantamount to successful mothering had been well
established by mid 20th Century through the mental hygiene and child guidance movements
(Nadesan, 2005, p. 70; also see Gibson, forthcoming, on parenting as in need of
professionalization). As sociologist and motherhood scholar O’Malley Halley (2007)
elaborates the contradictions during this time, “Not only were women to trust the experts
before all else; they were to trust themselves in a way that essentialized women, attaching
what it meant to be women to biological understandings of femaleness” (p. 52). Mother
blame – a mother’s damaging nature - now had a scientific basis (Sousa, 2011, p. 222).

A mother’s proximity to her child alongside the scientific requisite to order her
psychic life and desires had become both the cause of autism and the necessary condition
for her child’s normal development (McGuire, 2011b, p. 82; Rose, 1999, pp. 202-4). A
mother’s “heretical thoughts” (Park, p. 121) outside the guidance of science – trusting her
intuition or other mothers’ knowledge about childrearing – turned out to be dangerous. This
paradoxical governance of mothers as naturally nurturing yet potentially disordered,
necessary to the achievement of normal development yet harmful, and therefore in need of
scientific governance and maternal treatment is described by feminist and disability studies
scholars (Grinker, 2007, pp. 86-8; Hyvonen, 2004; McGuire, forthcoming; Nadesan, 2005,
pp. 69-70, 82-3, 97-9; Rose, 1999; Walkerdine, 1984; Walkerdine & Lucy, 1989, p. 29).
What seems new with the refrigerator mother, however, is how forms of visibility such as
maternal treatment and the case study, along with the affective technology of blame and
fear invited mothers to turn their gaze inward, toward the governance of their own so-called
disordered, suspect and potentially damaging feminine psyche, bodily movements and
desires, unbounded by its opposite, science. In hyperbolic terms, the new technology of
affect compelled mothers – perhaps all mothers – into their own scientific and moral self-
governance within the new linkages between a contradictory feminine (natural and
regulated, loving and scientifically guided, damaging and necessary), scientific
understanding of autism and regulation of the good/bad mother.

**Reflecting on Identity**

So far, I have traced how new forms of knowledge, visibility and technology (i.e.,
affect) in everyday talk and text circulating in Toronto during the years 1943-69 practically
linked the emergence of the refrigerator mother with scientific understandings of autism
and a contradictory femininity, regulating the good/bad mother in new ways, through her
own scientific self-governance. In order to consider forms of resistance to these scientific,
ableist and gendered regimes of power in new ways, I pause briefly to reflect on these new
identities themselves.

The new identity of refrigerator mother emerged as part of a larger re-imagining of
the good mother during the post-World War II years in North America. This mother was
thought capable of ordering her desires, feelings and bodily movements through her own
natural love and scientific self-governance, and of necessarily being proximate to both her
child as well as normal development. The refrigerator mother was an extreme example – a
kind of cautionary tale – of what would happen to the children of mothers (and to mothers
themselves) who did not or could not comply with either their so-called loving nature or
new scientific modes of governance. Yet despite this extreme and paternalistic treatment,
the refrigerator mother was an ironically privileged identity (and continues to be today), available only to those with temporal, financial and educational resources, in other words, to white, bourgeois, North American or Western European mothers (on differential access to subject positions see Dehli, 2008, p. 47). This mother emerged as part of – and perhaps as handmaiden to - the post-World War II reassertion of traditional gender roles and push of white middle-class mothers back into the home (Ladd-Taylor & Umansky, 1998, pp. 12-3; Nadesan, 2005, p. 83). Mothers’ role in the “heightened import of childhood in relation to the larger project of social engineering” was differentially shaped by the popular reach of psychoanalytic views (Nadesan, 2005, p. 83). Other bad mothers and their children (i.e., working class, unmarried, Black, overaffectionate) transgressed the bourgeois and white norm and were subjected to different – racist and classed – forms of regulation implying natural inferiority through vocabularies of ‘natural’ development (Caplan, 1998; Dehli, 1994b, p. 198; Grinker, 2007, pp. 86-8; Ladd-Taylor & Umansky, 1998; McGuire, 2011b, p. 82; O’Malley Halley, 2009, pp. 5-15; Walkerdine & Lucy, 1989). In the documentary Refrigerator Mothers, for example, a Black mother recalls, “According to my doctor, my son could not be autistic. I was not white, it was assumed that I was not educated and therefore he was labeled emotionally disturbed…You can’t even be a refrigerator mother. The irony of it all” (Hanley, 2002). To put the matter differently, through heteronormative, raced, gendered and classed logics, ones that included new forms of knowledge, visibility and affective technology, the identity autism mother emerged as a key cultural contradiction - privileged yet subject to extreme governance; naturally loving yet increasingly scientifically (self) ordered; proximate and necessary for normal development, yet linked to disorder and pathology. The refrigerator mother thus linked white, bourgeois
femininity and motherhood to the gendered post-war political economy. In addition, this new figure linked bourgeois motherhood to the ‘improvement’ of an emerging and predominately white, male and bourgeois identity of autism and its corollary – processes of racialized and classed exclusion of non-normative mothers from even the possibility of being good mothers, and their children from being normal (Ladd-Taylor & Umansky, pp. 9-10). It is to the identity autism I turn below.

Within everyday talk and text in Toronto during the 1950s and 1960s, autism was described in the starkest of terms, as a terrible problem, one desperately in need of a solution and only interesting as a problem (Abberley, 1998, p. 93; Mitchell, 2002, p. 15; Titchkosky & Michalko, 2009, p. 2). Suffering from the most “horrifying and far more hopeless” form of “emotional disturbance,” for example, autistic children were “withdrawn to the world…entirely cut off from reality” (Landsberg, 1965a, p. W1). These children were “fearful, illogical, uncontrolled” (Kirkwood, 1967, p. W1). They lived in “fantasies…out of contact with reality” (Darroch, 1965, p. 47), and in “lonely little worlds” (“Parents of autistic hear from experts,” 1969, p. 12). A “forgotten group,” autism was a “relatively rare condition” (“$9,081 Atkinson grant aids west end Creche,” 1960, p. 4) that nevertheless meant a pressing “problem that is too big” for parents to “solve” (Schill, 1957b, p. 13). Autistic children were, indeed, considered “not quite human” (Goffman, 1963, p. 5), their “differentness” an undesired disruption to the natural mother-child bond. Yet the identity of autism is somehow, too, something other and more than the disruptive production of stigma, which Goffman describes as an individual “attribute” interacting with stereotypes (norms) that make a person become “discredited” or discreditable within social processes and relationships (Goffman, 1963, p. 5). Autism emerged, after Kanner, as a
subtraction or lack rather than an attribute, a *withdrawal*, or *regression* “that incarcerated an otherwise ‘normal’ or non-autistic self” (McGuire, 2011b, p. 80) into a prison, state of aloneness or “empty fortress” (Bettelheim, 1967). Within such terms, it is impossible to imagine autism as anything beyond a tragedy, let alone a standpoint, different way of being-in-the-world, viable form of life, or even an identity to negotiate and manage (Butler, 2004). Even the most hopeful voices, like Drs. Ilg and Ames, understood autism as something to be remedied, only this time through mothers’ “Acceptance of them, and reasonable warmth…take part in their rituals, find the clues which are meaningful to them” (Ilg & Ames, 1960, p. 53). Autistic children were at best thought ‘improvable’ if not always curable through the emerging treatment regimes for mothers and children alike that might teach these “mentally disturbed youngsters how to be children” (“Taught to be children at this day nursery,” 1962, p. 5). Indeed, the call for treatment facilities was common in this time.

Bettelheim’s work was formative, along with some others, of the understanding of autism as aloneness and withdrawal from humanity (see, for example, Kanner, 1943; “Medicine: Frosted Children,” 1948). As a survivor of the Dachau and Buchenwald concentration camps, Bettelheim introduced troubling parallels between the trauma responses of prisoners he witnessed in the camps and the autistic children he observed at his school: “infantile autism is a state of mind that develops in reaction to feeling oneself in an extreme situation, entirely without hope” (Bettelheim, 1967, p. 68). He saw similarities between autistic children’s and prisoners’ manner - their “averted gaze,” “withdrawal into fantasy,” “self-stimulation,” “helpless rages” and “empty rote learning” (Bettelheim, 1967, pp. 67-8). All of this Bettelheim understood as evidence of a child being forced to cope
with utterly hopeless and extreme circumstances. Indeed, on *The Dick Cavett Show*, Bettelheim claimed:

This autistic child felt that everybody wants him to be dead as the Nazis indeed wanted all Jews to be dead. And when that cannot in one’s own inner feeling be counteracted – Yes, somebody cares terribly much about me! – then one is so hopeless that one has not the energy to fight back. (Bettelheim as cited in Hanley, 2002)

Like the prison guards, mothers’ neglect and destructive intent perpetrated near murderous harm, initiating a “massive withdrawal” from normal development and the human condition in the form of autism (Bettelheim, 1967, p. 126; on Bettleheim and mothers also see McDonnell, 1998, pp. 223-6). In a very disturbing and ironic sense, Bettleheim’s assertion that the “autistic child felt that everybody wants him to be dead” speaks not to mothers’ neglect or violence, but to Western culture’s violent intolerance of any difference outside of a narrow conception of the human as white, autonomous, rational, masculine, productive and indeed, ‘all grown up.’ The ‘feminine’ realm of dependency, difference, emotion and ambiguity – is a devalued and excluded standpoint from the human (Hughes et al., 2005). Understanding how mothers live with, and therefore both comply with and resist the cultural contradictions of their newly emerging identity as it appears in everyday talk and text calls for a rethinking and revaluing of ‘autism’ and the feminine as not only culturally produced identities but also viable, possibly even pedagogic ‘differences’ in the sense of challenging dominant understandings of the human, identity, difference and care. I
conclude below with a tentative beginning – a different reading of everyday talk and text that rethinks mothers’ resistance within scientific and gendered regimes.

Returning the Gaze? Rethinking Resistance

Ironically, it would be these newly emerged identities – autism and autism mother – together with the less dominant understandings of autism during this time (see, for example, Rimland, 1964) and mothers’ own contradictory experiences in the everyday with their autistic child, that would compose the terms of mothers’ growing resistance to overt forms of mother blame associated with psychoanalytic understandings. The intense scientific surveillance and blame of mothers for their child’s disorder through psychoanalytic practices and vocabularies was particularly heightened for mothers of children with disabilities (Blum, 2007; Ferguson, 2002; Panitch, 2008, p. 19; Ryan & Runswick-Cole, 2008, p. 206; Sousa, 2005, p. 222). A disordered child was evidence of a mother’s deeply defective feminine nature. This mother posed a significant threat not only to her child, but to the sanctity of the good mother, and her natural symbiosis with her child in the domestic realm, a role that anchored the patriarchal, raced, classed and ableist post-war capitalist political economy (Blum, 2007; Ehrenreich & English, 2005, pp. 4219-4237; also see Brodie, 1995 on gender and political economy; Weusten, 2011 on heteronormativity and the good/bad mother). Though mothering work has been both historically devalued and erased, the scientific, professional and public visibility and scrutiny of the bodily and psychic life of mothers with disabled children within everyday text and talk meant that it became “acceptable to blame mom…for being horrible rather than only human” (Caplan, 1998, p. 127; Sousa, 2005, p. 222). Within such intense
scientific mother-blame, autism mothers emerged in a complex relationship of both complicity and resistance with dominant regimes of the good mother and scientific blame. Nikolas Rose (1999), writing on the linkages between governance regimes, expertise and practices of the self suggests that “In the space between the behaviours of actual children and the ideals of the norm, new desires and expectations, and new fears and anxieties could be inspired in parents…” (p. 153-4). While guilt, fear and the impulse toward normalization may indeed have been among such “new desires and expectations,” mothers’ contradictory experiences caring for their autistic child also opened space in which the meaning of autism, mothering and care might be both resisted and imagined anew. Telling a small part of this story here means I begin to read this everyday talk and text about and by autism mothers a little differently.

As early as 1957, after the first 150 cases of autism were identified in a survey undertaken by the Hospital for Sick Children in Toronto, autism mothers and families began organizing (Schill, 1957a, p. 13; Schill, 1957b, p. 11; on the gendered nature of parent activism see Panitch, 2008). At a time when the governance of ‘abnormal’ populations was shifting to demarcate “emotionally disturbed” (including autism) and “mentally retarded” children in Ontario, mothers helped found the Ontario Association for Emotionally Disturbed Children, an early advocacy organization that “formed to discuss ways and means of treatment facilities as well as to discuss mutual problems” (Schill, 1957b, p. 11). In addition to self-help, this organization produced a newsletter and provided briefs to the provincial government on improving education, health care and treatment for their children (see, for example, Ontario Association for Emotionally Disturbed Children, 1964). Melanie Panitch (2008) traces the history of activist mothers during this time for
mothers of intellectually disabled children. She argues that mothers of disabled children emerged as a “vital force shaping advances in disability policy and providing lifelines of information to other parents” (Panitch, 2008, p. 7). While no similar scholarly history for autism mother activism in Ontario before the 1970s has yet been written, this small peek into autism mother organizing suggests that these mothers were, from the beginning, part of this larger movement. Activist mothers challenged custodial forms of care with short-term or community models, established new treatment facilities that included pedagogical possibilities for their child (albeit in the problematic language of rehabilitation and treatment) and spoke from their experience to recast autism outside of psychoanalytic vocabularies, thus recuperating mothers from more overt forms of blame (McGuire, 2011b, p. 84; Panitch, 2008; Sousa, 2005).

These accomplishments are significant. From the extremes of patriarchal ableist governance that composed mothers’ lives including scientific blame and exclusion from the good mother role, autism mothers and families collectively resisted power through new spaces such as self-help groups made possible by their encounters with professionals, the labeling of their children as well as their “natural” caring role in the domestic (Panitch, 2008; Ryan & Runswick-Cole, 2009). Mothers’ caring roles were complex, and included not only caring work in the home and love for their autistic child, but also the extension of “care beyond their own child to broader community or societal concerns” (Traustadottir, 1991, p. 217). Revaluing mothers’ contributions and skills in this historical moment as leaders and organizers, as well as recognizing the expertise that grew out of their mothering experiences and activism as formative in challenging the devaluation of mothers and autistic persons more broadly is one way to begin to tell the hidden “disability story of
parents” a little differently (Avery as cited in Ryan & Runswick-Cole, 2009, p. 43; also see Panitch, 2008; Ryan & Runswick-Cole, 2008; Thomas, 2003). In some ways, the work of activist mothers to “improve the quality of life for people with disabilities and their families” (Panitch, 2008, p. 2) aligns with the social model’s aspirations around disabled person’s right to care. For some disability studies scholars, too, mother’s activism was an important thread within the forming of the disability rights movement within North America (O’Toole, 2004; Panitch, 2008, p. 4). Mothers’ activism is an indication that as powerful as tactics of governance are, they can never be complete. Difference, and human agency, always exceeds. In disability historian Stiker’s words, “We are always other than what society made us and believes us to be” (1999, p. 51). In a sense, mothers’ activism is an example of a different kind of technology of affect formed within the matrices of normalizing scientific and patriarchal regimes – a politicized anger and love as a response to blame, and force of resistance transformative of their child’s treatment as well as their own. For these mothers, the “personal” had become “political” long before the forging of this 1970s feminist rallying call (Boler, 1999, p. 114).

At the same time, it is important to notice how mothers’ resistance took place on the same terms as the regimes of scientific, raced, classed, gendered governance discussed in detail above. Constituted as the living cultural contradiction of the identity autism mother, mothers are complicit. While activist mothers pushed the limits of the meaning of autism and care and sought to address larger social structures of exclusion, they also oriented to disability through a medicalized “crusadership” orientation that seeks systemic change to normalize family life (Darling, 2003; also see Traustadottir, 1991). Rehabilitative, short-term treatment models, as radical as they were, nevertheless seek to achieve identity and as
such, are complicit with understandings of autism as an “undesired differentness” (Goffman, 1963, p. 5; Stiker, 1999, p. 128). What’s more, this kind of advocacy and activism involved a new requirement of proximity and resources accessible only to the most privileged of mothers, yet demanded by all. These contradictory demands, as we shall see, continue to shape the role of autism mothers today: this mother is necessarily proximate yet potentially destructive, loving yet scientifically regulated.

Working at the intersection of interpretive and critical approaches within disability and feminist studies as informed by feminist studies of science suggests there is a way to understand mothers’ resistance and complicity in a more radical sense and revalue embodiments identified as autistic and mothers in the process. Panitch (2008) describes how activist mothers in her study “…express themselves in two streams. One is informed by socially conventional expectations and values and the second is informed by their lived experience” (p. 12). It is the pedagogic possibility of mothers’ complex negotiations within the space between social convention and experience I am interested in attending to here. In her work on everyday text and talk as a site of social action, Titchkosky is helpful. She describes a “liminal space between subject and ground” (2007, p. 21). I understand this space, much like the space I encountered as an autism mother described in Chapter One, as the creative, embodied pedagogic space opened up by both the constraints and the incompleteness of power, in this case, through mothers’ everyday encounter with text as readers. Lewieki-Wilson and Cellio (2011) also describe the potential generativity of this liminal space in mothers’ lives, “…in liminal space, cultural constructions of the subject and situated, embodied experiences intermix, and from/in this fluid boundary state, resistance to cultural scripts and emergent knowledge can potentially arise” (p. 2). Indeed,
mothers’ activism itself suggests that mothers did not completely come to experience or conduct themselves through the ever-inwardly turning gaze of psychoanalytic regimes (Dean, 1999). As Park (1967) states about the overt mother blame in the mass media, popular science and autism research at the time, “These were threatening ideas to confront. Yet somehow they did not take hold” (p. 127). What’s more, says Park, in everyday life with her autistic daughter Elly there are “heretical thoughts” that “hover at the edges of my mind” (p. 121). It is to the radical potential of the liminal space where dominant ideas do not “take hold” and heretical ones “hover” that I finally turn.

Using an adaptation of the case history, autism mothers turned the gaze on themselves and began to ‘write back’ to psychoanalytic power in the form of first-person narratives about life together with their autistic child (these narratives are now proliferating). An early example is Clara Park Claiborne’s The Siege (1967), published in the same year as Bruno Bettelheim’s The Empty Fortress. Park’s is the story of the author’s “siege” upon the solitary world of her autistic daughter Elly, told in the form of a middle-class, educated white mother’s narrative of their life at home, with family and within the maze of professional psychiatry and popular psychology. Trying to understand her daughter’s autism and her role as mother, she reads not only all of the autism experts (i.e., Bettelheim, Kanner, Rimland, etc.) but also other autism mother narratives and mass media accounts as key pedagogical terrains for mothers,

We hear on every hand that what we do in the first months of life…may mark our child for ever. Who are we to qualify this account of our responsibility? Even the parents of normal children move with a certain knowledgeable edginess. What goes
through the minds of parents who know they have a child whose development has gone wrong? (p. 125)

Park’s response to this central question she articulates here is complex, both complicit with and a radical challenge to the psychoanalytic and gendered regimes dominant at the time. She comes quite resoundingly to qualify expert accounts of mother-blame and to reclaim maternal expertise and autistic difference as grounds of knowing and being together differently even while she invokes conventional understandings of autism, advocates for expert guidance and engages various normalizing therapies. Landsman (2009, p. 212) and Sousa (2005, pp. 229) both note this tension in their work on contemporary mothering and disability. Here, I consider these complex tensions during the heyday of psychoanalysis to pry open space where autism, and autism mothers, might be read anew. As such, my re-reading of Park’s well-known and much cited autism mother narrative is its own site of social action that both attempts to reveal the ground that (continues to) make sense of this narrative, as well as open space between this ground of knowing and my re-reading of it as an act of resistance that attends differently to the difference of autism and a mother’s care (Smith, 1999; Titchkosky, 2007).

In some ways, Park’s narrative proceeds on the same terms as those of Kanner (1943), Bettleheim (1967) and mass media accounts, in other words, on the terms of a good mother identity, normal development and emerging views of autism as bizarre, otherworldly, solitary and tragic: “Elly’s eerie imperviousness, her serene self-sufficiency, belonged to those who, like the fairies, can live somehow untouched by the human experience” (Park, 1967, pp. 5-6). Here, Park invokes conventional metaphors of autism as

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40 Other examples of early autism mother narratives included *Dibs: In Search of Self* (Axline, 1964) and *The Child in the Glass Ball* (Junker, 1964).
aloneness - a child who exists in our world yet is not touched by the presence of others. Park seems to have no language to describe Elly’s difference in familiar terms (Weusten, 2011, pp. 66-7). Kanner himself helped to forge this understanding of autism as aloneness in his original 1943 article when he set out to newly describe and distinguish this group of children who were “happiest when left alone” (p. 218). As Jack (2014) points out, Kanner also introduced autistic children as “markedly and uniquely” different from other disordered children too (Kanner, 1943, p. 217). They were, unlike the category of “mental retardation” (the earlier category of “feebleminded” did not make this distinction) emerging in North America during this time, thought by Kanner to possess a potentially normal intelligence, and therefore capable of learning, improvement and even normalization (Jack, 2014, pp. 52-3). Park makes note of Kanner’s distinction, and in some ways uses the privileged, white identity of autism and intelligence to drive her hero narrative of trying to break through to the otherworld and rescue the presumed normal, intelligent child trapped and aloof inside this seeming fortress (1967, pp. 36-7). Indeed, Park recounts several moments along the way within her narrative of middle-class mothering where she tirelessly experiments with various maternal pedagogies to try and catch glimpses of Elly’s intelligence and further her normal development, “Three days after I had made a cross, she made one. Surely, it took more intelligence to copy a figure from memory at a remove of three days than to imitate it immediately afterwards as a normal child would do?” (Park, 1967, pp. 15-6). Even while “these were lights that flickered and went out” (p. 16), they were, for Park, hopeful signs that there might be potential in Elly for normal development, and that good mothering might unhinge her captivity by autism.
Yet even on these now-familiar and problematic terms (i.e., mothers’ love as necessary to normal development, autism as aloneness and the withdrawal of a normal child), Park’s narrative introduces an alternative way to care about ‘autism’ and autistic persons through the pedagogical and ethical moments that open up within her descriptions of her life together with her daughter Elly. While her tale parallels the romantic hero narrative prevalent in the psychoanalytic approaches outlined above (Jack, 2014), Park offers no resolution. “It has been a long siege,” says Park. “As a siege, it has been successful, for we have reached Elly. Whatever else she is, she is no longer walled off from affection. Yet we are not the first to discover that to reach another human being is not in itself to cure” (1967, p. 261). Park does not claim to recover her daughter Elly through her love nor her engagement with psychoanalytic approaches and professionals (Jack, 2014, pp. 50-6). Rather, she challenges the notion of natural love and the prestige of scientific expertise. First, based on her experiences with Elly, Park suggests that love is more than just an emotion. Like Sarah Ruddick’s “maternal thinking” (2005, pp. 13-27), Park argues that love is also a practical form of intelligence and reflection arising from everyday life together caring for children, “Intelligence and love are not natural enemies. Nothing sharpens one’s wits for the hints and shadows of another’s thinking as love does…There are millions of parents who practice this love daily…knowing that love is a technique as well as an emotion” (1967, p. 195). “Intelligent love” means that being a good mother involves thoughtful practices and reflection gleaned from everyday life together as well as science, rather than somehow ‘natural’ practices that flow from a mother’s ‘natural’ love. In this way, Park redefines the meaning of being a good mother as thoughtful care, one that might also be taught and learned (Weusten, 2011, p. 60). Park also confronts professional
and psychoanalytic expertise, inverting the metaphor of cold mothers and mother-blame
after she and her husband encounter professionals more aptly described by these terms, “I
think I can guess how we appeared to them – highly intellectual, cool, controlled, well-
инformed, prime examples of Kanner’s parents. We were controlled. We had no alternative.
Refrigerator professionals create refrigerator parents” (1967, p. 140). While she fit the
description of a refrigerator mother, Park refuses its pathologizing terms. Rather than
recovery, Park negotiates the tensions between love and scientific expertise as a form of
practical love grounded in experience and the valuing of embodied difference identified as
autism. This kind of love undermines the age-old Reason/Nature and mind/body
oppositions as well as the prestige of science, and recuperates the devalued feminine realm
from the grip of psychoanalysis.

Park negotiates the irremediable ethical paradox of being an autism mother – to love
our unique autistic child and scientifically remedy their difference by achieving normative
identity – by subverting scientific expertise and embracing Elly’s unique way of being (on
uniqueness see Arendt, 1998/1958, pp. 175-181; on alterity and ethical violence see
Levinas, 1969, pp. 33-52, 72-81; on identity see Stiker, 1999). She narrates “long, slow”
progress for Elly in which speech and other skills emerged in their own unique patterns
through Park’s recognition that “we must speak to her in her own language” (Park, 1967, p.
217). For Park, it is this re-claimed maternal love and expertise on the ground of a mother’s
caring role and autistic ways of being as an alternative site of knowledge, as well as a
critical engagement with scientific theory and professionals (Park both read and challenged
current scientific and professional views) that might slowly bring shape to her daughter’s
life: “The wise and gentle professionals of the most famous children’s clinic in the world
had given me the reassurance I could not give myself. They did not think that in my lonely and presumptuous work I had injured my child” (Park, 1967, p. 158). While complicit with normalized, scientific understandings of human development and progress, Park simultaneously shifts the ground of knowing about autism. Maternal expertise, love and experience – “parents are there” (Park, 1967, p. 176) and know the “language” of their children (p. 179) – as an alternative site of knowledge about our world together could now challenge the rational ground of scientific authority and professionals in the understanding and treatment of both autism and autism mothers.

Park’s narrative articulates (albeit in somewhat normalizing language) the possibility of what might be considered a different kind of care, one that is grounded in pedagogy – learning from the ‘difference’ of our autistic child in order to insert new understandings of the human that challenge dominant Western scientific regimes:

We have always made up little songs to fit recurring situations; like many parents we had a good-night song, and others of which we were scarcely conscious. One of these was a car song; to the simplest of tunes, we sang, “Riding in the car Riding in the car Elly and her mama Go riding in the car.”…Surprisingly, she sang it first not when riding in the car, but one day after I had merely spoken the words. This was the beginning of a curious and encouraging development; what we came to call Elly’s leitmotifs. We became aware that this strange child who could not take in the simplest word could absorb a tune and make it do duty for an idea. (p. 83)

Elly’s ‘difference’ is humanized - she uses music, not spoken language, to relate with her mom and communicate her ideas. In this more embodied view, autism mothers become
something more than disordered. Their engagement intellectually and practically is curious and creative rather than cold and disordered. Another moment of such pedagogic care and loving, thoughtful engagement with difference marked as autistic difference is in moments of what Weusten (2011, pp. 62-4) calls “wordless proximity”:

I crouch beside her, ready to enter her world in a way she can appreciate if she will and ignore if she wants to. My finger goes under the blanket, then my hand. No response. My head follows. Elly knows I am there. There are two of us now, withdrawn from the world but near each other. It is very inward, warm and dark – a physical expression for undemanding intimacy. There is nothing difficult here – nothing to do, nothing to say. The only thing you need is time and willingness to spend a lot of it with your head under a blanket. (Park, 1967, p. 92)

Here, Park engages a different way of being together with Elly, opening beyond that of the normative demands of communicative language to be ‘near’ yet not ‘in’ Elly’s world, a moment of warm intimacy and uncertain distance that is perhaps suggestive of the fundamental humanness of ambivalent togetherness and the alterity of us all (on alterity see Levinas, 1969, pp. 33-52, 72-81; on the uncertainty of communication see McGuire & Michalko, 2011). This kind of pedagogic care is echoed in other autism mothers’ stories of their life together with their different child: “They are whole people,” one mother in the documentary Refrigerator Mothers tells the viewers, “They just have a different culture. A different way of communicating. A different language” (Hanley, 2002). Perhaps it is in the (re)turning of our gaze toward these shared yet disqualified knowledges and practices that “hover” at the edges of scientific discourse (whether mid-century psychoanalysis or today’s
biogenetics) yet dwell at the centre of mothers’ lives together with our children that
mothers might work together with feminist and disability studies scholars and activists
across our differences and engage critical forms of resistance grounded in ‘different’
embodiments and love. Chapter four moves now to consider – and re-read - everyday talk
and text during the years 1970-1999 when biological views of the human (behaviourism,
cognitive psychologies, biogenetics) eclipsed psychoanalytic understandings and added
new layers of meaning and forms of governance to autism mother subjectivity as a key
cultural contradiction.
CHAPTER FOUR

Autism’s ‘Mother Therapists’: A New Cultural Hero

This chapter traces the remarkable shift from the decline of autism’s ‘refrigerator mothers’ to the emergence of autism’s ‘mother therapists’ as a new, and newly contradictory, cultural hero within everyday text and talk for the years 1970-1999. During these years, biological understandings of autism, particularly as articulated within neurocognitive approaches, rose (Nadesan, 2005). In many ways, these years were also witness to an emerging Western cultural fascination with autism (Murray, 2008). Manifold everyday depictions of ‘horrifying’ as well as so-called exceptional biological aspects of autism appeared, couched within newly configured narratives of research, recovery, advocacy and coping – everything from biologically grounded behavioural methods of retraining disturbing autistic behaviours, to facilitated (typed) communication with autistic persons, the biology of autistic brains as well as so-called autistic savants (see, for example, Bower, 1986; Dineen, 1991; on autistic savants see Rimland, 1978). Diagnostic criteria of autism also changed during these years, reflecting the shift from understanding autism as a rare disorder to that of a spectrum of disorders that began to be diagnosed somewhat more frequently. At the same time, ‘autism mother’ (and father) narratives followed Clara Park Claiborne’s (1967) The Siege, and an emergent neurodiversity movement began to

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41 Frith (1993), for example, estimates that autism diagnosis using broader criteria during these years changed the rate of diagnosis from 1 in 10,000 to 1 or 2 in 1000...
articulate ‘autism’ as a viable and different way of being-in-the-world, a being in neurodiversity (see, for example, Sinclair, 1993).\footnote{While I am allied to the aims of the neurodiversity movement in terms of valuing different ways of being and equal rights, I do not proceed from the understanding of autism as grounded in the biology of ‘differently wired’ brains. I orient to neurodiversity through an ethic of disruption, that is, through a critical understanding of autism and orientation to disruption’s creative possibilities for being together differently. I employ scare quotes to indicate that I approach ‘autism’ and ‘autism mother’ as culturally produced subjectivities rather than ways of being grounded in biology or as things in and of themselves. I use scare quotes the first time the terms ‘autism’ and ‘autism mother’ are introduced in each chapter, and intermittently, in order to remind the reader of my orientation.}

Autism would be primarily understood during these years, however, as a tragic biological disorder and problem that autism mothers must now work heroically to overcome through their intensive love as well as their practical embodiment of new scientific understandings. This chapter traces this shift genealogically, with interpretive pauses along the way, working to reveal the cultural ground of the “scene” of everyday text and talk in Toronto during the years 1970-1999 in terms of power, identity, resistance and interpretive possibility (on sceneography see Butler, 1993, p. 28; Michalko, 2010, p. 71). During this time, ‘autism mother’ was re-configured as a key cultural contradiction through which a contradictory neoliberal femininity and biological understandings of autism began to regulate the good/bad mother anew. While other mothers of disabled children would also emerge as activists, heroes and ‘mother therapists’ during this time (see, for example, Panitch, 2008, on histories of mother activists and intellectual disability), autism mothers became the hero \textit{par excellence} of newly emerging Western scientific understandings of the human, as well as intensifying Western cultural contradictions between freedom and constraint, love and science, masculine and feminine, for example, themes I explore throughout the chapters to come. I also explore what might be thought of as mothers’ \textit{complicit} resistance within these new biological and intensive mothering regimes, particularly in terms of how mothers began to challenge the paternalism of scientific
authority with the maternal, as well as, at certain moments, narrate the difference of autism
and their love for their autistic child in ethical rather than tragic, ways of being human
together. This chapter thus covers a lot of historical ground in some detail, including the
emergence of biological views, autism advocacy and de-institutionalization.


By the 1990s, the number of everyday texts about autism and mothers (newspapers,
books and magazines) retrievable from the Proquest database grew from the hundreds (129
for 1970-79) to the thousands (4996 for 1990-99). While this is suggestive, and perhaps the
beginning of the “discursive explosion” around autism in our own time (Foucault,
1976/1980a, pp. 17-8; Hacking, 2010), it is the quality of the shift from psychoanalytic to
biological approaches, rather than the quantity, that will occupy me here. A genealogical
approach helps me trace the emergence of new understandings of the human and
approaches to caring for each other and ourselves during this time. An interpretive
sociological approach means that everyday text and talk can also be generatively pursued as
a rich cultural location through which the meaning of our human life together might be
gleaned (Titchkosky, 2011, p. 74). Below, I describe how I went about gathering everyday
text and talk to create a rich archive through which I might both trace new emergences of
‘autism mother,’ as well attend to her appearances in everyday text and talk in order to
pause and begin to reveal the cultural ground that is productive of the constraints and
possibilities of the meaning of being human for us all.

My search for everyday text and talk for this time period was similar to the search
for earlier years when psychoanalysis was the prominent discursive orientation animating
autism talk and conduct. I conducted extensive online searches through the EBSCO
*Reader’s Guide Perspective* and Proquest *Historical Newspapers* databases, and consulted
1985, 1990, 1995) to get a sense of circulation numbers for magazines, which proliferated.
Newly formed or re-organized specialty magazines devoted to public engagement with
issues of parenting as well as science emerged during these years, including *Mothering*
*Science News* (1967). My working assumption, based on Mary Vipond’s (2011) work on
the mass media and television in Canada, is that American magazines, television shows and
motion pictures were readily available to readers in Toronto during these years. I include a
number of American as well as Canadian magazines in my archive. I maintain my focus on
local Toronto genealogy by limiting my newspaper searches to the two major Canadian
circulations in Toronto during this time, the *Toronto Star* and the *Globe and Mail*.
American-based motion pictures such as *Son-Rise: A Miracle of Love* (Rosenbloom, 1979)
are also part of my archive. In terms of books that would have circulated through Toronto
autism mother networks during this time, I include first-person autism mother narratives
(and two autism father narratives) and popular books by autism ‘experts’ that were
reviewed and referred to within magazine and newspaper articles available to a Toronto
audience during this time. Once again, familiar characters from autism history appear in my
narrative - Ivar Lovaas and Bernard Rimland – as well as Toronto’s own emerging cast –
Dr. Wendy Roberts and Dr. Peter Szatmari, for example.

Because the number of magazine and newspaper features about autism and autism
mothers during these years started to become somewhat unwieldy, and because ‘autism’
and ‘autistic’ became the dominant terminology used within scientific research and everyday renderings (versus ‘childhood schizophrenia’, ‘emotionally disturbed’, or ‘psychosis’), I limited my Boolean search phrase used to search databases to ‘autism AND mother’. Full text versions of magazine and newspaper articles were more readily available for these years than for 1943-69, although again, some could not be located (Life Magazine, for example, is difficult to locate in hard copy after 1972 and before the 1990s). Rather than pouring over microfilm, I found myself in the archives of University of Toronto libraries – often in the basement – retrieving and photocopying hard copies of magazines.

Like chapter three, this chapter engages genealogy and what Foucault calls a “history of the present” (Foucault, 1975/1995, p. 31; see also Bordo, 1987, p. 5) in order to trace the emergence of autism and autism mother during this time as well as rethink maternal resistance. I draw from a plentiful and unique collection of everyday text and talk described above to trace emerging forms of governmental power – new forms of knowledge, visibility, technology and identity - that reconfigured the normal human and care (Dean, 1999, p. 30-2). It would be through the re-training of autism mothers’ gaze onto their own self-governance that such lines, at least in part, would be redrawn, and the mother therapist would emerge for all mothers. I also continue to engage my reading of everyday text and talk as its own site of interpretive resistance, one that is faithful to fashioning alternatives to the pathologization and correction of disabled and female bodies through science and technology (Davis, 1995; Stiker, 1999; Thompson, 2001). As such, I take interpretive glances along the way to get at what else might be “behind” (Ahmed, 2006, p. 549) the appearance of the newly emerged autism mother therapist.
Re-training the Maternal Gaze

It would in part be the biological arguments and advocacy of American psychologist Bernard Rimland (1964) together with parents searching for alternatives to institutionalization and condemning psychoanalytic views that the mother-child relationship would be opened to governance anew during these years (see below on the de-institutionalization movement). Bolstered by Rimland’s biological arguments, beginning in 1971 in Toronto and elsewhere, parents, particularly mothers, worked to recuperate the refrigerator mother and educate the public about biological views, fundraise for scientific research and secure public support for therapies, services and respite. Local, provincial and national autism associations were formed in Toronto and elsewhere (Kirkwood, 1972, p. 12; “National society formed: Group will seek aid for autistic,” 1976, p. 14; “Parents seeking help for handicapped children,” 1972, p. 61). This was the “birth” of autism advocacy in Canada (see McGuire, 2011b, p. 84 on the “birth” of autism advocacy in the UK and elsewhere pp. 82-6). Although advocacy is a typical part of most parents’ everyday lives together with their child - from calls to the teacher to guidance of friendships - autism advocacy emerged as a complex, heightened form of organizing akin to activism in that it called for systemic change and moved beyond concern for individual children (Ryan & Runswick-Cole, 2009; Traustadottir, 1991, p. 217). Parent advocates adopted what Darling calls a “crusadership” orientation to disability, one that presses for systemic change in order to achieve normalization broadly conceived for families – access to educational placements, medical treatment, financial support, employment and community living (Darling, 2003, pp. 882-3). Autism mothers fought to maintain institutional ties that supported educational inclusion within the community (i.e., supports to go to school), for
example, and raised sharp concerns about the lack of community supports (Enright, 1989, p. D3; Galt, 1995, p. A1; Wright, 1995, p. A7). Mothers were also involved in innovating alternative modes of communication for autistic children (typed, or facilitated communication; see Dineen, 1991, p. A1) and advocated for scientific research as well as services and respite care (“Families of disabled confronting crisis,” 1989, p. D3). While many parents who adopt a crusadership orientation disengage from their activist work once a level of normalization is achieved for their family, this was not the case for many autism advocates, who continued their activist work on behalf of other families (Darling, 2003, p. 882-3; Ryan & Runswick-Cole, 2009). As we have seen in chapter three, the achievements of mother activists are significant as important sources of information and support for families as well as possible beginnings – ones that go back to the 1950s in Ontario - of the disability rights movement itself (O’Toole, 2004; Panitch, 2008, p. 7; Schill, 1957a, p. 13; 1957b, p. 11). This continues the “disability story of parents” (Avery as cited in Ryan & Runswick-Cole, 2009, p. 43) begun in chapter three, and is a testament to parents’ key historical involvement in work to ameliorate the quality of their disabled children’s lives (Panitch, 2008, p. 2).

Given emerging biological views, however, mothers’ resistance to overt blame through their activism would also ironically be the ground of new forms of governance and lived complicity within biological and intensive mothering regimes during this time (Foucault, 1976/1980a, p. 94; on intensive mothering see Hays, 1996). That is, biomedical remediation and the achievement of identity for autistic children also became a key goal – perhaps the overriding goal - of much autism advocacy, and mothers became its primary
engineers. Breaking away from the earlier Ontario Association for Emotionally Disturbed Children, autism advocacy recast lines in Ontario between “autism,” “the emotionally disturbed” and “the mentally retarded” (Gorril, 1976; Shamsie, 1977; Stone, 1981). Within such reconfigured terms, a mother’s gaze was re-trained away from her disordered psychic life and the mother-child relationship and toward the shaping of a mother’s participation in her child’s remediation. Below, I turn first to consider new forms of knowledge that emerged during the years 1970-1999. Though echoes of the refrigerator mother and her disordered psyche would remain in everyday text and talk, ascending biological views meant autism mothers were relieved of their damaging feminine nature and could now be a potentially therapeutic (healing or corrective) rather than destructive force in their child’s lives (see, for example, Callwood, 1976; Ross, 1989). While the mother-child relationship would still be central to the governance of mothers, biological views shifted governance away from maternal treatment and overt mother-blame and toward a mother’s intensive practice of new scientifically grounded therapeutic techniques to ‘correct’ her child’s autistic behaviour. This newly emerging ‘good’ mother was that of the mother therapist.

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43 For further reading on autism advocacy, see McGuire (forthcoming), *The War on Autism: On Normative Violence and the Cultural Production of Autism Advocacy*. McGuire argues that autism advocacy emerged with biological views as a powerful response to oppressive psychoanalytic regimes and overt mother blame. I agree with McGuire that autism advocacy is a powerful “productive force” generative of the dominant meaning of autism as disorder and Western(izing) regimes of normative violence that impose constrictive understandings of the human as white, bourgeois and abled in increasingly global terms. Throughout my dissertation, I also consider how mother activists, through advocacy, also opened space in which mothers might reclaim maternal authority and resist intensive mothering and normalizing scientific and therapeutic regimes.

44 For examples of this new mother therapist and the behavioural treatment methods she was required to learn, see Chance (1974), Kaufman (1976), Kirkwood (1972) Kohl (1979), Maurice (1993), Schreibman & Koegal (1975), Segal & Segal (1992) and Stone (1981).
New Forms of Knowledge: Cognitive Psychology

First, let us consider American psychologist Bernard Rimland’s biological arguments in *Infantile Autism* (1964) and their place within autism advocacy history and ascending cognitive psychological views more broadly as key within the shifting forms of maternal governance during this time. Similar to Bettleheim’s *The Empty Fortress* (1967), many of Rimland’s arguments would weave their way through everyday text and talk and autism mother networks in Toronto for the years 1970-1999, although other autism experts also helped along the way (see, for example, Frith, 1993; and Moser, 1965 on Ivar Lovaas). An autism father himself, *Infantile Autism* was Rimland’s attempt to refute oppressive understandings and treatments like that of psychoanalysis that physically removed children from mothers and their families. Rimland emerged as both a scientific authority and as what sociologist Howard Becker calls a “moral entrepreneur” – a person of privilege who crusades with near religious fervor to change the rules around a perceived “evil” within a particular arena of social life (Becker, 1963, pp. 147-9). For Rimland and other autism advocates, this included (among other things – see below) debunking the psychoanalytic view and replacing it with the biological. In 1965, Rimland started *The Autism Society* (later renamed *The Autism Society of America*) in order to widely disseminate behavioural and other treatments for autism grounded in his biological theories as an alternative to mother-blame and psychoanalytic views (Rimland, 1993, p. xiv-xv).45

Rimland’s work was part of a larger shift in scientific understandings of the human during these years. Cognitive psychology and the newly emerging neurosciences rose to dominance (Nadesan, 2005, pp. 80-137). One common theory of autism that emerged

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45 For a history of parental involvement in autism advocacy as a powerful generative force of the contemporary meanings of autism, see McGuire (forthcoming).
during this time, for example, is that of Theory of Mind (ToM), a cognitive structure thought to be lacking or disordered in autistic minds (ToM remains a popular approach today). ToM is understood as an innate, evolutionary structure that is the precondition for joint attention and normative empathy, the presumed bedrocks of human sociality (Baron-Cohen, 1995; Baron-Cohen, Leslie & Frith, 1985; Frith, 1993; McGuire & Michalko, 2011; Yergeau, 2013). According to Baron-Cohen, Leslie & Frith (1985) in their pivotal article on ToM and autism, autistic people do not comprehend “that other people know, want, feel, or believe things” (p. 38). In his later essay Mindblindness (1995), Baron-Cohen elaborates, “A theory of mind remains one of the quintessential abilities that makes us human. …The theory of mind difficulties seem to be universal among such [autistic] individuals” (p. 3).

As autistic rhetorician Yergeau points out, within this biological logic, one that has now become an “empirical fact” supporting “whole academic enterprises,” autism is the inhuman that grants those with Theory of Mind their humanity (2013, n.p.). The “empirical fact” of Theory of Mind and dehumanization of autistic persons echoed in everyday text and talk, “Their [autistic person’s] worlds are peopled not by fellow beings with thoughts, feelings and agendas but by skin-covered bags that approach and withdraw unpredictably” (Cowley, 1995, p. 67; also see Adler, 1994, p. 248). During the years 1970-1999, new technologies such as positron emission tomography (PET) and magnetic resonance imaging (MRI) mapped cognitive structures such as ToM onto physical brains themselves, producing ever-deepening and penetrating images of a troubled autistic interiority, images of disruption that were now biological and visual – empirical fact - instead of psychical and emotional (see, for example, Bower, 1986; Nadesan, 2005, pp. 156-7; Rose, 1999a). These newly emerging forms of knowledge brought the autistic population and mothers into view.
in radically new and discontinuous ways from that of psychoanalysis and the refrigerator mother.

In *Infantile Autism* (1964), Rimland conducted an in-depth “review of the evidence” for and against the “psychogenesis of autism” and biological understandings of autism. Evidence in support of the psychogenesis of autism means both the absence of “organic” causes and the presence of possible psychological origins of autism, including emotionally “deficient” parenting (the prevailing psychoanalytic view), maternal deprivation or damaging psychological events in a child’s life (Rimland, 1964, p. 42). After a number of comprehensive review chapters Rimland concludes that there is “no support for the psychogenic point of view. The evidence is instead highly consistent with expectation based on organic pathology” (1964, p. 61). In fact, wrote Rimland, the evidence suggests that autism is the result of brain impairment, one he thought might be located in the “reticular formation of the brain stem” (p. 93). He believed that this sort of impairment led to the cognitive impairments seen in autism, making it impossible for autistic children to link incoming perceptual stimuli to memory, the primary disability associated with autism, he thought. Like Kanner’s (1943) earlier assertion that autism was present from birth, Rimland speculated that disordered behavior in children, including autism, is very probably

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46 The concept of maternal deprivation derives from the work of Ainsworth (1964), Harlow (1961), Bowlby (1951) and others on psychological attachment (through experiments and studies on attachment and monkeys and the effect of hospital care on war orphans, for example), beginning in the 1950s. Similar to Bettleheim’s theory of maternal rejection, maternal attachment theory placed primacy on a mother’s constant availability and care, and identified grave effects including physical illness and autism from her absence, whether total or partial (Ehrenreich, 2005, pp. 4278-4326). While historically linked to psychoanalysis, maternal attachment has been taken up mainly in developmental psychology where ethological rather than psychoanalytic concepts have been influential (Blatt & Levy, 2003, p. 103). Maternal attachment theory did not appear in everyday text and talk about autism and mothering in the same way that Bettleheim’s refrigerator mother and Rimland’s biological view did. Maternal attachment theory and her “chilly” mother continues to revise its understanding of a mother’s role in autism. For examples of the ways the “chilly” vs. sensitive mother haunts Western research see Jack (2014, pp. 61-3) and Koren-Karie, Oppenheim, Dolev & Yirmiya (2009) on maternal “sensitivity” and attachment. Also see Walkerdine & Lucy (1989, pp. 47-63) for their critical analyses of class, maternal attachment theory and sensitive mothering.
affected by prenatal factors—injury to fetal brain development during pregnancy through stress or birth injury, for example. In addition, Rimland postulated a genetic vulnerability to autism due to “an inborn capacity for high intelligence” (p. 120). He concludes with a neurological theory of behavior, positing that impairments to the reticular formation inhibit autistic children from making the so-called normal associations between positive rewards (food, love, comfort) and social behaviors (communication, affection). In these ways, Rimland rethought autism as a neurocognitive impairment, one linked to fetal brain development, prenatal maternal factors, impairment of the physical brain, genetics, intelligence and a biological, rather than relational (i.e., mother/child relationships) view of disordered behaviour and disruptions to normal development.\footnote{For further reading on Rimland’s role in autism history see Jack (2014, pp. 47-8), McGuire (forthcoming), Nadesan (2005, p. 148), Silverman (2012, pp. 106-12, 111-2, 171-77) and Waltz (2013, pp. 119-20).}

Other everyday text and talk about autism and mothers circulating in Toronto during the years 1970-1999 also refuted the refrigerator mother theory in favor of biological views. In “Living with an Autistic Child,” an article that appeared in Parents magazine in 1992, Segal and Segal say, for example, “Cold, remote, and unfeeling, the so-called refrigerator mother was long viewed as the chief architect of her child’s miserable existence…Today we know better. In fact it is clear the disorder’s origins are the result of biological problems” (1992, pp. 90-1).\footnote{Also see, for example, Bower (1981, p. 154), Bower (1989, p. 312), Kaufman (1976, p. 15), Kirkwood, (1972, p. 12), Maurice (1993, p. 75), Rimland (1964, pp. 39-66), Schreibman & Koegel (975, p. 62), Stone (1981, p. T1).} Rimland’s (1964) popular Infantile Autism was perhaps the most comprehensive, scientific and polemical of these refutations. He began to appear within newspaper articles in Toronto as an authority on the biological view of autism, particularly as linked to the new landscape of autism advocacy. As one Globe and Mail article (1976) reported about the founding of the Canadian Society for Autistic

\footnote{For further reading on Rimland’s role in autism history see Jack (2014, pp. 47-8), McGuire (forthcoming), Nadesan (2005, p. 148), Silverman (2012, pp. 106-12, 111-2, 171-77) and Waltz (2013, pp. 119-20).}

Children, for example, “Dr. Bernard Rimland of the Institute of Child Behavior Research in San Diego said too many psychiatrists have blamed parental treatment for the child’s condition” (“National Society Formed,” 1976, p. 14). The article also describes Rimland’s research on elevated brain chemical levels in autistic children, as well as his recommendations for educational (behavioural) treatment and “megavitamins.” Indeed, Rimland’s neurological theory of behaviour would lend weight to the dominant therapeutic approach to autism that arose during these years as key in the re-configuration of the refrigerator mother as mother therapist, that of behaviour modification (see below).

Unlike the psychoanalytic emphasis on the relationship between mother and infant, one that directed a mother’s gaze inward toward her own psychic life and disordered love as the initiating factor in autistic withdrawal, neurocognitive understandings meant that mothers and families might now positively contribute to their child’s (normal) development, a compelling, if medicalized, view for parents. Consider the following excerpt from a lecture that Rimland delivered to a number of chapters of the *National Society for Autistic Children* throughout the United States between 1967 and 1970:

The psychogenic theory has cast blame on the parents, and thus immobilized the child’s strongest ally in what should be his struggle to recover. It has caused stagnation in research – what biochemist wants to analyze a “fractured oedipus complex”? It has caused educators to shrug their shoulders and leave the problem in the hands of the psychiatrists, psychologists and social workers. It has cost families untold fortunes in money, time, convenience and human dignity. And worst of all it has cost far too many children’s lives. Such children are not medically dead – just
psychologically dead, existing like human vegetables in institution after institution.

(Rimland as cited in Silverman, 2012, p. 87)

There are a number of key features to notice in Rimland’s speech to parents. First, he advocates with fervor. Rimland is Becker’s (1963) “moral entrepreneur” of the emerging neuropsychological regime. He at once challenges Bettleheim’s theories, calls for a bio-scientific research agenda in autism, invokes a “recovery” discourse for autism incipient in earlier decades, and calls to parents and professionals alike to take up the new role of “their child’s strongest ally” in recovery. Here, Rimland conflates “ally” with that of advocacy for the biological remediation and psychological recuperation – the “recovery” - of autistic children who otherwise are “psychologically dead, existing like human vegetables” within institutions. The neurodiversity movement of autistic self-advocates that emerged in the 1980s would eventually challenge Rimland’s view of what it means to be an ally to autistic persons:

For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means… Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with. (Sinclair, 1993, para. 3-4)

Being an autism ally then, means recognizing that autism is a different, viable way of being in the world with its own embodiment and language; for the neurodiversity movement, a being in neurodiversity. I employ a somewhat different understanding of ally. While I
support different ways of being in the world as viable and valuable, I orient to
neurodiversity through an ethic of disruption, holding the meaning of ‘autism’ open as an
historically and culturally produced subjectivity, thus subjecting ‘autism’ to critical inquiry
rather than grounding it in the biology of ‘differently wired’ brains. It is this understanding
of ally that I employ rather than Rimland’s or the neurodiversity movement’s, along with
the understanding that the choice for parents is not that of recovery vs. abandoning a
“psychologically dead” child. Creative possibilities for different ways to care about autism
beyond the biomedical and normal/abnormal binaries are the promise of such an ethic.

Rimland also, and importantly, linked the neuropsychological agenda of the
recovery of autistic children to de-institutionalization, a movement that was emerging in
North America at the same time he undertook his advocacy campaigns. De-
institutionalization refers both to the political movement and social policy that sought to
close large-scale custodial institutions and to establish community living, supports and
services for disabled persons and their families, although such supports were inadequate
from the beginning (see, for example, Enright, 1989, p. D3; Galt, 1995, p. A1; Levinson,
2010, pp. 19-36; Panitch, 2008; Wright, 1995, p. A7). In Ontario, de-institutionalization
began, in part, with the work of mother activists in the 1950s. And while the movement of
people out of institutions peaked during 1975-2005 in Ontario, this movement continues in
some respects today (Panitch, 2008). Thistletown Regional Centre in Toronto, for example,
where the most “extreme” autistic children have been in custodial care since the 1950s (“A
Fine Start,” 1958), is still in the process of closing.49 Professionals, policy makers and
parents have been a key part of the de-institutionalization movement (Levinson, 2010).

Influential, too was the work of sociologists such as Erving Goffman (1961), Howard Becker (1963) as well as Michel Foucault (1965/1988a) and others who began to expose professional authority and categories of ‘mental retardation’ and ‘mental illness’ as social and historical processes rather than objective or measurable attributes of individuals (Levinson, 2010, pp. 30-6). Everyday text and talk, too, influenced governments in closing institutions by exposing their often violent, neglectful and dehumanizing conditions (Levinson, 2010, p. 20-1). A 1973 Toronto Star article, for example, describes a reporter’s chilling visit with an emaciated autistic girl who had been institutionalized at eighteen months, screaming as she was taken away by staff for therapy, “Not shocks! Not shocks! Please!” (“The girl who began life in mental homes – at 18 months,” 1973, p. 21).

Mothers’ role in de-institutionalization has been contradictory and complex, and has often been a missing part of scholarly histories (Panitch, 2008). In the 1950s and 60s, pressure from medical professionals to institutionalize medically ‘hopeless’ children who might also be ‘damaging’ to siblings was intense and often traumatic (Levinson, 2010; Manning, 2011). While some mothers abandoned their child to institutional care during this time, many others engaged in activist pursuits to improve the quality of life within institutions (Dolmage, 2011; Levinson, 2010; Manning, 2011; Panitch, 2008). Mothers also innovated and pressed for ways to keep their children at home and fought for educational and community inclusion (Dolmage, 2011; Hopper, 1976; Manning, 2011; Panitch, 2008; Stone, 1981, p. T1). With the closing of institutions like Thistletown in Toronto, Ontario, some mothers also publically fought against de-institutionalization, arguing that community supports were inadequate (Enright, 1989, p. D3; Galt, 1995, p. A1; Panitch, 2008; Wright, 1995, p. A7). Rimland’s conflation of autism “ally” with “recovery” and the de-
institutionalization movement is troubling. It glosses complex, layered and locally inflected histories in which mothers were often already working strategically and collectively as their child’s “best ally.” Rimland’s advocacy also occurred in an historical moment when care was beginning to be pushed back into the home and community as women’s responsibility. It would be the rise of the ‘mother therapist’ and intensive mothering within this restrictive environment (rather than the public investment in living well in difference, for example), and the possibility of “recovery” opened by neurocognitive understandings of autism that would newly layer ‘autism mother’ as a cultural contradiction during this time.

**New Forms of Visibility: Mother Therapists**

While the disordered refrigerator mother of the 1950s and 1960s was included in her child’s healing through “maternal treatment” that often also meant the physical separation from and institutionalization of her child, emerging biological understandings of autism opened a different ground of possibilities. Within everyday text and talk, the ‘mother therapist’ emerged as a key, and new, form of visibility and impulse towards Western culture’s heightening “duty and…urge to act” to achieve self-same identity for all persons (Bauman, 2004a, p. 20; Stiker, 1999). Through detailed descriptions of systematic, intensive and even violent methods of training, and the strategic use of ‘before and after’ photographs of autistic children as diagrams of power, everyday text and talk re-trained a mother’s gaze away from her so-called disordered inner life and toward the scientific reshaping of her everyday, embodied practices of mothering. Clara Park Claiborne’s subversion of psychoanalytic views of natural mothering through her argument that love melds emotion and technique (1967, p. 195), would ironically find its full embodiment in the mother therapist. Mothers were now to be trained in behavioural techniques in order to
take on the role as key healers of autism, rehabilitators of disordered autistic biology and midwives to normal development. This new, and newly intensive role was ironic. Mothers, particularly white middle-class mothers (working-class, Black and other mothers had always participated in the paid workforce), were entering the workforce in record numbers during this time. Care was being pushed back into the home and community, and public support of social programs cut (Brodie, 1995; Ehrenreich & English, 2005, pp. 5754-5844). The autism mother therapist, vis-à-vis new biological understandings of autism, emerged as an intensification of a contradictory intensive feminine who could – and should – work heroically to recover her autistic child within the heightening demands of a shifting and gendered political economy of and care and paid labour force (Hays, 1996; also see Ringrose & Walkerdine, 2008 on the intensification of contradictory neoliberal femininity). As Hays (1996) elucidates, not only does this ideology of intensive mothering conceal unequal gender relations, it pathologizes and individualizes the failure, particularly of non-privileged mothers, to care intensively in this way, excluding many mothers from the ‘good mother’ role (p. 165). I consider how the autism mother therapist operated as a key form of visibility in everyday text and talk in Toronto, bringing intensive bourgeois mothering practices and new modes of scientific governance of the good/bad mother into dramatic view for all mothers.

Among other popular autism researchers during these years, Rimland felt that a “structured, purposeful education program” using behaviour modification was key to reshaping disordered autistic biology, and should replace psychoanalytic therapies (“National Society Formed,” 1976, p. 14; also see Rimland, 1978). This included Rimland’s public support, with some reserve, of psychologist Ivar Lovaas’ experiments on
autistic children using both positive reinforcers for normal behaviours – food, play and hugs for attending to lessons or using spoken language - and violent aversives – slaps, electric shocks and reprimands for autistic behaviours such as flapping, rocking or averting one’s gaze (Rimland, 1978, p.101).50 Here, the role of “moral entrepreneur” and “expert” (Becker, 1963, pp. 147-163) comingle in the figures of Rimland and Lovaas, both of whom lent scientific expertise as well as moral conviction to the emerging behavioural treatment regime of autistic persons and mothers’ role within it. In May 1965, the much-read article “Screams, Slaps and Love” appeared in Life magazine describing Lovaas’ experimental study at the University of California, Los Angeles. Lovaas was hopeful that his experiments would provide a scientifically grounded behavioural method for all parents and professionals to use with children with “broken minds” (Moser, 1965, p. 94; also see Lovaas, 1987). Unlike psychoanalysis, behavioural views of human learning and sociality are not interested in causes or the psychic interiority of human behaviour and cognition, although they typically accept biological views of the human. Instead, changes in the external environment – rewards (reinforcers) and aversives – result in changes in human cognition and behaviour, and, according to Rimland, possibly even biology (Lovaas, 1977, 1984; Rimland 1964, 1978; Skinner, 1963).

In “Screams, Slaps and Love,” mother and child are brought into view in graphic “before and after” photographs and behavioural descriptions. As viewers, we literally “see” the wild and intense disruption of untreated autistic biology in “before” photographs of writhing, raging, contorting, rocking and flapping youngsters, and read about it within descriptions of life with an untreated autistic child. “It was like living with the devil,” one

50 See McGuire (2011b, pp. 88-9) for a discussion on Lovaas’ simultaneous involvement with UCLA’s Feminine Boy Project, a similar approach to “correcting” feminine behaviours observed in boys.
mom shares (Moser, 1965, p. 101). These are “…utterly withdrawn children whose minds are sealed against all human contact and whose uncontrolled madness had turned their homes into hells” (p. 90A). Reason and science in the form of therapeutic behavioural techniques are offered by Lovaas as what might bring control and certainty to the “madness” of an uncivilized (wild) and dangerous (hellish) autistic Nature within the domestic realm (on science and certainty, see Bordo, 1987, p. 5). Therapists working with rewards and aversives are pictured and described in the article until finally the reader “sees” normalcy in “after” photographs and “reads” normalcy in their accompanying descriptions – two children hugging and being rewarded with food, affection for a therapist, attention during a lesson and a mother “overjoyed” with hands clasped at her heart and head thrown back in wonder at her son’s progress toward normal behaviour (Moser, 1965, pp. 90A-D, 91-6, 101). Here, mother becomes a joyful observer of normative correction in her child by any means. Through behaviour modification, the article tells us, Lovaas had “broken through” to the most unreachable of humans, “by alternating methods of shocking roughness with persistent loyal attention” (Moser, 1965, p. 90A) and had succeeded, at least in part, in normalizing them.

Some years later, Lovaas would extend his crusade for behavioural treatment and the moral framework already apparent above –autism as bad (even evil) and normalcy as good - articulating violence as the link through which caregivers must fight for their child’s humanity in love, “Nobody punishes a child who doesn’t also love that child…Once you lay your hands on a child, it morally obligates you to work with that child” (Lovaas as cited in Chance, 1974, p. 80). This behavioural approach is, first, a mechanistic view of the human and mother-child relationship that leaves little room for agency, ambivalence,
reciprocal influence or learning from or with her different child. What’s more, the
behavioural approach conceals the unarticulated background of the prestige of science in
the lifeworld as one that has already accomplished the meaning of autism as “bad” and
“wrong” such that the disruption of autistic bodies are rendered intelligible, and remedied,
through these same interpretive schemes (Husserl, 1970, p. 110; Schutz, 1967, pp. 82-3;
Natanson, 1970, p. 63). In other words, the “biomedical ethics of remedy” (Michalko,
2002, p. 99) and “normal human” make “sense” of this everyday appearance of violent
corrective treatment as shocking, but ordinary, acceptable, and even “humane” acts of love,
care and moral enterprise (these therapies were, after all, for the benefit of disordered
children, their families and the wider society; on moral entrepreneurs see Becker, 1963, pp.
147-63). As we shall see, through training in behavioural techniques, the mother-as-
therapist would, ironically, again come to embody “coldness,” only now she is rejecting of
“autism” rather than her child (recall Bettleheim’s understanding of autism as the
withdrawal of an otherwise normal child). While she no longer causes autism through
rejection, she now “cures” it (Sousa, 2005) through scientifically defined and measured
techniques that include both rejection (slaps, punishments and other aversives) and love
(reinforcers and rewards). The “duty” to shape the embodiment of normalcy in her child
would soon be the clarion call of the mother therapist.

It would be a short distance to travel from mother as the joyful observer of “expert”
intervention to mother therapist – the rehabilitator of her child’s so-called disordered
biology through the paternalistic guidance of science. In 1974, less than a decade later,
Lovaas himself would state, “The parents become the principal therapists and we become
consultants to the parents” (as cited in Chance, 1974, p. 76). Of course, earlier ties to
psychoanalytic approaches did not entirely disappear in Toronto during these years. The Crèche Institute, for example, continued to involve mothers in their child’s therapy through maternal treatment: “…West End Crèche works on developing parental skills by bringing parents together in group discussions of their problems and by meeting with them individually to help them sort out their own childhood misadventures” (Callwood, 1976, p. 7). Here, it was mothers who still needed therapy. Overwhelmingly, however, beginning in the 1970s, everyday text and talk in Toronto brought mothers into view as co-therapists and behavioural interveners in their child’s disrupted neuropsychological development. In 1972, for example, the Globe and Mail described a talk given by Dr. Eric Schopler at the newly formed Toronto Society for Autistic Children. Founder of the North Carolina-based TEACCH program for autism, which uses a combination of approaches including behaviour modification, “Dr. Schopler…trains the parents to be co-therapists for their autistic children” (Kirkwood, 1972, p. 12). Later that same year, the Toronto Star reported one Toronto family’s long journey to find treatment for their autistic child. The article describes their advocacy with the Toronto Society for Autistic Children to secure more programs like the new “rewards program” at the Clarke Institute that continued into the home each night for this mother, “Within 18 months of day long therapy sessions he could make vowel sounds and say simple words…Each night I went over the vowel sounds, holding Graham’s chin and sometimes even shaping his mouth” (Cornell, 1972, p. 87). Parents in Toronto also worked to innovate in-home behavioural modification programs with staff in the autism program at Thistletown - the institutional setting for the most “severe” autistic children in Ontario: “Why, they asked, couldn’t they pay a worker to come to their home and work with their son. The parents would see how the treatment
worked and continue it when the worker wasn’t there” (Stone, 1981, p. T1; also see Hopper, 1976).\footnote{Incidentally, this program would go on to become a self-proclaimed success, win awards and establish the first integrated school program in Toronto. This propelled its leaders to give workshops and advocate for the establishment of such parent-professional-institutional partnerships in Ontario and beyond, including the United States (see Stone, 1981).} Here again, “parents” – a common slippage for “mothers” during this time - were understood as “co-therapists who help design and implement programs to treat their own kids” (p. T1). The ‘mother therapist’ not only brought mothers’ domestic practices into view as a re-configured space of scientific governance for all mothers (a shift that was only just emerging when Clara Park Claiborne (1967) guiltily confessed to her made up “games” at home with Elly), it also helped retrain the maternal gaze away from ordering her disordered inner life and toward the scientific ordering of her embodied mothering practices.

In *Let Me Hear Your Voice* (1993), for example, autism mother of two, Catherine Maurice, details her therapeutic and emotional journey to recover her two autistic children through a behavioural treatment regime. After the devastating diagnoses, she frantically researches and tries all the available therapies she can find, from psychogenic (holding therapy) to biomedical (mega-vitamins). Eventually, Maurice learns of the work of Rimland and Lovaas. After a long consultation with Rimland, she invests her hope for the recovery of her children in the “rigorous” methodology of psychology: “verifiable data, accountability, controlled research, openness to peer scrutiny” (1993, p. 168). She debunks approaches she calls “anti-behaviourist” as anti-scientific and antiquated, still committed to psychogenic views of autism as a normal, beautiful child trapped inside a shell (1993, pp. 271-285), and urges parents to keep an “open mind” about behaviour modification.

Behavioural principles, she tells her reader, are based on “discrete trials, breaking down
tasks, the systematic use of reinforcement and praise…and an extensive curriculum
developed over the past twenty-five years by Ivar Lovaas and other researchers in the
professional community” (1993, p. 331). Maurice both learns and adapts this curriculum
from Lovaas himself at his UCLA clinic, as well as from (1981) Teaching Developmentally
Disabled Children: The Me Book, where he coaches parents in behavioural techniques. She
quotes an example from his book:

    Select two behaviors, one that your child definitely prefers and one that he does not
    prefer. For example, you may ask a question such as, “Do you want candy?” as
    contrasted to the question “Do you want a spanking?” Ask one of these questions,
    and then prompt the correct response…(Lovaas as cited in Maurice, 1993, p. 208)

While Lovaas coaches parents to “let the child experience the consequences of his using the
terms yes and no correctly” (in other words, slap them if they say yes to spanking), Maurice
resists his authority, and adapts. She includes less “harsh” aversive choices such as ice
cream vs. spinach rather than candy vs. violence (p. 208). Through this moment in
everyday text and talk, the mother therapist brings mothers into view both as moral
entrepreneurs of the scientific production of normal embodiment in their child, as well as
challengers of scientific authority (Becker, 1963; on mothers’ confrontation of expertise see
Jack, 2014, p. 60; also see Lagan, 2011; Sousa, 2005, p. 225). This mother is, ironically,
now scientifically governed at a distance through her own “freedom” (Rose, 1999a) to
shape her mothering practices, at least in some small part, on the ground of her maternal
authority.\footnote{For further reading on mothers challenging scientific expertise see Nathanson & Tuley (2008).}
Coupling the male authority of science through her work with Rimland and Lovaas, together with her own intuition and maternal knowledge of her children, Maurice creates and implements her own behavioural curriculum. As she moves from trial to trial, the skills she teaches become increasingly complex. Maurice begins with the skill of “attending” and moves over time to “following one-step instructions,” “play,” “making choices,” “toilet training,” “begin asking ‘when’ questions” and “elicit spontaneous questioning,” for example (1993, pp. 334-52). Teaching her child how to “be” human is broken into skills and mechanized, seen most ironically here in the scientific control of human spontaneity itself (presumably autistic spontaneity is not considered).  

Skill number eighteen from Maurice’s diary for the period September 1 – November 15, 1990 includes the following:

18. *Monitor Tuning Out, Tantrums, Whining, Aggression, Self-stimulatory Behavior*

Increase pace of material to counteract tuning-out behaviour. Spend no more than five minutes at a time in chair. Use DRA [differential reinforcement of alternative behaviour] for “Good sitting,” “Good listening,” “You’re not whining,” etc. Increase reinforcement schedule. Experiment with different motivators. “Time out” for aggression (hair pulling). Note: One way to unpry little fingers from your hair is to press firmly down on the knuckles: his fingers will open naturally. For hand-flapping, body-tensing, and toe-dancing, state “Quiet hands,” at each occurrence, and hold his hands by his side for three seconds. Praise for being still. (Maurice, 1993, p. 343)

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53 This breaking down of the relationality, locatedness, particularities and processes of meaning-making caught up in “being human” into the mechanized teaching of “skills” seems linked to larger processes of modernization including capitalist production, industrialization and scientific management of social life (see Braverman, 1998).
Biological vocabularies deliver the disordered autistic body as an object available for both the scientific expert and the mother therapist to “work on” (McGuire, 2011b, p. 76, 95). Recuperated from her infantilized psychoanalytic subject position as natural mother, the mother therapist becomes a “skilled worker,” a natural fit for her biologically disordered child (McGuire, 2011b, p. 76, 95). Her primary goal is to work for the achievement of normalcy, the shape of which she knows in advance. Her methods are pre-determined, scientifically guided normalizing techniques learned from experts and adapted through her own embodied maternal love and practice: reinforce and increase so-called normal behaviour like “Good sitting,” gently reprimand (“Quiet hands”) and restrain autistic embodiment (“hold his hands by his side for three seconds” rather than slap). In other words, while tempered by her adaptations of the “harsh” methods of experts, this mother must still conform to the ideal of the good mother who produces productive citizens, in this case by caring for normalcy and extinguishing autistic embodiment – tuning out, hand-flapping, body-tensing and toe-walking. Tracing how the mother therapist/scientific expert coupling emerged in practice as a new form of visibility and site of intensively lived governance for mother and child extends McGuire’s point when she says that normalcy emerged as an “embodied practice” (versus a natural attribute of some bodies and not others) during this time (2011b, p. 94). Normalcy becomes the practical “achievement” (McGuire, 2011b, p. 94) of an intensive and constrained good mother therapist who is self-governing, simultaneously shaping her embodied practices through both scientific expertise and her own authority.

The mother therapist has come to newly embody and bring into everyday view a key contradiction for all mothers. She is guided by natural love for her child and (self)
guided by the Reason of Cartesian science where, to borrow philosopher Susan Bordo, “The key term is detachment: from emotional life, from the particularities of time and place, from personal quirks and prejudices, and most centrally from the object itself” (1986, p. 451). This contradictory mother therapist must both love (as good mothers do) and reject the particularities of her unique child in front of her (the “object”) from the cold remove of science. For Maurice, this means softening the approach of experts while also complying by scientifically observing, containing (literally, through physical restraint) and therapeutically correcting (making identical) her child’s autistic embodiment and caring for (rewarding) the production of normalcy (on uniqueness see Arendt, 1998/1958, pp. 175-181; on alterity and ethical violence see Levinas, 1969, pp. 33-52, 72-81). Understanding the “particularities of time and place” or cultural ground of a world that produces her autistic child as a problem object to be “worked on,” at times violently, through good mothering is not part of the mother therapist role. Her irremediable contradiction – to love and eliminate, scientifically govern and naturally love – is brokered through the scientific ordering of her intimate loving bodily practices as ones that must also include the rejection of difference.

Ironically, the detailed descriptions of the mother-therapist by some of Maurice’s “anti-behaviourists” experimenting with alternate methods of “rescuing” autistic children – through love and intensive child-centred approaches rather than scientifically calculated rewards and aversives - also contributed to this new form of visibility and governance for mothers. While the content of alternative approaches did not directly follow Lovaas, and certainly retained threads of psychoanalytic understandings of autism, these alternatives were also deeply embedded in scientific ways of knowing the world – through maternal
attachment theory, biological understandings of autism and normal human development, as well as empirical observation as key elements of a scientific method, for example. In the book *Son-rise* (1976), Barry Neil Kaufman describes the extensive research, “marathon sessions of observation” (p. 38), and intensive experiments with a child-centered approach he and his wife Suzy undertook to recover their son Raun from autism. While the Kaufmans retained a psychoanalytic understanding of autism, they also loosely invoked Rimland’s (1964) biological theory based on the “evidence” of their observations. Their son was “Encapsulated behind an invisible and seemingly impenetrable wall” (Kaufman, 1976, p. 2) even while “The question was one of perception and the problem was recognition, retention and recall” (p. 46-7). And while the Kaufmans endeavored to love and accept their “brain-blessed” (p. 2) different son rather than “roboticize,” “train,” “force” and “punish” him into this world (Kaufman, 1976, p. 48), love and acceptance was only their beginning point.

Kaufman presents a detailed diary of how his wife Suzy, along with him observing her in the place of the male authority of science, initiated a 75-hour per week intensive therapeutic intervention to recover Raun. Suzy begins in Raun’s “world,” imitating his rocking, spinning, staring and flapping for hours at a time as an attempt to entice Raun out from the “wall” that encapsulated him. Sounding much like the behavioural approach, Suzy next offers physical affection and encouragement (rewards?) as she systematically (scientifically?) breaks down teaching tasks into “small, digestible parts” (p. 49). These

54 The approach I describe here began with the popular book *Son-rise* (1976) by Barry Neil Kaufman, and grew into what is now known as the Option Institute, an “empowerment” method of treating human suffering and unhappiness (autism, depression, chronic fatigue) (see http://www.option.org/index.php). While not as popular, but nevertheless also widely disseminated, another mother-as-therapist approach to autism that emerged during this time was Floortime. This was a child-directed, intensive “round-the-clock” intervention that directs parents to get down to their infant’s/child’s level (literally, on the floor with them), where they are to lovingly enter and attempt to normatively shape their child’s developmental trajectory. For an example in everyday text and talk see Stone (1999, p. 110). Also see http://www.stanleygreenspan.com/about-floortime/.
teaching tasks included all of the markers of normal human development: making eye contact, physical affection, games and spoken language, for example. Kaufman describes his wife as the embodiment of the intensive, sensitive mother who “works on” her child - “tireless,” “superhuman,” “active but gentle” and “[a]live but peaceful” (1976, pp. 51-64). Photographs of an increasingly engaged, normalized Raun (i.e., from averting his gaze to making eye contact) and gentle-looking teaching sessions also appear in the book. In addition, despite a commitment to working differently than behaviourists to “embrace all the beauty” of Raun (p. 37), the Kaufman’s approach still makes autism interesting only insofar as it is a problem to be solved, this time by an all-loving (never overtly violent or restraining) mother therapist as an intensified version of the intense mother deeply committed, though more covertly than dominant approaches, to normalcy (Hays, 1996; on the intensification of the intensive feminine see Ringrose & Walkerdine, 2008). If, as disability studies scholar David Mitchell describes, “nearly every culture views disability as a problem in need of a solution, and this belief establishes one of the major modes of historical address directed toward people with disabilities” (2002, p. 15), then the mother therapist is one major mode of historical address to the “problem” of disability that centrally implicates mothers as its key workers. A few years later, Suzy’s intricate intervention into Raun’s life was made into a popular television movie entitled Son-rise: A miracle of love (Rosenbloom, 1979).

Despite the behaviourist/anti-behaviourist philosophical tensions between Maurice (1993), Kaufman (1976) and others (see, for example, Baron & Baron, 1992; Greenfeld, 1972; Stehli, 1991), detailed descriptions within everyday text and talk shaped the mother therapist as a lived cultural contradiction for all mothers – she was both loving and
scientific, accepting and rejecting, violent and healing, intensive and distant. ‘Autism mother’ was no longer a destructive force but a healer, teacher and skilled worker – one who, ironically, used both love and rejection to “humanize” her child. And she held “lessons” for all mothers. The 1975 article in *Psychology Today* entitled “Autism: A defeatable horror,” for example, draws from experiments with autistic children to prescribe “five essential steps” to successful behaviour modification for all parents struggling to “civilize their children, autistic or normal” (Schreibman & Koegal, 1975, p. 61). ‘Before’ photographs show frustrated parents and broken household items, while ‘after’ photographs depict affectionate, attentive autistic children engaged in therapy sessions and play. Such depictions of autism and mothers in everyday text and talk invited all mothers to re-train their gaze, this time on intensively ordering and governing their own mothering practices in systematic and scientific ways, “…you cannot depend on experts alone to straighten out your child. You have to get involved too” (Segal & Segal, 1992, p. 92; also see Bower, 1981, 1989; Chance, 1974, 1987; Schreibman & Koegal, 1975). Indeed, say Segal & Segal in their description of behaviour modification and life with an autistic child, “…the courage and dedication of these mothers and fathers can be a source of inspiration to all” (1992, p. 89). The contradictory figure of the mother therapist, and biological understandings of autism and normal human development, had now come to regulate the good/bad mother in new ways for all mothers, directing a mother’s gaze toward the intensive and scientific self-governance of her own embodied mothering practices, time and emotional investment in the achievement of normalcy. This achievement was the product of a new coupling - the scientific expert and the skilled mother therapist - both of whom also lent their power and privilege to the moral enterprise to scientifically order the disorder of autistic children.
A New Technology of Affect: Implicit Blame

No longer the overt cause of autism, autism mothers had now become responsible for their child’s recovery - or at least for training their child to behaviourally approximate normal development. This shift in responsibility would involve a new and subtle technology of affect, one that would take place through a mother’s own scientifically shaped self-governance. Indeed, part of what seems new in everyday text and talk by and about autism mothers during the years 1970-99, is the re-training of a mothers’ gaze onto the scientific and systematic re-ordering of her mothering practices not as that which causes autism through disordered love, but as that which must now remedy, heal, treat or cure autism (Sousa, 2005).

Interestingly, the new neurocognitive understanding of autism offered a number of different ways mothers might have been enticed to care about their child’s treatment and govern their own maternal practices in addition to dominant behavioural approaches, including biomedical, genetic and prenatal interventions. During the 1970s, for example, early advocates of biomedical interventions such as mega-vitamin B therapy, including Rimland, also appeared in everyday text and talk (Dempsey, 1972, p. 85; Maurice, 1993; “National Society Formed,” 1976, p. 14; Segal & Segal, 1992). Neuropsychological research supported such biomedical interventions. B vitamins helped regulate the production of the neurotransmitter serotonin, it was thought, found to be higher in many autistic children (Bower, 1981, p. 154; “Medics find new clues on autism,” 1973, p. 82; Ross, 1989, p. D4). And brain autopsy studies confirmed the serotonin/autism link - neurological abnormalities in Purkinje cells in the cerebellum were found, cells caught up in the production of serotonin (Bower, 1986, p. 154-5). Everyday text and talk also reported

The rise of biomedical, preventative and genetic mothering would wait for the turn of the 21st Century, however. These alternate interpretations of autism and mothering, here in their incipient beginnings, would vie for power with behavioural views and the mother therapist with the rise of genetic views of the human and the ‘warrior mother’ (see Chapter 5). For the years 1970-1999, it would be the success or failure of the mother therapist and her use of intensive, systematic and scientifically guided interventions into her child’s disordered biology - behaviour modification or the more ‘loving’ educational approach – through which a technology of implicit blame would come to operate anew. We can again grasp this moment in Foucault’s genealogical sense as the emergence of different interpretations of human life through histories of struggle and forces of domination and
subordination (Foucault, 1984, p. 86; 1982), in this case, as we shall see, through newly emerging neoliberal instrumentalities of intensive mothering and scientific regimes within the heightening marketization of care and human social life (on neoliberal political economy see Brodie, 1995; on intensive mothering see Hays, 1996).

The first noteworthy point in the operation of this new form of implicit blame during these years is that despite new neuropsychological understandings of autism, it was still the scene of the mother-child relationship upon which normal development was to unfold or fail. The difference, however, is that it was now through a mother’s scientifically guided self-conduct and proximity to her child as mother therapist (a kind of distant/loving figure) that development was to unfold and be corrected. In a behaviour modification training program for parents (read, mothers) of autistic children, for example, the experimenters note that the successful parent-therapist:

…cared a great deal about succeeding, showing happiness when the children improved, and anger when the children interrupted the sessions…instead of pitying and excusing bizarre behaviour, they concentrated on increasing normal behaviour. They showed a willingness to commit a major personal effort to helping their child, instead of relying on professional help. (Schreibman & Koegal, 1975, p. 66)

Here, a mother’s disordered natural love is no longer considered a factor in autism, which is now squarely located within individual biology rather than between (disordered) mother and child. Instead, the parent (read, mother) is now a skilled worker and healer responsible for externally shaping her autistic child’s biology “gone-wrong” (Michalko, 2002, p. 22). She must learn to ‘read’ her child’s behaviour through the vocabularies of neuropsychology
as “normal” versus “bizarre” and provide corrective, therapeutic responses – happiness or anger. Autistic behaviour meets aversive, extinguishing responses while “normal” behaviour meets loving, encouraging ones, all with the goal of reshaping behaviour to appear more normal. While the mother-child relationship remains the scene of this mechanistic developmental drama, a mother’s role and responsibility have changed to that of a scientifically guided therapist. Changed, too is the view of human development underpinning this new therapeutic mother’s work. Development is now a vulnerable yet universal biological unfolding (as opposed to psychic) with predictable stages of “normal development” known in advance (Ehrenreich, 2005, pp. 4057, 4071) and susceptible to various threats along the way (environmental, genetic), thus in need of a mother’s constant attention and scientifically guided, corrective intervention in addition to her ‘natural’ love (see McGuire, forthcoming, pp. 23-4 on autism, development and mother advocates as “human developers’). No “excusing” - explanation, defense, justification or tolerance – of autistic behaviour is allowed for by the “successful” mother therapist. Autism appears as an already accomplished fact of biological deviation and mothers as the therapeutic solution, leaving the cultural ground and interpretive work of the accomplishment of normal development “concealed” (Husserl, p. 1970, p. 104). In a sense, too, this new technology of blame adds a new layer of contradiction to the autism mother therapist: left on her own, without the paternalistic guidance of science and professional help, a mother’s love is not adequate, yet she must also, and simultaneously, be intensely self-governing and demonstrate a “willingness to commit a major personal effort to helping their child, instead of relying on professional help” (Schreibman & Koegal, 1975, p. 66).
The ideology of intensive mothering that arose through these years meant that a mother’s (or her hand-picked alternate’s – preferably another female caregiver, but also perhaps a father) commitment and attention to this kind of scientific care for normalcy in her child had to be self-directed, intense and constant (Ladd-Taylor, 1998, p. 14; Hays, 1996, pp. 8). As Sharon Hays (1996) writes on intensive mothering, “…a mother must acquire detailed knowledge of what the experts consider proper child development, and then spend a good deal of time and money attempting to foster it” (p. 8). One article in the magazine Commentary (1972), for example, describes an autism mother’s journey to treat her autistic child as the “…dogged, powerful, single-minded commitment of a mother…providing every day a kind of attention unimaginable in any treatment center” (Rubikoff, 1972, pp. 65-6). Kaufman, too, explains that his wife Suzy’s program to draw Raun out of his autistic world “would take many hours of constant work” (1976, p. 38). In Parents magazine, twenty years later, autism researcher Laura Schreibman is quoted as describing this mother in similar terms, “Since parents are with their children more than anyone else…they can create an around-the-clock treatment environment” (Segal & Segal, 1992, p. 92). And again, in an article in Today’s Parent in 1999, “Matthew has a team of people…when they leave, mom takes over…It’s a round-the-clock job rewarded by Matthew’s progress…” (Stone, 1999, p. 110). This again shows the shift to locate autism squarely in individual yet-to-be-developed bodies as objects constantly available for mother therapists to “work on” (the feelings, experiences and preferences of autistic children within such intensive therapeutic regimes were not a topic of concern in everyday text and talk). Within intensive mothering and biological logics, the mother therapist, along with her objectified child, is tied to the clock of normal development and its orderly stages. Armed
with therapeutic techniques, a scientifically guided gaze and natural love for her child, the mother therapist must constantly strive against the relentless threat of autistic biology gone wrong and its “too slow” (McGuire, 2011b, p. 8, 158) or not quite right development. A mother and child’s time together has become factory time in the service of “progress” – an endless production toward normalcy through an unending consumption of autism therapies. This mother’s clock and productivity never stops. She is both intensely governed through her own practices as well as privileged to be available to mother in this way (see below). She is producing future workers and it is urgent. In Capital (Vol. I), Marx says this about factory production, “…it is not the workman that employs the instruments of labour, but the instruments of labour that employ the workman…” (as cited in Braverman, 1998, p. 157). Here, a mother’s domestic space and intimate bodily practices are on the clock of capitalist production and ordered through its instruments – therapies, love and science – tuned toward the interests of capital and played out upon the objectified bodies of autistic children.

Given these new scientific and intensive capitalist logics, the mother-child relationship was re-configured as a space of governance that operated at a distance, ironically, through a mother’s own self-conduct – an implicit form of blame. While she was no longer responsible for initiating autistic withdrawal in her child, the autism mother therapist was now responsible for correcting – treating, re-shaping and ameliorating - such biology “gone wrong” (Michalko, 2002, p. 22). The implication was that in her failure to treat successfully, this mother continued to cause autism. As Amy Sousa puts it,

Whereas seemingly cold mothers…were once considered responsible for causing their children’s intellectual disabilities…mothers are now responsible for curing the
disability, or at least accessing the intervention that will mitigate the disability’s impact on their children. (2011, p. 221)

Re-configured neo-liberal family-market-state relations and heightening ideologies of intensive motherhood that placed care back in the home as the primary responsibility of mothers during the 1970s-1990s (even as they entered the work force; see Brodie, 1995) meant that not all mothers could work on the clock of capitalism to provide such intensive, expensive, time-consuming interventions (Hays, 1996). It took a particular kind of mother, one with courage, determination, commitment (to love her child to normalcy), and the individual ability to shore up resources and time to practice this kind of mothering. “You are relentless. That is why she got well,” stated one doctor to author Stehli at the end of her journey to recover her autistic daughter (1991, p. 215). “We used everything we had, - our love, our rage, our frustration, patience, inventiveness, violence, ignorance and humor,” states mom Judy Barron in There’s a Boy in Here (1992, pp. vii-viii), to set her son “free”. This newly configured technology of blame was not only gendered, but also raced, classed and abled, subtly linking the meaning of the normal human to intensifying Western, white, bourgeois mothering practices for all mothers (on mothering and class, for example, see Walkerdine & Lucy, 1989). This also inserts autism into continuing Western scientific histories and hierarchies of developmentalism that pathologize and devalue alter embodiments – racialized, classed, gendered, queer bodies and so on – and link disorder to femininity, this time through implicit mother blame (see, for example, Paré, 1982; Thomson, 1996, 1997, 2001; also see McGuire, 2011b, p. 23).

Within this new technology of blame, little room is left for caring about autism differently, as anything other than a tragic, biological problem to be solved in large part by
mother therapists (on disability as a problem, see Abberley, 1998, p. 93; Mitchell, 2002, p. 15; Titchkosky & Michalko, 2009, p. 2). One mother articulated the problem of autism in a 1972 Toronto Star article this way, “…this thing [autism] has its ups and downs and is a terrible strain” (“Parents seeking help for handicapped children,” 1972, p. 61). The article goes on to clarify that “more research and intensive therapy aimed at changing behaviour through the reward system will change this for many” (p. 61). In other words, when a mother and family inevitably falter in their “round the clock” treatment regimes (autism was a “terrible strain”), parent advocacy for relief programs, scientific research and more services was forwarded as a crucial part of the solution, “…this family is so burnt out they are hanging onto their life by a thread…parent relief means time off…from the never-ending responsibility” (“Families of disabled confronting crisis,” 1989, p. D3). A little bit of rest would free mothers to continue in their intensive mothering. More services would give families “emotional resources…strength and courage” to “educate and advocate” for their child (“Families of disabled confronting crisis,” 1989, p. D3). While services and relief are crucial (indeed, for any family!), it is the meaning of advocacy and its link to implicit blame and normalizing regimes I want to note here. Rather than advocate for autistic difference as a viable way of being-in-the-world or the creation of shared knowledge about how to live well in autistic difference within families, for example, advocacy for more services, research and rest breaks bolstered implicit mother blame and its requirement of constant therapeutic mothering in the service of normalcy and future productive workers.

Within everyday text and talk then, the failure of a mother to achieve normalcy, or at least “progress” in her child, was understood not only as her individual failure, but also the failure of governments to provide enough services, relief programs and support for scientific research, as well as the inevitable result of the “terrible strain” of living with an irretrievably disordered autistic child. At best, accepting failure meant a grief-filled, frustrating, isolated and anguished journey to accept that you could not recover your disordered, brain-damaged child in a world which values – and expects - progress, productivity, normalcy and sameness. Although involvement in Lovaas’ experiments yielded some hope and minimal skills for their son Noah, for example, author Josh Greenfeld and his wife Foumi, who had trained at Lovaas’ California institute to be a “therapist” to her son, lived the failure to normalize their son: “Yesterday I told Foumi I have little faith in any therapy – vitamins or operant conditioning or anything. She said, ‘Then why don’t we just put him in an institution?’” (1972, p. 175). Throughout A Child Called Noah (1970), the Greenfelds’ battle with the idea of the institution (which remained one of the only alternatives to home-care in 1972 when the book was published) operates as a place-holder for the anguish of the ultimate failure of mothers within this Western scientific capitalist scheme - failing to normalize your child so that she might live a normal life (also see Greenfeld, 1978a; 1978b; 1986). At worst, failure appeared within everyday text and talk as the abandonment or murder of an autistic child by a parent, the tragic yet inevitable defeat of some mothers and fathers as fallen heroes in the face of the constant proximity to the “terrible strain” of autism and the failure of services. One article describing the murder of six year-old Charles-Antoine by his mother in 1996, for example, quotes the president of the Quebec Society for Autistic Children, Peter Zwack, “Her life
was a nightmare. She was all alone and that would have made things even more impossible” (“Autistic son dies, mother charged,” 1996, p. A8; also see, “Montreal tragedy,” 1996, p. 23; Rae, 1998; Unland, 1997, p. A6; White, 1997). Rather than question the cultural ground of possibility that values sameness and scientific conceptions of the normal human so completely that mothers and families must work constantly, intensively and even violently to systematically treat and normalize (or eliminate) their autistic child, this newly configured technology of blame subtly and obliquely conceals this cultural ground through the spectre of failure. Life with an autistic child was a “nightmare.” Outside of the hope of treatment and some measure of normalcy, it was no life at all.

During 1970-1999, the new implicit technology of blame compelled mothers – perhaps all mothers – to retrain their gaze and scientifically reorder their mothering practices toward the achievement of normalcy in their child. The article “Living with an Autistic Child,” for example, instructs parents in a section entitled Lessons all Parents can Learn, “To change behavior, use positive reinforcements instead of painful punishments, and be sure to reward brave efforts even if they fail” (Segal & Segal, 1992, p. 92). A 1975 article in Psychology Today entitled “Autism: A Defeatable Horror” coaches parents based on the authors’ behavioural research with autistic children on the “five general procedures” in becoming a parent (read, mother) therapist. This includes “presenting proper instructions” to their child: “…the [parent] therapist must first wait until any inattentive or disruptive behavior has stopped, then establish eye contact with the child. Then the [parent] teacher should present a simple instruction such as ‘touch red’” (Schreibman & Koegel, 1975, p. 62). Lovaas, too, had tips from the behavioural expert to the mother therapist, “You can help the child formulate the correct answer [to your question] by grossly
exaggerating your gestures when you ask…” (Lovaas as cited in Maurice, 1993, p. 208).

Through this subtle and invitational technology of blame – being invited to be a co-therapist and held responsible for her child’s recovery - biological ways of knowing human life invaded conceptions of mothering and tied her to her child’s disorder (and its elimination) anew, through her own scientific self-governance rather than her maternal treatment. What’s at stake in such middle-class mothering, state Walkerdine & Lucy (1989), is nothing less than the “future of civilization” itself (p. 63): “Mothers, many studies concluded, were so good at all of this that they were inimitable and irreplaceable. It was they that would ensure their children’s mental health…” (p. 62). Like the refrigerator mother before her, the autism mother therapist emerged as a cautionary tale, only this time she was implicitly blamed for the stubborn persistence of autism through her failure to succeed as a skilled, intensive worker. This more implicit technology of blame compelled a new kind of self-governance for mothers, one that was at once bodily intimate and attuned to her child while scientifically distant and even violent. Autism mother had emerged in newly layered ways, as a key cultural contradiction through which new biological versions of autism and an intensifying feminine came to regulate the good/bad mother in new ways for all mothers. This mother was now scientific and intimate; loving and rejecting; violent and therapeutic; intense and ordered; self-governing and intensively governed.

**New Forms of Identify: Mother Heroes**

I briefly address what has become of ‘autism’ and ‘autism mother’ as new forms of identity made possible by the rise of biological views of autism and neoliberal shifts in the political economy of care. Through this section, I also gather the threads of the chapter before turning to consider new forms of maternal resistance that emerged during the years
1970-1999. While neurocognitive views would come to eclipse the psychoanalytic, threads of the latter still glimmered within everyday text and talk during these years. In her diary about the “recovery” of her son Sean, for example, autism mother Judy Barron weaves the cognitive and psychogenic together, “Sean and I have written the story of his release from the terrifying imprisonment of his own mind” (Barron & Barron, p. viii). Here, Bettelheim’s “terrifying imprisonment” meets cognitive psychology’s disordered “mind” in the identity of autism. Other voices within everyday text and talk were less equivocal about the meaning of autism. In an article in *Scientific American* (1993), for example, Uta Frith, a pioneer in Theory of Mind and cognitive neuroscience offered an understanding of autism that erased any trace of the psychoanalytic view. Autism is not a “beautiful child imprisoned in a glass shell” (1993, p. 108). Autistic people “are not living in rich inner worlds but instead are victims of a biological defect that makes their minds very different from those of normal individuals” (p. 108).

That “different mind” – one understood as mapped onto defective brains and rooted in neurobiology - packed quite a wallop. Associations with the uncivilized and amoral abound within everyday text and talk about autism during this time, as well as popular expert works. One mother quoted in a magazine article outlining a behaviour modification study, for example, describes her son as crushingly “unresponsive,” “violent,” a “wild animal, a living terror” (Schreibman & Koegel, 1975, p. 61). Here, autism is an untamed animalistic Nature that is “violent” and therefore “unresponsive” and unpredictable, terrifying and even dangerous. Autistic difference means brains and bodies as non-human objects outside Western civilization, implicitly identifying the rational, certain, scientific and controlled with the good *human* subject (on science and certainty, see Bordo, 1987, p.
Frith also draws on metaphors of the uncivilized as she describes histories of educating “feral children” in the late 1700s and early 1800s in her popular book *Autism: Explaining the enigma* (1989) as likely instances of autism in history (pp. 16-35). Also, as we saw above, in his much cited (in everyday text and talk as well as scholarly sources) essay *Mindblindness: An essay on autism and theory of mind* (1995), developmental psychopathologist Simon Baron-Cohen (a student of Frith’s) suggests that autistic children lack Theory of Mind as what most makes us human (according to evolutionary psychology). To reiterate, for Baron-Cohen, this is an evolutionary cognitive structure that bridges the gap between animal and human and allows us to ‘read’ the contents (desires, intentions) of others’ minds through empathy (for a disability studies critique of ToM, see McGuire & Michalko, 2011; Yergeau, 2013). The non-human, feral and ‘cold’ view of autism depicted in everyday text and talk is not only reminiscent of Goffman’s “not quite human” characterization of stigmatized individuals (1963, p. 5), it is also a destructive biological force that victimizes children, particularly white, male children (who continued to be disproportionately diagnosed), who are then understood in need of remedy. Within this universalizing biological “gaze” (Haraway, 1991, p. 188), the possibility of understanding autistic embodiment as a way of *being* human within mother/child or disabled/nondisabled relationships disappears.

If autistic children were victims of destructive neurobiological defects, mothers and families were too. Upon learning about her child’s diagnosis, for example, Maurice (1993) depicts her shock in victimizing language, “A fist was crashing into my chest…I felt no grief, only shock. And numbing fear” (1993, p. 25). Similarly, Greenfeld (1972) states, “not the least victims of this common but rarely forseen malady will be the child’s parents and
family” (p. 5). Autism meant “endless days and sleepless nights of frustration and confusion” (Cornell, 1972, p. 87) and a life for mothers that was “a burden” (Kohl, 1979, p. H10), raising the possibility of a disability studies critique of feminist political economy and care research that conceives of caring for a disabled child as a burden for mothers, a point I return to below (see Hughes et al. 2005; Kelly, 2013; Kröger, 2009; Williams, 2001). Here, autism’s destructive force victimizes mothers and families physically, emotionally and, presumably, financially too as families cope with this “burden.” And while life together with an autistic family member can indeed be difficult and costly, within everyday text and talk during this time autism appears as little more than this: an individualized, terrifying, burdensome problem of defective biology in need of a solution – the “taming and teaching” of autism (Moser, 1965, p. 96). It is interesting to note that although disordered autistic brains and bodies appear as stubbornly “wild,” the notion that they might be tamed and taught relies upon the emerging concept of “neuroplasticity,” a neuroscientific tenet that holds brains/minds are malleable, changeable over time and remediable (Nadesan, 2005; McGuire, 2011b, p. 94). Nevertheless, other possible ways to approach the disruptive, novel and surprising of autism’s wildness – as something to “think with,” for example (Michalko, 2002, p. 168; Snyder & Mitchell, 2006b, p. 192) – as well as other possible understandings of alterity, caring mother/child relationships or the constraints of our late modern life together, are lost within the neurocognitive understanding of autism and autism mother animating everyday text and talk during this time.

As we have seen, autism mother as skilled therapist/worker was the ‘natural’ fit for biological understandings of autism during this time. By the 1990s, autism mothers had
come to embody the intensive mother *par excellence* within everyday text and talk,

“Mothers became the primary advocates, spokespeople, service providers, researchers, and first responders for their children” (Sousa, 2011, p. 227). However as the above suggests, more than biology “gone wrong” (Michalko, 2002, p. 22) was at stake for autism mother identity. Autism was also a biological force that victimized mothers, families and children. Autism mothers, then, were also tasked with taming and civilizing this unruly, violent biological force. This was the task of a hero. This heroic mother appears, for example, in a *Publisher’s Weekly* (1999) book review of a popular guide to autism by mother Karyn Serrousi:

> When her son was diagnosed with autism at 19 months, Serrousi, a small-business owner and wife of a research chemist, determined to do everything in her power to help her child achieve normal functioning. In addition to pursuing recommended speech and behavior modification therapies for her son, Serrousi devoted her considerable energies—often against medical advice—to researching alternative approaches… Now a crusader for dietary intervention, Serrousi has written a book that will give hope to many families. (Zaleski, Geidman, Abbot & Gold, 1999, p. 71)

Seroussi not only pursues conventional behavioural therapies, she also confronts medical authority, develops expertise out of her maternal experience and scientific research, writes books, innovates her own approach, “crusades” for alternative approaches and starts a dietary intervention organization. The identity autism mother had become an intensification of the intensive mother as a *cultural hero* waging battle against the force of defective biology as well as inadequate public services, research and supports needed for her journey
(Sousa, 2005). Unlike many of Western culture’s heroes, autism mothers were driven by natural parental love. As Kaufman put it for his wife Suzy’s intensive treatment of her son Raun, “…in our love for our son and for his beauty we had found a determination to persist” (1976, p. 19). Autism mother Kephart, too, narrates “love as the only possible solution” and a “fierceness of heart” for this hero’s task (1998, p. 235). Researchers Segal & Segal describe this mother’s “courage and dedication” within the exhausting battle for normalcy (1992, p. 89). To sum up, this mother must now fight heroically to civilize (normalize) her child or suffer the potential defeat of both mother and child as autism’s victim (recall the “wildness” of autism, this mother’s exhaustion and even murder of her child). The good/bad mother was now regulated through this newly contradictory feminine hero figure and biological understandings of autism. The ‘good’ mother was at once self-governing and governed at a distance through patriarchal scientific regimes; active (heroic) and passive (nurturing); expert-driven yet experientially grounded; loving and rejecting (of autism); constantly proximate (whether physically or by hired proxy) and distant in her advocacy and paid work roles. This consideration of autism mothers as normalizing cultural heroes, too, brings into relief how disability and feminist scholars and activists of care, as well as feminist scholars of science, might “bridge” (Kelly, 2013) the tensions of ableist and gender privilege and oppression (also see Hughes et al., 2005; Kröger, 2009; Williams, 2001) to reveal the ways in which intensive mothering and scientific conceptions of the human constrain and do violence to the humanity and freedom of us all.

**New Forms of Resistance: Maternal Authority and Ethical Narration**

It would be both the constraints and possibilities engendered by new biological views of autism and intensive heroic mothering beginning in the 1970s that would open the
ground for mothers’ resistance against earlier psychoanalytic forms of mother-blame. I addressed some of this resistance at the beginning of this chapter. In this section, I re-read autism mother narratives as a significant form of “maternal text” that rose to some prominence during the years 1970-99 (on the emergence of the “maternal text” see Clews, 2001 as cited in Thomas, 2003). I approach my re-reading a little differently, as a site of social action and its own form of resistance. I do so in order to first, tease out how the new identity ‘autism mother’ in everyday maternal text and talk – as skilled therapist and cultural hero – generated constraining cultural understandings and practices of mothering, care and autism. And secondly, I read differently to show how this new maternal identity also challenged scientific expertise and offered moments of ethical narration of autistic difference as potential disruptions to the cultural ground upon which regimes of normalizing care appear as sensible and ordinary (Titchkosky, 2011, pp. 73-6).

Reading in this way is to engage what Megan Boler calls *testimonial reading*: “What is at stake is not only the ability to empathize with the very distant other, but to recognize oneself as implicated in the social forces that create the climate of obstacles the other must confront” (1999, p. 166). Testimonial reading moves beyond “passive empathy” (Boler, 1999, p. 166) with difference, in our case with autism as a tragic neurobiological defect and heart-rending autism mother hero/therapist narratives. Instead, testimonial reading engages a form of empathy that retains something of the irreducible difference of “distant others” and thus re-trains the reader’s gaze onto our own complicity within normalizing regimes. Thinking about my re-reading as testimonial is particularly helpful for the years 1970-99, when moments of autistic ‘difference’ emerge in everyday text and talk (after Park, 1967), even as autism mother narratives are firmly entrenched within
highly conventional biological understandings of autism and a ‘maternal’ solution. I return, then, to the “liminal space between subject and ground” (Titchkosky, 2007, p. 21; also see Lewieki-Wilson & Cellio, 2011) to work the edges of interpretive, critical and feminist approaches in disability studies and reveal moments of the ethical narration of difference as ones that might open creative possibilities about human difference, love, and care a little differently than autism advocacy and biological regimes. Narrating in this way means grappling with the limits of available language to disrupt and expand narrow conceptions of the human while trying to avoid the pitfalls of essentializing. My language inevitably slips in this ethical task of narration. It also means attending to how difference might ‘exceed’ or ‘remain’ despite attempts to govern, categorize, regulate, describe or even emancipate difference. As we shall see, within everyday experiences of the paradox of loving a ‘different’ child and the demand to participate in normalizing care that seeks identity, something of this excess is revealed, an excess that gestures to the fundamental alterity of us all and contains the ethical call to respond to the other without reducing them to the same (Boler, 1999; Levinas, 1969).

In some ways, this chapter has catalogued how everyday text and talk by and about autism mothers was a generative part of oppressive scientific and neo-liberal regimes of normalizing care and intensive mothering during the years 1970-99. Autism mother Catherine Maurice (1993), for example, narrates an heroic tale of her children’s full recovery through her own intensive scientific self-governance – her intellectual, emotional and practical investment in the scientific method of behavioural modification, understanding of autism as a tragic, biological defect, and of normalcy as an unquestioned good. Working with her daughter’s first behavioural therapist, Maurice describes, “I just
wanted her [daughter’s] autism to go away and a normal personality to blossom…” (1993, p. 71). Behavioural therapy became the vehicle for this blossoming, “a radical but necessary means in assisting her to form a self” (p. 131). The possibility of a viable autistic self did not arise. Compared to emotion-based, psychogenic treatments, the scientific approach represented “voices of reason within the wilderness” of autism treatment to Maurice (p. 117). Any “moral scruples” about the “authoritarianism” (p. 130) of behavioural therapies were justified by the controlled scientific delivery of the normal Enlightenment autonomous, reasoned and “civilized” self (also see Broderick, 1993 for an analysis of Maurice). The behavioural approach was compelling for mothers searching for proven alternatives to oppressive psychoanalytic blame and treatment, “…one of the most rigorous long-term evaluations of a therapy program ever conducted…it indicates that many autistic children can not only be helped but can go on to lead normal lives” (Chance, 1987, p. 44). Disability studies education scholar Alicia Broderick calls Maurice’s best-selling Let Me Hear Your Voice a “watershed moment” (1993, n. p.) in public autism discourse, one in which behavioural therapy was widely disseminated as the only scientifically proven hope that recovery from autism may be possible. Autistic self-advocates and critical scholars have also articulated a key critique of the behavioural approach as a form of normalizing violence toward autistic persons (see, for example, Broderick, 2011; “Loud Hands: Autistic People Speaking,” 2012; McGuire, 2011b, 86-90).56

56 Now called Applied Behaviour Analysis, or ABA, this approach is widely accepted today as a scientifically based treatment for autism. It is used within autism agencies, schools and home therapy programs, and is compared favorably to other treatment options (such as nutritional intervention, the Son-rise approach) as a more scientifically supported approach (see, for example, Williams & Williams, 2011). As an example of its reach, consider that the Ontario Ministry of Education issued a policy/program memorandum in 2007 for the compulsory use of ABA in Ontario schools, identifying the rationale that ABA “uses methods based on scientific principles of learning and behaviour to build useful repertoires of behaviour and reduce problematic
At the same time as autism mothers appeared in everyday text and talk alongside Rimland, Lovaas and others as the “moral entrepreneurs” (Becker, 1963) of oppressive normalizing regimes and intensive motherhood, mothers also appeared as challengers “wresting authority” away from medical doctors, psychiatrists, psychologists and other professionals during these years (on mothers challenging medical authority see Fisher & Goodley, 2007, pp. 72-4; Jack, 2014, p. 60; Sousa, 2005, p. 225). By moving to challenge professionals and reclaim maternal authority and expertise, mothers also began to pry open space where glimpses of something different – a way of being together that began to value both the maternal and the humanity of autistic difference – could emerge. Barron writes, for example,

For better or worse, we were going to depend on ourselves from now on. We’d fight for Sean our way…We couldn’t bear to raise our hopes again by taking him to one more professional and encountering yet another dead end…And Sean did not need to be the object of another experiment. “I’m not sick!!!” he had screamed one day as he sat facing twenty-seven vitamins and minerals he was supposed to swallow. (1992, pp. 171-2)

As skilled therapist/workers, and despite intensive governance from a distance that invited the maternal “conduct of conduct” in normalizing ways (Foucault, 1982, 1994), a mother occupied spaces with her child – here as Barron’s son faces twenty-seven supplements and implores “I’m not sick!!!” - that fell outside of the direct control of scientific authority and professional intervention, as well as linear Western narratives of progress and development ones” (Ontario Ministry of Education, 2007, section 3, para. 1). It is significant to note the grounding of ABA in empirical evidence as opposed to the philosophical or moral, for example (Portelli & Konecny, 2013, p. 93), a scientific approach of which this thesis is both a sustained critique and alternative.
(Fisher & Goodley, 2007). Indeed as Foucault tells us, governance is never total, “Where there is power, there is resistance” (1976/1980, p. 94). In these spaces, ironically opened to mothers by the push of care back into the home, the emergence of intensive mothering, and regimes of self-governance, mothers experimented with alternatives, adapted conventional approaches, and narrated a different kind of knowledge and care. Barron responds to her son’s experience as an object of normalizing therapies with empathy and resolve not to erase his subjectivity, “we were going to depend on ourselves from now on.” Many parents, including Maurice (1993) and Greenfeld (1972), both of whom had worked with Lovaas directly, wrote about modifications they made to his forceful treatment, learning “…how to take what worked, how to learn from those who could teach us, and how, finally, to trust our own instincts and reason” (Maurice, 1992, p. 209). This alternate way to care and know was grounded, at least in part, in mothers’ experience of the humanity of their child as well as in ‘maternal’ qualities - empathy, intimacy, and instinct, for example - even as mothers’ care remained tied to dominant recovery narratives, autism advocacy, therapies and understandings of autism. Rather than a route to truth, maternal experience represents a different, disruptive and often occluded site from which to begin to know and care about our autistic child in relation to the world, a moment in which we can grasp knowledge as an interpretive, political and ethical endeavor and ways of being together beyond that of the rational, autonomous, solitary Enlightenment self (Haraway, 1991, p. 187; Scott, 1991; Smith, 1992, p. 91).

The tension for mothers between loving the unique and ‘different’ autistic child who appears in front of her, and therapeutically (sometimes violently) intervening to achieve identity with normal development played out within everyday text and talk during
this time (on uniqueness see Arendt, 1998/1958, pp. 175-181; on alterity and ethical violence see Levinas, 1969, pp. 33-52, 72-81; on identity see Stiker, 1999). Manifold maternal hero narratives with the goal of normalization and recovery emerged (see, for example, Barron & Barron, 1992; Kaufman, 1976; Maurice, 1993; Stehli, 1991). At the same time, moments within everyday text and talk that grappled with what it means to care and be human together also began to circulate (see, for example, Dineen, 1991; Enright, 1989, p. D3; Greenfeld, 1972; 1978; McDonnell, 1993). McDonnell (1993), for example, narrates her self-transformation toward the acceptance of her son’s personhood, “At first I thought of Paul [autistic son] as a changeling, a shadow of his real self which had been taken away…Only later did I begin to see Paul as complete and whole, an entirely wonderful person in his own right, exactly and precisely the way he was” (1993, p. 324). As one mother of an autistic adult son hoped during an interview with the Toronto Star, “I’d like to know he’s [autistic son] somewhere where he’ll be cared for…and not in an institution” (Yaffe, 1977, p. 4). Such moments in everyday text and talk granted ways of being identified as autistic at least a hint of a viable “standpoint” in the world and opened space to imagine new possibilities for a “good life” together in what is identified as autistic difference and outside of painful normalizing therapies, ideas of victimizing biology or practices of institutionalization vs. autism advocacy (on standpoint see Schutz, 1970, pp. 73-4; on the “good life” as exclusive of difference see Taylor, 1989, pp. 22-3; Titchkosky & Michalko, 2012; Schutz, 1962, p. 13). Noticing the tensions between the intense governance and enterprise of mothers and mothers’ resistance within normalizing patriarchal regimes as depicted in everyday text and talk is a “bridge” (Kelly, 2013) across and between feminist and disability studies approaches to care. Care is fraught with
ambiguity, power, and paradox for mother and autistic child alike, “it represents the failure of medical cure and neoliberal progress; it is a deep compassion and empathy; a highly intimate relationship; an institutionalized approach to disability; a transnational supply and demand of feminized labour; a dependency on state funded programs…” (Kelly, 2013, p. 790). Attending to ethical moments of the narration of ‘difference’ within everyday maternal texts foregrounds the ambiguities and tensions of care and begins to disrupt conventional ways of caring and being together.

Descriptions through which alterity shimmers are also moments within everyday maternal text and talk in which mothers grappled with what it means to care and be human together. McDonnell (1993) describes the uniqueness of her son’s way of being on a car trip to a friend’s cottage, for example:

Paul had recently discovered flashlights and preferred them to any toy we could give him. So the weekend before we were to leave for Devon, I went to a local hardware store and bought five flashlights, beginning with the tiniest penlight size, on up to one that was about then inches long. On the trip to Devon sitting in his car seat in the back, Paul could take the flashlights apart. I knew this would keep him happy for hours as he unscrewed the bottom, took out the batteries, and removed the light bulb and the spring behind the batteries. Then he could put them back together again. (McDonnell, 1993, p. 51)

Although McDonnell offers this to readers as her way of managing her autistic son’s ‘disordered’ mind and sociality (he did, after all, prefer flashlights to toys and people), there is something of the stubborn uniqueness of her autistic son in this description, as well
as McDonnell’s acceptance of him - his love of repetition, sameness, order and ‘adult’ objects rather than toys. Similarly, many autism mothers during these years attempt to include the ‘voice’ of their autistic child within their narratives through co-writing (see, for example, Barron, 1991; McDonnell, 1993), subtly disrupting otherwise easily consumed and seductive narratives. Despite traces of a psychoanalytic understanding of autism and a commitment to recovery narratives, for example, There’s a Boy in Here (1991) features Judy Barron’s son Sean, who described his experience of spending hours flipping light switches on and off: “I loved repetition. Every time I turned on a light I knew what would happen” (pp. 20-1; also see McDonnell, 1993). Another such moment in which alterity flashes is when a mother loses her ability to make sense of her autistic child: “I couldn’t understand” (1991, p. 61), Barron writes about her son’s inconsistent memory for tasks he had previously learned. Here, in Barron’s failure to contain the ‘difference’ of her son’s memory in her description, or to reduce it to the ‘same’ cultural ground by making it a disorder to be remedied, Sean’s irreducible alterity is revealed, pointing to other possible ways of being human (Levinas, 1969, pp. 79-81; 1989). Such moments have the potential to reach across non-disabled/disabled difference and touch us, as readers, humanizing the difference of what is identified, reified and othered as ‘autistic’ difference. This ‘disruptive’ and ethical re-reading of maternal texts reveals how maternal care might also be pedagogic, disrupting dominant understandings of autism as pathology and mother as solution, even if just for a moment (Michalko, 2002; Van Manen, 1990, p. 23). Here, conventional understandings of autistic difference give way, and space is opened where we might, as readers, encounter difference and care as ethical, relational and pedagogic, perhaps revelatory of the fundamental alterity, and fundamental humanness, of us all (Levinas,
1998). I turn now to trace the emergence of a newly configured and intensified contradictory mother – the ‘warrior mother’ – in everyday text and talk in Toronto during the years 2000-2015. During this time, genetic understandings of autism rose, and both autism mother recovery narratives and mothers’ ethical engagement of autistic ‘difference’ within everyday text and talk intensified.
Shifts in everyday text and talk by and about autism mothers for the years 2000-2015 seem in some ways an intensification rather than a new way to understand autism and mothering like that of the change from psychoanalytic to biological views beginning in the 1970s. I first describe the key elements, including autism advocacy and research, surrounding this shift to provide my reader some required background, and then provide an overview of how the rest of the chapter will unfold. Biological approaches still prevail for 2000-15, and while the predominance of neurocognitive approaches (i.e., Theory of Mind) and behavioural therapies have been overtaken by a genetic approach in autism research and potential therapies (Nadesan, 2005), these earlier approaches continue to have considerable contemporary influence (see, for example, Baron-Cohen, 1995; Blacher & Howell, 2007; Renzetti, 2011). The incipient “discursive explosion” (Foucault, 1976/1980a, p. 17-8) – a bringing of ‘autism’ and ‘autism mothers’ into everyday text and talk and scientific discourse - and Western cultural fascination with autism I noted for 1970-99, also proceeded to intensify over the years 2000-15 (Grinker, 2007; Hacking, 2010; Mallet & Runswick-Cole, 2012; Murray, 2008). A search on the Proquest database, for example, using ‘autism AND mother’ as a Boolean search term now yields tens of thousands rather than thousands of hits for magazines, newspapers and blogs (31 868 in

57 I employ scare quotes to indicate that I understand ‘autism’, and ‘autism mother’ as culturally produced subjectivities rather than ways of being grounded in the biology of different brains or bodies, for example, or as things in and of themselves. I use scare quotes the first time the terms ‘autism’ and ‘autism mother’ are introduced in each chapter, and intermittently, to remind the reader of my orientation.
Manifold autism mother (and autism father) narratives depicting the ‘good’ and the ‘bad’ of life with autistic children and heroic tales of recovery have flourished (Hacking, 2010; also see, for example, Barnett, 2013; McCarthy, 2007). Television shows such as Parenthood and The Big Bang Theory, as well as motion pictures like Mozart and the Whale, feature autistic as well as autism mother characters. Autism mother blogs abound (see below). Autism mothers appear, too, in fictional accounts during these years such as Love, Anthony by Lisa Genova (2012), a novel that tells its story, in part, through a mother’s imagined conversations with her son in her own and her autistic son’s voice.

Rates of autism spectrum disorder diagnosis have also increased sharply over the past fifteen years. In 2010, the Centre for Disease Control (CDC) released a report on the prevalence of autism spectrum disorder (ASDs) diagnosis for eight-year old children in the United States during the years 2004 and 2006. The figure at this time was an average of 1 in 110 children (recall that during 1970-99 rates of diagnosis shifted from 1 in 10 000 to 1 or 2 in 1000 – see footnote. 38, p. 136). The CDC concludes their report with an alerting message, “ASDs continue to be conditions of urgent public health concern” (p. 27). The most recent CDC figure around ASD prevalence, heightening the urgency of this “public health concern,” is 1 in 68 children, making autism a relatively common rather than rare diagnosis (Centers for Disease Control and Prevention, 2014, p. 14). Urgent public health concerns call for urgent action. Within everyday text and talk, this has included the “discursive explosion” of talk and text around the cause of what appears to be a sharply increasing prevalence of autism (versus diagnosis) linked with everyday advice and practical implications for mothers: Is the increase in autism diagnosis due to exposure to
environmental toxins? Childhood vaccinations? Genetic mutations? A child’s diet? More accurate diagnostic criteria? Prenatal risk factors? The result of better education for parents and professionals to identify autism?... (see, for example, Belli, 2010; “Does the MMR Vaccine Contribute to Autism?” 1998; Jack, 2014, pp. 64-104; McCarthy, 2009; Nadesan, 2005, 194-6; Rutter, 2000, p. 5; Seroussi, 1999)? It is interesting to note the slippage between diagnosis and incidence of autism at play here. This slippage betrays the Western scientific impulse to describe the presumably “natural” (and therefore universal) body governed by discoverable “natural” laws, and to “explain” disability as a deviation from it (Michalko, 2002, p. 30). As a number of disability studies scholars including Grinker (2008), Jack (2014), McGuire (2011b, p. 101) and Nadesan (2005) have shown, however, ‘autism’ and the rising diagnosis of autism, is a cultural, historical and interpretive production linked to 20th and 21st Century Western scientific and neoliberal capitalist understandings of the ‘normal’ and ‘natural’ human. And, as poet and activist Eli Clare invokes, biomedicine’s cure is not far behind the mythical “natural” body, “As an ideology seeped into every corner of Western thought and culture, cure rides on the back of normal and natural” (2013, first para.). Indeed, as we shall see, working ever-more intensively against what appears as the rising incidence of autism for a ‘cure’ – or at least for the achievement of normalcy (care through cure) - is the mark of the ‘good mother’ in our time (Blum, 2007; Sousa, 2005).

Mothers’ everyday implication within the search for the cause and cure of what appears as an increased incidence of autism has co-occurred with the insertion of the language of an ‘autism epidemic’ in everyday text and talk by autism advocates and professionals (see, for example, Autism Speaks, 2012; Scherer, 2012; for a critique of
epidemic language see Gernsbacher, Dawson & Goldsmith, 2005). The language of epidemic introduces a new and pernicious layer of meaning onto the cultural scene of everyday text and talk during our time, including allusions to autism as an uncontained, unpredictable global spread of a contagious disease akin to the plague, “threatening the ones you love” (Grinker, 2008, p. 3; also see McGuire, 2011b, p. 102). Epidemic rhetoric is frightening, and lends all the more urgency to mothers’ “duty and urge to act” (Bauman, 2004a, p. 20) to circumvent autism and respond quickly, earlier and with maximum resources to any “warning signs of autism” in her child (“10 early warning signs of autism,” 2013). Indeed, over the past fifteen years, the skilled ‘mother therapist’ who emerged as a cultural hero during 1970-99, has intensified in newly contradictory ways as a ‘mother warrior.’ The mother warrior, as we shall see, is a newly contradictory cultural (super)hero and mother-expert fighting in both a masculine and feminine register against the ‘enemy’ autism and its environmental and genetic causes, as well as against ‘incompetent’ medical practitioners and government systems that block her crusade to secure services, scientific research and therapies that will normalize her child and family (on crusadership see Darling, 2003; on the ‘mother warrior’ see Jack, 2014, pp. 64-5; also see Sousa, 2005). She is Becker’s “moral entrepreneur” (1963), enlisting the expertise of scientists, policy makers, health care providers, lawyers, popular and social media and international health networks (including the World Health Organization – see Rosanoff, 2013) as well as her own maternal expertise in her crusade against autism and its threat to the “good life” (Jack, 2014, pp. 64-104; McGuire, 2011a, 2011b; on the “good life” as exclusive of the standpoint of difference see Titchkosky & Michalko, 2012; Schutz, 1962, p. 13). As the work of this chapter will show, this newly contradictory intensive feminine
and biogenetic understanding of autism have come to regulate the good/bad mother in new ways during the years 2000-2015.

The language of war that only skirted everyday text and talk before 2000 – fortress, imprison, fight, siege, courage - has become a central feature during 2000-15. Everyday text and talk about war in relation to autism and mothering is one site within what Anne McGuire calls “the ‘cultural war on autism’” (2011b, p. 19), an intensifying western/izing autism advocacy, research, media and policy response to the so-called autism epidemic infused with the scientific and moral understanding that autistic life is a non-viable, non-valued tragic and disordered life, a significant financial and personal threat to the health of individuals, families, nations and indeed, the world. The only possible response to the problem of autism framed as such is to scientifically, medically and therapeutically elevate and co-ordinate a “fight” to “defeat it” (McGuire, 2011b, p. 105). Everyday text and talk by and about autism mothers is one generative site within the “cultural war on autism,” both contributing to, and, at times, resisting this war as “…hostile to autistic difference; an environment that…structures and supports possibilities for violence against those noticed as embodying autistic difference” (McGuire, 2011b, p. 105). Autism advocates are also exporting the Western ‘war on autism’ globally, through Internet campaigns, websites and international health initiatives (McGuire, 2011b, p. 103), simultaneously exporting Western culture’s enduring commitment to a very particular yet universalizing version of the human – rational, autonomous, self-enterprising, productive, bourgeois, white and Western/izing. This signals the importance of proceeding with an ethic of disruption that is attentive to the complicity of the lived identity ‘autism mother’ within ongoing Western capitalist projects and their enlistment of scientific hierarchies of femininity, race, and disability in the
colonization of bodies and minds, as well as the importance of fashioning alternative understandings (Mitchell & Snyder, 2003). I do not invoke colonization as a metaphor here (Tuck & Wang, 2012), but point to the “deadly political” (Hall, 1997, p. 290) global exportation of universalizing scientific understandings, normalizing therapeutic practices, health policies and autism industry as a force within colonizing projects (McGuire, 2011b, pp. 157-209; also see Titchkosky & Aubrecht, 2015). Such enterprise operates on and profits from the ‘making the same’ of alter non-Western bodies, and emanates, at least in part, from everyday text and talk by and about autism mothers in the Western world and global North.

Against the backdrop of rising rates of diagnosis, the language of epidemic and the “cultural war on autism,” the field of disability studies and emergent self-advocacy and neurodiversity movement of autistic adults have also brought ‘autism’ and ‘autism mothers’ into discourse during 2000-15 in more intensive ways. As McGuire (2011b, pp. 105-7) explains in her work on autism advocacy, the term ‘neurodiversity’ was first introduced by autistic sociologist Judy Singer in a New Yorker article, in which she describes her activist aspirations, “I was interested in the liberatory activist aspects of it – to do for the neurologically different people what feminism and gay rights had done for their constituencies” (Solomon, 2008). Importantly, neurodiversity has been a formative concept within the recent establishment of several autism self-advocacy organizations by and for autistic persons, including the Autism Self Advocacy Network (“Autism self advocacy network,” 2012) in the United States, as well as for many autistic bloggers\(^\text{58}\) who argue that autism is a viable way of being, and that autism advocacy should not advance a world

\(^{58}\) See, for example, Amanda Baggs [https://ballastexistenz.wordpress.com/] and Michelle Dawson [http://www.sentex.net/~nexus23/naa_02.html]
without autism as its goal (McGuire, 2011b, pp. 105-7). I support the aims of the neurodiversity movement to value different ways of being human and achieve equality for autistic persons. However, rather than ground understandings of autism in “neurological difference,” I orient to autism through an ethic of disruption as well as pedagogic care. That is, I understand autism as a culturally and historically produced subjectivity open to critical inquiry that might yield different ways of being together, disrupt normal/abnormal and us/them binaries and move beyond biomedical, curative remedy (Michalko, 2002, p. 99; Runswick-Cole, 2014).

The field of disability studies has also brought autism and autism mothers into discourse more intensively during these years. A number of scholars committed to understanding the cultural, socio-political and historical contexts of autism and autism mothers, who also support the emancipation of autistic persons, have published books and articles. Nadesan’s (2005) *Constructing autism: Unraveling the ‘truth’ and understanding the social*, is a formative contribution within this new discursive field. It is one of the first scholarly books to trace the constructed nature of ‘autism’ within historical shifts in scientific discourse.59 Another important contribution in the field of disability studies is Mallet & Runswick-Cole’s (2012) article, “Commodifying autism: The cultural contexts of ‘disability’ in the academy.” Mallet & Runswick-Cole argue that the proliferating study of autism within social scientific disciplines has traded on the capitalist commodification of our Western cultural “fascination” with autism. Unlike disability studies, social scientific studies of disability (rather than of the cultural contexts productive of the meanings of

disability) produce it as a “thing-like form,” a “commodity” and an “unsatisfied desire” (p. 36) that can then be “produced, traded and “consumed” (33) within an ever-proliferating academic market of autism. Mallet & Runswick-Cole argue that the commodification of autism undermines the emancipation of autistic persons. Given the contemporary backdrop described above, Mallet & Runswick-Cole’s article further demonstrates the importance of fashioning alternative approaches to mothering, autism and care that are committed to working together with autistic persons and disability studies scholars and activists to reveal oppressive cultural contexts and contribute to emancipatory struggles.

I turn now to an examination of the shifts and intensifications to ‘autism mother’ identity within everyday text and talk – popular books, magazines, women’s magazines, blogs and newspapers - by and about autism mothers for the years 2000-2015. I first describe how I went about gathering my archive, and discuss my methodological decision to turn more directly to phenomenology for my discussion of mother warrior identity. After this discussion, I detail new forms of knowledge, visibility and technology genealogically within everyday text and talk for these years. I then perform an in-depth interpretive phenomenological description of one version of today’s ‘warrior mother’ identity – the feminine warrior - within one autism mother Internet recruitment campaign. I continue to take methodological direction from disability historian Stiker (1999) who says, “At most my goal is to enlarge the understanding that we already have” (p. 18).

Creating an ‘Autism Mother’ Archive, 2000-2015

Part of my search for everyday text and talk for this time period was carried out using the same approach as chapters three and four. Using the Proquest database, which
includes the most current media sources, and the search term ‘autism AND mother’, I conducted extensive searches for magazine and newspaper articles, as well as autism mother blogs. Despite the ready Internet availability of international newspapers, I maintained my focus on Canadian newspapers readily available to a Toronto audience consistent with my previous chapters – the Toronto Star and The Globe and Mail - in order to continue tracing local genealogies. Rather than a question of whether or not magazine articles, television shows, motion pictures and books were circulating in Toronto, the main challenge became how to limit the manifold texts, including blogs as a new form of text and talk, that became available during this time. To address this issue, I used the relevance setting on the Proquest database, and scanned the top 100 search results (out of many thousands) to identify magazine and newspaper articles for my archive. For film and television, I also applied relevance as an inclusion criterion, in this case meaning that autism mothers had to appear directly and be a major focus. The documentaries The Autism Enigma (Sumpton, Bender & Gruner, 2011) and A Mother’s Courage (Ericsdottir & Fridriksson, 2010) fit this criterion. To identify relevant blogs, I used the blog discovery tool Alltop (http://alltop.com/) in addition to the Proquest database search tool. From this I was able to identify blogs that fit my criterion of relevance – blogs authored by autism mothers that directly reflect on the meaning of ‘autism mother’ from a variety of perspectives. Again, my aim was not to catalogue or survey every blog, magazine, book or newspaper article available, but to trace the many tangled threads of emergence of the identity ‘autism mother’ during the years 2000-2015. I include three autism mother blogs: Kim Stagliano, author of best-selling All I Can Handle: I’m no Mother Teresa (2010a) and blogger for the Huffington Post (http://www.kimstagliano.com/index.html); Leigh
Merryday, contributor to *Chicken Soup for the Soul: Raising Kids on the Spectrum* (Landa, Mardsen, Burrows & Newmark, 2013), and author of the blog “Flappiness Is”; as well as local Toronto blogger Estee Klar (http://www.esteeklar.com/), critical disability studies scholar and founder of York University’s Autism Acceptance Project in Toronto (http://www.taaproject.com/). For autism mother narratives and popular books by autism ‘experts’ I defined relevance consistently with my previous chapters, as those books that appeared in newspaper and magazine book reviews available to a Toronto audience.

Given that these years are also ones for which I moved through autism mother networks as a mom in Toronto, some of the items in my archive were previously encountered, shared with other mothers, intellectually engaged, intellectually discarded, practically adopted, resisted and emotionally resonant with me as I made my way with my sons, and through my writing, in my everyday. My archive broadens my lived path through Toronto autism mother networks during the years 2000-15, offering a rich and unique collection of online and print everyday text and talk in Toronto. I first work genealogically with my archive to trace the multiple emergences and intensifications of ‘autism mother’ identities during these years. I then extend the way I have been proceeding thus far in previous chapters where I inserted interpretive moments along the way and re-read moments of maternal resistance as its own act of resistance. I extend this method by offering an in-depth, critical and interpretive phenomenological description of one version of the warrior mother – the *feminine warrior*. This shift in approach attempts to reveal a little more of the cultural ground that composes today’s warrior mother by exploring what ties us to her from a different standpoint. I engage everyday text and talk through my own experience as a mother and scholar reading, writing and living this identity. This is not
perspectivism or a move to imbue experience with the authority to speak the ‘truth’ (Scott, 1991). Rather, I engage maternal experience as an additional site through which we might know and understand the world, and phenomenology, a little differently (Smith, 1999). This method acknowledges reading and writing as fully social activities that might also, even if only slightly, reshape the world (Smith, 1999, p. 145). It also recognizes knowledge production as an interpretive, political and ethical endeavor that is always partial and situated (Haraway, 1991, pp. 188-201). Thus I return to the embodied “liminal space” in which power and embodied subject irrevocably entwine a little differently (on power and subject see Butler, 1997b, p. 15; on liminality see Lewieki-Wilson and Cellio, 2011; on liminality, subjectivity and power see Titchkosky, 2007, p. 21). Phenomenology offers another entry point into this liminal space that might help reveal new aspects of autism’s ‘mother warrior’ as an intensive normalizing figure of war, as well as new possibilities for being together within the constraints of intensifying capitalist, scientific intensive mothering regimes.

**New Forms of Knowledge: Genetics & Biomedicine**

The turn of the millennium would be a turning point in terms of forms of knowledge that would come to dominate Western culture’s understanding of autism and of the human. Everything from obesity to diabetes was supposed to now have a genetic basis (see, for example, Abraham, 2011, p. F6). In the year 2000, psychiatrist Michael Rutter, a prolific research scientist in developmental psychopathology in the UK, published a pivotal review article on genetic studies of autism since the 1970s. In this article, Rutter asserts that twin and family studies show that “the heritability of an underlying liability to autism was above 90%” (Rutter, 2000, p. 5). Rutter confidently states that genetic studies will
successfully uncover the causes of autism, along with “effective means of intervention or prevention” (p. 11). Similar stories began to appear in everyday text and talk about autism, such as the article, “The Early Origins of Autism” published in the same year in *Scientific American*. This article describes genetic research into mutations of the gene *HOXA1*, located on chromosome 7, and thought to be a trigger in some cases of autism (Rodier, 2000; for other examples see, De Rubeis & Buxbaum, 2014; Rosen-Sheidly, Wolpert & Folstein, 2004). For autism, as for other genetic disorders, “…observable and measureable expressions of “mental illness” are directly caused in degree and form by the underlying organic disorder such that the observed expressions of the disorder are seen as mere epiphenomenon of the “underlying” condition” (Nadesan, 2005, p. 141). Ways of being identified as autistic such as flapping, rocking or averted eye gaze are thus linked directly to disordered biology and become mere symptoms of an underlying organic disorder. In its “conquering gaze from nowhere” (Haraway, 1991, p. 188), the Western scientific “god-trick” erases the social and interpretive processes and histories – ones that my chapters describe in some detail - through which all bodies come to have meaning, eliding the constitution of the ‘normal’ human through the marking of autistic bodies as object and Other. This is Western culture’s search for certainty and control, a 21st Century version of eugenics that harkens back to scientific studies of measurable traits (such as craniometry and its measurement of bumps on skulls) in the late 1800s and early 1900s that attempted to link heredity and race to “degeneracy” – criminality, deficient mothering, mental retardation and so on (Nadesan, 2005, p. 140; also see Mitchell & Snyder, 2003).

A genetic understanding of autism has also supported the emergence of large-scale, international, collaborative public/private research efforts to map individual autism genes
as well as the full genomic sequences of families. Projects of this ilk include, for example, the Autism Speaks-BGI (Beijing Genomic Institute) Genome 10K Project, which aims by the end of Phase 3 (Phase 1 is complete) to sequence 10,000 genomes of “families affected by autism” (Autism Speaks, n.d. b, para. 8). The Autism Genome Project, “…a global scientific effort to discover the genes responsible for causing the disorder” (Autism Speaks, 2007, para. 1) brings together over fifty academic and research institutions in a consortium seeking to identify autism “susceptibility” genes. Phase 2 of the project, announced on March 11, 2007, includes a $14.5 million dollar investment by Autism Speaks and six of its partners, including The Canadian Institutes for Health Research and Genome Canada (Autism Speaks, 2007, para. 3). Dr. Stephen Scherer, who is the director of the Centre for Applied Genomics at Toronto’s Hospital for Sick Children, and his team have reported “breakthrough” findings as part of this international consortium. These findings include the identification of genetic risk in a greater number of cases of autism (now 25-50% rather than 20%), and progress towards the development of a DNA test for autism, one that might be given prenatally, raising complex issues for mothers, as we shall see (Abraham, 2007, p. A1; 2008, p. A8; 2010, p. A1; Talaga, 2013). What kind of ‘progress’ are such projects ‘investing’ in? A version of the human that excludes autism as a viable way of being, to be sure, locating autism in individual disordered bodies and brains that become the objects of and for scientific study within an academic research market where autism is a ‘hot’ commodity (Mallet & Runswick-Cole, 2012). After all, the purpose of these international efforts is to reduce, prevent or even eliminate the expression of autism in the human population by finding autism’s cause as well as by offering genetic counseling to ‘at risk’ families, and DNA tests more broadly (which may soon be on the market) that screen for
autism susceptibility in family members and fetuses (McGuire, 2011b, p. 96; Nadesan, 2005; Rosen-Sheidley, Wolpert & Folstein, 2004). The effect of such international efforts, too, has been the public and private ‘investment’ in and generation of “multi-million dollar biomedical autism research industries” (McGuire, 2011b, p. 98). What was formerly the crusade of “moral entrepreneurs” such as Bernard Rimland (1964) to establish autism on biological research agendas, is now professionalized and institutionalized “big business” (Mallet & Runswick-Cole, 2012, p. 40) that is self-perpetuating and proliferating in its search for new problems to be solved (more genes to discover, different subtypes of autism, DNA tests for the general market) and new solutions (prenatal screening, new technologies, pharmaceutical interventions) to be found for the unsolved enigma of autism (Becker, 1963, p. 153).

Because so many genes are understood by research scientists to be involved in a complex relationship to the expression of autism and other ‘genetic disorders’ in individuals, researchers also believe that environmental influences must play a role. The field of epigenetics, in lay terms, studies how environmental factors, for example prenatal stress, diet, exposure to toxins, viruses, pesticides, antibiotics or drugs chemically alter gene function and expression in the developing fetus or child, leading to ‘turn on or turn off’ conditions such as autism (see, for example, Abraham, 2011, p. F6; Jimenez, 2009, p. L1; Parsell, 2004, pp. 311-12). Environmental influences include “anything that affects pregnancy” says pediatric neurologist Zimmerman (as cited in Parsell, 2004, p. 311). These influences are, along with our DNA, beginning to be understood as heritable. “There’s an epigenetic memory” for environmental influences such as maternal stress or malnutrition, explains epigenetics researcher Rosanna Weksberg at Toronto’s Hospital for Sick Children
Epigenetic memory affects not only cell regeneration, but also transmission across generations, through sperm and egg cells, finding expression in generations to come beyond mother and child (Skinner, Manikkan & Guerrero-Bosagna, 2011). Rimland’s (1978) earlier advocacy for a biomedical approach to understanding autism and autism treatment has also thrived in the age of genetics. Biomedical approaches fault the toxic environment for triggering autism, whether childhood vaccinations, prenatal exposure to toxic chemicals or oral antibiotic use in young children, for example. Autism, in this view, is an illness from which recovery is possible through biomedical interventions (see, for example, Belli, 2010; Jack, 2014, pp. 64-104; McCarthy, 2009; Nadesan, 2005, 194-6; Seroussi, 1999). The risk of autism, to borrow Anne McGuire’s words, can now “come from anywhere” (2011b, p. 102), including the very practices mothers engage to protect our child, adding new layers of contradiction – a mother is now also both ‘risky’ and protective; as well as a ‘hot’ new commodity within ever-expanding research markets searching for autism’s cause – regulating the ‘good’ mother in our time.

Given that dominant genetic science is a proliferating research market that animates popular renderings of autism and autism mothers with an as-yet-unsatisfied demand for a solution to the enigma of autism (Mallet & Runswick-Cole, 2012), I try to “make sense” of knowledge production in another sense, one that moves beyond the location of identity and difference in our genes and the environmental influences that turn genes ‘on or off’. Philosopher Rosalyn Diprose says,

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60 In 1998, Andrew Wakefield published research findings in the medical journal The Lancet that implicated the Measles, Mumps and Rubella vaccination given in early childhood in causing autism through harming children’s immune systems. Amidst much controversy over Wakefield’s falsified data, this article was later retracted (“Retraction - Ileal-Lymphoid-Nodular Hyperplasia,” 2010). Some researchers have also implicated thimerosal mercury in vaccines as the trigger for autism (see, for example, Geier & Geier, 2003). The vaccine theory continues to be advocated by some autism mothers and advocacy organizations as the primary environmental trigger for autism (see, for example, McCarthy, 2008; http://www.generationrescue.org/).
It is as bodies that our finitude and uniqueness are signifyed to others; hence it is as bodies that we are both social and moral beings. This uniqueness is expressed through, and is inseparable from being open to others within a context of social discourses (scientific, ethical, sociological). As such, identity, and therefore difference, is never self-present; the body makes sense, but never completely, or in and of itself. (2005, p. 237)

Through our openness as embodied beings irretrievably caught up with and in social and discursive relations with others, the meaning we make of bodies comes to make sense. Diprose suggests that there is a remainder in the openness between us, in our embodied uniqueness and finitude. She directs us to recognize the ways genetic discourse makes sense of bodies as objects in and of themselves, as well as to pry open space in which knowledge production might proceed ethically by remaining “open to the openness by which bodies make sense” (p. 238). I proceed below with my effort to fashion alternatives to objectifying dominant science and social science by prying open the openness of how the ‘good’ mother and autistic child appear in everyday text and talk.

**New Forms of Visibility: Mothers as ‘Risky Environment’**

Mothers would continue to be brought into view as their child’s ‘therapist’ during 2000-2015, a skilled worker ‘working on’ – normalizing - the behaviour of their autistic child. However, the rise of genetics, epigenetics and biomedical approaches also brought mothers into view in new ways, opening spaces of self-governance through which a newly contradictory feminine and genetic understanding of autism would come to regulate the good/bad mother anew. Now a potentially ‘risky environment’– from her genes, to her
epigenetic influences – mothers’ bodily and psychic “movements of life” (Titchkosky, 2007, pp. 158; Foucault, 1976/1980a, p. 25) have become a site of heightening visibility and intensifying governance. In addition to honing her skills as therapist, a mother is now invited to ‘watch out’ for…everything that might pose a risk to her not-yet-conceived or unborn child. In the magazine babytalk (2013), for example, an article entitled “Is it something I did?” not only reviews genetic research, rehearses the “red flags” of autism (“signs” for mothers to watch for in their growing child), advocates for preventative mothering – “take extra care to point at and label objects” (p. 32) - and supports early intervention (starting as early as 6 months) as protective practices against autism mothers can engage to “alter the course of brain development” (p. 30). The article also cautions mothers about potential epigenetic factors:

…new thinking: You can take steps before and during pregnancy that may reduce the risk…Environmental factors may turn many autism genes “on” or “off”…For instance, women who take a folic acid supplement before and during pregnancy are 40 percent less likely to have a child that develops autism…Expectant mothers who have a fever for longer than a week also pass along a higher autism risk (33 percent) as do those who contract the flu (25 percent). Other increased risk factors: living near a freeway (50 percent) or being overweight or diabetic (60 percent). (Heyworth, 2013, pp. 30-3)

Mothers are now doubly implicated as ‘risky environments’. A mother must, first, ‘watch out’ for everything - from germs, to her health (diabetes), the food she consumes (lest she

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61 On the “red flags” of autism – public health and advocacy campaigns that aim to “raise awareness of autism’s ‘signs’” see McGuire (2011b, p.108).
be overweight), where she lives (by a freeway), the supplements she takes (or doesn’t take) and so on. Her intimate movements, personal and consumer ‘choices’ are now visible spaces of self-governance through a mathematically calculated risk of autism in her not-yet-conceived or unborn fetus. Mothers who don’t watch themselves are implicitly riskier. But more, mothers bear both mathematical risk factors themselves and can “pass along a higher autism risk” to their child. ‘Autism risk’ (rather than the expression of autism in her child) may bodily inhabit a mother’s child, a risk passed along to that child, that child’s child, and so on, turned ‘on or off’ along the way depending on environment. This ‘double whammy’ of blame and risk – both bearing (an autistic child) and passing along risk – bodily installed in conceptions of today’s risky mother who watches herself through new mathematical and genetic forms of visibility, regulates the good/bad mother anew. It is a mother’s self-governance of her intimate bodily movements and choices as calculated epi/genetically and mathematically - rather than her skilled technique as a therapist alone or her disordered love – that now, at least in part, regulates the good/bad mother.

Biomedical approaches also intensify new modes of ‘risk’ visibility and self-governance for mothers. These non-conventional approaches include links to organizations such as DAN! (Defeat Autism Now), and “tend to be anti-drug and pro-supplement, and they insist that autism is, indeed, a treatable condition” (Belli, 2010, p. 28). Added to the list of things to ‘watch out’ for by biomedical advocates are childhood vaccinations, antibiotics, environmental toxins, poisoned food sources, corrupt governments and more. Author, blogger and autism mom turned biomedical advocate Kim Stagliano (2010b), for example, says this in her Huffington Post blogpost about vaccines: “Clobbering parents with the concept of ‘herd immunity’ rings hollow when your baby calf is the one who falls.
Bludgeoning parents of autistic children has failed to connect with parents in its utter transparency to protect corporate and governmental interests” (para. 5-6). Here, the ‘good’ mother makes ‘choices’ about risk (not to vaccinate), rejecting conventional science based on her maternal authority and love for her child (this mother’s “baby calf” has fallen) (Jack, 2014, p. 88-95). She also combats risky environments that include violent corporations, corrupt governments and paternalistic medical practitioners as new antagonists in her story (Jack, 2014, pp. 80-1; on ‘risk society’ also see Beck, 2005). Mothers who make different choices (to vaccinate, or to value her child’s way of being) are implicitly brought into view as risky, too. Biomedical approaches also insert new “expensive” and “intensive” (Hays, 1996, p. 8) treatments onto a market aimed at ‘recovery’ for mothers to ‘choose’ from, including “…chelation therapy, gluten and casein-free (wheat- and dairy-free) diets and even hyperbaric oxygen therapy” (Belli, 2010, p. 28).62

To gather up what has become of new forms of visibility so far, both biomedical and epi/genetic approaches bring mothers into ‘view’ as bodily linked to ‘risky environments’, whether through a mother’s genes, epigenetic influence or consumer and maternal ‘choices’ (i.e., whether to vaccinate, serve wheat and dairy, try chelation, live by a freeway). The mother-child relationship remains the scene where normal development unfolds, however, today’s mother is ever-more intensively proximate and governed – her risky influence begins before her child is born and is sustained into future generations through her epigenetic influences and maternal consumption (of food, supplements, expertise etc.). Mother as ‘risky environment’ proliferates spaces of neoliberal governance in which mothers are governed anew within what Nikolas Rose (1996) calls “[a]dvanced

62 For other examples of biomedical approaches in everyday text and talk, see McCarthy (2008), Rones (2008) and Seroussi (1999).
liberal rule” (p. 41). This is a neoliberal form of rule that “does not seek to govern through ‘society’, but through the regulated choices of individual citizens, now construed as subjects of choices and aspirations...Individuals are to be governed through their freedom” and within communities based on identities like that of autism mother (p. 41). Further, within advanced liberal rule and the dismantling of the welfare state, expertise is relocated within “a market governed by the rationalities of competition, accountability and consumer demand” (p. 41). Within such new neoliberal instrumentalities, mother as ‘risky environment’ introduces new contradictions and meanings that regulate mothers in new ways – this mother is both risky and defending; consuming and protective; expert and motivated by love; free to ‘choose’ and intensely governed. This mother is also implicitly privileged and governed through a consumerist capitalist market (this mother is industrious!). Her differential access to resources such as high quality food, housing, safe working conditions and expensive treatments, unlinked from the material reality of inequity through this individualizing form of visibility, is erased through the scientific language of individual ‘risk’ and ‘choice’. Privilege, and inequality, is now not only (epi)genetically heritable through a mother’s ‘choices’, but it prevents or causes autism, too, as the case may be.

It is interesting to note other, less ‘risky’ and even ‘accepting’ voices emerging on the scene of everyday text and talk that bring mothers into view differently for 2000-15. In *The Women’s Health Activist*, for example, medical librarian Rachel Walden (2012) writes, “Now, sadly, explicit mother-blaming has shifted to implicit mother-blaming. The latter is less likely to be challenged as misogynist, but continues to identify women’s actions as potential causes for ASD” (2012, p. 11). In the weekly science journal *Nature*,
developmental origins of health and disease (DOHad) researcher Sarah S. Richardson (2014) and her colleagues identify “the long shadow of the uterine environment” (p. 131) cast for mothers as the source of ills in their offspring, including autism. They add, “exaggerations and oversimplifications are making scapegoats of mothers, and could even increase surveillance and regulation of pregnant women” (2014, p. 131). ‘Former’ autism mother Cammie McGovern (2006) goes further in challenging ‘risky’ views of mothering. McGovern, who, initially tried all the therapies, conventional and biomedical, to normalize her child, describes laying down her past identity as ‘mother warrior’, defeated in the fight against autism and for an autism-free future by the “finitude and uniqueness” (Diprose, 2005, p. 237) of her son in the present, “All the families I know who wage war come to a point where they lay down their arms. Sooner or later, battling the disorder starts to feel like battling the child” (McGovern 2006, p. 140). McGovern’s appearance in everyday text and talk begins to open an alternative way to care about autistic children and mothering. It is no tragedy that McGovern has admitted defeat against the problem of ‘autism’. Rather, McGovern breaks the tragedy/heroism binary of disability, interrupting “linear narratives” of “progress” toward normalcy through a mother’s participation in therapies and controlling (future) risk factors (Fisher & Goodley, 2007). A different kind of risk, that of missing out on the uniqueness and love of your child in the present, is brought into view by McGovern in her moments of ethical narration, “When he [son] laughs at the same intersection whenever you go through it, and says, “I don’t know, I just love that traffic light,” you think, Well, there are worse things to love” (p. 140). Though each of these authors also continues to bring mothers and mothering into view in more conventional, normalizing and ‘risky’ ways, mothers are also brought into view as “challengers” of risk and conceptions of
autism as a ‘problem’ and mothers as the ‘solution’ (Fisher and Goodley, 2007; on mothers’ adherence to both challenge and convention see Panitch, 2008, p. 12; Sousa, 2005, p. 229-30). The ethical risks inherent in ‘waging war’ against a unique and very present autistic child, as well as the risks of misogynistic scientific mother-blame and increased surveillance of all mothers, are brought into relief by these mothers.

Toronto autism mom and blogger Estee Klar also brings autism mothers into view differently, grounding her ‘view’ in a maternal standpoint as well as autism acceptance. In a blogpost entitled “Mental ability and the discourse of disease: Another comment on the Globe and Mail article on ‘Treating the brain and the immune system in tandem’,” for example, Klar responds to the article’s suggestion that “mental illness” (including autism) is a “disease” with the following reflection:

Recently, I am interested, as a woman, theorist and mother, in the lovely intimacy I share with my son as caregiving can be a very physical act. Touted as a burden by many charities and the like – including fellow parents who yearn to have an independent child – I have been grateful to be put into a situation where my expectations have been radically altered; where caring has become an important part of my treasured (ever-changing) identity. This has been created by the reality of caring and the mutually negotiated relationship I share with my son. Therefore, reading accounts of genetically ameliorating autism, or relentless and repeated suggestions that disability (often shoved under the “mental illness” umbrella) is biologically caused or wrong, is troubling for my son and I on many fronts… (Klar, 2015, last para.)
Two aspects of Klar’s response to the pathologization of “mental illness” and disability within the Globe and Mail article are particularly striking. First, in her invocation of the physicality and mutually negotiated reciprocity of care with her son, practices that continually re-make and shape her identity, Klar draws a “bridge” (Kelly, 2013) between this expressed feminist ethic of care and the call from disability studies to reconceive care and disability beyond that of devalued dependence, rights perspectives or (physical, economic, emotional) “burden.” This revaluing of care and disability in the midst of pathologizing everyday depictions of difference is vital work towards challenging oppressive notions of autonomy within a gendered political economy of care for both carers and disabled persons (Hughes et al., 2005; Kelly, 2013; Kröger, 2009).

Secondly, it is striking how for Klar, as the mother of an autistic son, this popular rendering of “mental illness” (including autism) as a problem in need of a solution – something that is “wrong” - means “trouble” for her and her son (on disability as a problem in need of a solution see Abberley, 1998, p. 93; Mitchell, 2002, p. 15; Titchkosky & Michalko, 2009, p. 2). From within the biomedical problem/solution dialectic of disability, the only possible way to care for what is “wrong” – a biological defect – is to objectify autism and care about its elimination, thus making it “right.” Yet Klar, and other moms, care for children identified as autistic. Klar shares a “lovely intimacy” with her son. In this landscape, caring for what is “wrong” becomes “troubling.” It becomes an impossible situation. In this rub, between mothers who care for and love children identified as autistic in their everyday, and ‘mothering’ or ‘caring’ as an unimaginable solution, conceived as caring for what is “wrong,” the problem/solution dialectic of disability begins to break down. ‘Autism’ becomes something more than a problem of defective biology. ‘Autism
mother’, too, begins to mean something different, something outside of the Western cultural contradictions of femininity and scientific understandings of autism that regulate the good/bad mother. Different questions about autism and mothering emerge from the my work here, and the provocations of Klar’s blogpost: How might mothers already care for their ‘different’ child outside of the constraints of biogenetic understandings of disability and mothering? What else might be possible for being together under late modernity? I return to these questions in chapter six, but for now I turn to a consideration of the emergence of new forms of affective technology in what Gail Landsman (2006) calls “the age of ‘perfect’ babies,” technologies that have come to bodily install ‘freedom’ and ‘choice’ into mothers’ everyday practices as implicit forms of mother-blame.

**Freedom and Choice as a New Technology of Blame: Mothers as ‘Experts’**

New forms of visibility for mothers as ‘risky environments’ meant that more was required than becoming her child’s behavioural ‘therapist’ for the ‘good’ mother during 2000-15, although she must also continue to do so. In an age where the prevention of disability – or at least its control - via new technologies and treatments is expected of mothers (Landsman, 2008; also see Sousa, 2005, p. 223), the mother-expert emerged more prominently on the scene of everyday text and talk in Toronto. Communication through the Internet is a particularly intensive sight of such mother expertise. Autism mother blogger Leigh Merryday (2012), for example, ‘expertly’ describes at least ten “signs” of autism in a young child to the wondering and worrying parents who follow her blog, including: “doesn’t seem to know how to play with toys correctly,” “may not show affection,” “does not point to what he wants (a big red flag),” and “hand flapping.” Through such everyday text and talk, the ‘expert’ and bodily re-education of a mother’s way of seeing her child,
drawn from a scientific version of autism that ‘flags’ particular embodiments as problematic, is installed in mothers’ ‘watchful’ practices (McGuire, 2011b, p. 99). This mother expert must also acquire ‘expert’ knowledge about how to respond to the signs of autism in her child. Becoming ‘expert’ now includes learning how to navigate an ever-expanding capitalist market of treatments aimed atremedying autism, bolstering the “duty and urge to act” Bauman (2004a, p. 20) describes in the achievement of modern forms of identity. In an article in the popular women’s magazine Redbook (2008), one mother’s journey becoming an mother expert included, for example, hiring behavioural consultants, working with occupational therapists and homeopaths, learning about the science of the brain-gut connection (see, for example, Gordon, 2013; McCarthy, 2008), practicing Floortime, consulting a DAN! (Defeat Autism Now) doctor, studying nutritional supplements and mastering a gluten-free, casein-free diet (Rones, 2008). As the article concludes, “There’s no magic bullet for treating autism spectrum disorders…But given the many treatment options there are to explore, there is plenty of hope. Using a combination of methods is usually most effective” (Rones, 2008, p. 179). Expertise that was once situated within interactions with professionals is now resituated within a market of expanding “choice” (Rose, 1996, p. 41) at mothers’ fingertips (literally, through the Internet) that includes both conventional and biomedical approaches. A mother’s “hope” for the child she loves has come to mean the ‘freedom’ to ‘choose’ from “the many treatment options” to achieve normalcy, and constitutes a new technology of mother-blame, one that invites and impels all mothers in this normalizing quest (Jack, 2014, p. 68).63 ‘Bad’ mothers like Klar

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63 A Mother’s Courage (Ericsdottir & Fridriksson, 2010), is another compelling example of the new technology of mother-blame through freedom and choice. This documentary follows autism mother Margret as she leaves her Icelandic home and travels through the United States and United Kingdom to search for the expertise that might “unlock her autistic son’s mind.”
(see above) who move outside of this problem/solution dialectic are often dismissed as deluded about their child’s problems (Blum, 2007, p. 203).

It is love and self-sacrifice that drives the ‘good’ mother in her ‘choices’ to accumulate scientific expertise about autism, and act to achieve normalcy in her child (Jack, 2014, pp. 88-89). This is depicted with particular salience in the specialty magazines, autism mother memoirs and parenting guides that emerged during 2000-2015.64 The Autism Trust, for example, a parent-initiated autism advocacy organization in the U.K. committed to biomedical intervention and recovery, publishes the magazine The Autism File as both a “labour of love” and an “…ongoing source of support and advice, together with informative scientific content…to challenge, debate and discuss the issues regarding autism no matter how controversial they might be…” (http://www.autismfile.com/sample-page, last para.).65 In a paradoxical twist that faintly echoes the instinctual mother of psychoanalysis, whose coldness and so-called disordered love manifested autism in her child, the ‘good’ mother expert is also grounded in ‘natural’ love for her child, only this time, signs of autism in her child become measures of her success or failure to intensively accumulate scientific expertise and make the right ‘choices’. Blum (2007) argues that today’s ‘good’ mother of children with disabilities is held to a “standard of relentless action” (p. 221) as her child’s “proximate” rather than direct cause, which “reinforces normative femininity and women’s ‘natural’ devotion” (p. 222). A recent autism mother narrative, The spark: A mother’s story of nurturing genius (2013), powerfully depicts these

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64 For other examples, see Ericsdottir & Fridriksson (2010); Guernsey (2006); McCarthy (2008) and Seroussi (2000).
65 Similarly, Autism Speaks, a U.S. based, influential autism advocacy organization, publishes the more scientifically conventional Autism Speaks Science Digest (see https://www.autismspeaks.org/science/science-news/announcing-autism-speaks-science-digest). Also, Science News Digest was published in the early 2010s by U.S. based organization Autism One committed to biomedical intervention, as “the place for doctors, researchers, and expert moms and dads to share information about treatment, research and recovery” (http://www.autismone.org/content/autism-science-digest, para. 1).
new contradictory layers of mother-blame as installed through a mother’s ‘freedom’ and ‘choice’. *The Spark* is the story of autism mom Kristine Barnett, who reclaims expertise from professional therapists and merges it with her love and intuition about the “spark” she sees in her son in order to “reach” him (who emerges from autism as a genius):

I wasn’t formally trained to administer the kind of therapy Jake needed…But like every other parent of an autistic child, I’d been in the trenches with Jake’s therapists since day one. Plus I knew my child better than any expert could. And I saw a spark in Jake. (Barnett, 2013, p. 58)

Barnett went on to start Little Light Daycare, where she “recovered” her son and helped other autistic children by beginning from their strengths. While Barnett draws on familiar autism narratives (a trapped, intelligent child, a commitment to recovery and the language of the war), what’s new with this mother is how intensively she now reclaims authority from scientific experts and professionals, both on the ground of the maternal - her love, experience and intuition – and through her ‘freedom’ and ‘choice’.

In some ways, like the mother therapist before her, today’s mother expert “wrests authority” away from paternalistic science and professionals, revaluing maternal authority and expertise (Jack, 2014, p. 60). Landsman also identifies this revaluing of the maternal in her study of the meaning mothers make of mothering an “imperfect” disabled child in an age where “perfect” babies are both a ‘choice’ and commodity promised by the control of science and technology (1998, p. 3). In Landsman’s study, “[m]others repeatedly describe coming to recognize and value their own expertise” (p. 99). Mothers have an intimate knowledge of their child as well as commitment and passion to gather biomedical

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66 This mother expert role was incipient in earlier decades. See Maurice (1993) and Kaufman (1976).
knowledge that opens a different ground of knowing, one that merges the maternal with the scientific on a mother’s terms. This is an important challenge. At the same time, it is now through her very freedom to fashion herself as ‘expert’ – one whose level of commitment to achieving normalcy has been intensified to that of a warrior - that a mother is governed and implicitly blamed. This ‘freedom’ and ‘choice’ is paralleled by the heightening constraints of neo-liberal capitalism that continue to push care back into the family and private market while expecting – perhaps more than ever – the performance of the natural, intensive mother, and the achievement (in herself and her child) of a scientific and Western version of the normal human as autonomous, productive, self-governing, rational and non-autistic (Rose, 1996, pp. 40-1). Gender, class and race inequities, and the neoliberal marketization of human life are elided within this newly intensified version of mother-blame (Hays, 1996, p. 157, 165; also see Blum, 2009; Sousa, 2005, p. 221). A new layer is added to ‘autism mother’ as a key cultural contradiction – a mother’s ‘freedom’ and ‘choice’ to achieve a ‘normal’ child is also a new site of governance through which the intensifying normative feminine and its link to a restrictive neoliberal capitalist political economy and Western scientific version of the normal human has come to regulate the good/bad mother, and orchestrate cultural understandings of the “good life” for us all.

**New Identities: ‘Mother Warriors’**

I turn now to take another ‘look’ at what has become of, and what is “behind” the identities ‘autism’ and ‘autism mother’ in our time, only this time I do so with the perceptual “backwards glance” of phenomenology (Ahmed, 2006, p. 570). So far, it has been through the historical backward glance of genealogy, alongside interpretive moments
of re-reading everyday text and talk, that I have worked to draw the seemingly ‘natural’ link between autism as disorder, on the one hand, and a mother’s duty to achieve normalcy in her child on the other, into question. In this section, I draw from phenomenology to pursue the cultural ground of the dominant meaning of autism mother in our time in more depth – that of ‘mother warrior’ – an identity that holds mothers, in Blum’s words, to a “standard of relentless action” (2007, p. 221). I consider one particular example of this mother – the feminine warrior - within a global autism mother recruitment campaign. I include my own response to the campaign as a way to ask questions about how seemingly natural ties come into being over and over again in ordinary acts of everyday interpretive consciousness. I then ask what the doing of my description suggests about how these ordinary acts unfold and achieve their effects. The work of this section is exploratory. It unfolds in a circular fashion that deepens with each turn in order to re-read what’s behind the phenomenon of autism mothers. It is its own site of social action in this way, one that attempts to disrupt any ordinary or passive reading. It is my hope that by critically exploring maternal experience as a place we might know and understand the world differently, and by engaging the “backwards glance” of perception (Ahmed, 2006, p. 570), I might show how there is nothing ‘natural’ about the meanings we make of, and the ties we have to autism and autism mothers. My hope is to open new possibilities of what being together might mean under late modernity.

An Aside: Choosing a Warrior Mother Text.

There are many salient everyday texts I could have chosen for my phenomenological description, each offering a slightly different slant on autism’s ‘mother warrior’. I briefly touch on two others here in order to tie in different threads of this
mother’s story. The motion picture *The Autism Enigma* (Sumpton, Bender & Gruner, 2011) is one such everyday text. This documentary, narrated by Canadian environmentalist David Suzuki, and aired on the popular science show *The Nature of Things*, tells the story of three Canadian autism mothers – two white Western mothers and one black Westernizing Third World immigrant mother - as they grapple with the meaning of autism in their lives vis-à-vis their children and the current state of genetic and other scientific research. The viewer is presented with the ‘facts’ of autism and mothering as she watches these moms move through their daily lives, engaging intensively in autism therapies, advocacy, medical appointments, autism conferences, specialty food preparation, research and so on. Autism, Suzuki tells us, is a neurodevelopmental disorder - a biological enigma located in individuals that must be remedied. It is caused by an unknown combination of genetic and environmental factors. It is on the rise. And it is a tragedy immediately caught up with the intensive labour, love, grief and care of mothers. If, as ethnomethodologist Harold Garfinkel (1967) suggests, such ‘facts’ are a practical “accomplishment” (p. vii) of social interaction within everyday occasions through which they come into being and are given meaning, then the documentary *Autism Enigma* engages viewers in such an occasion (Garfinkel, 1967, p. 3). I describe two of these mother’s stories here to highlight the new meaning this documentary is making of autism and mothering.

Despite her young adult son’s “delightful” presence in her life, ‘expert’ mother Ellen Bolte tells viewers, “I cling to the hope that research is going to be done in time and that he’ll be able to receive treatment and that he will be able to still respond…” She narrates her years of intensive research, based on her intuitions regarding what triggered her son’s autism, in her attempt to fight against autism in her child. Her fierce advocacy
with scientists based on her efforts results in a new research project in Canada investigating the autism gut-brain connection and antibiotic use. Ellen shares home videos and detailed records with viewers of her young son’s behaviour ‘before’ and ‘after’ the biomedical treatments that resulted from this research. In the ‘before’ videos, viewers see Ellen’s son running back and forth, ignoring her attempts to get his attention, and at times, curled up in a ball, rocking. In ‘after’ videos we see her young son talking to the camera, smiling and cuddling playfully with his mom. Despite Ellen’s “delight” with her adult son (who is depicted talking, smiling at and hugging his mother, incidentally), she speaks openly of her grief after the biomedical treatments fail to permanently eliminate his autistic behaviour (also see Gordon, 2013). For Ellen, a kind of ‘warrior mother’ who fights against autism through accruing expertise as well as intensive advocacy for ‘better’ science, a life together with her son “in” the difference of autistic embodiment seems inconceivable (Titchkosky & Michalko, 2012). Autism, as it is made to appear in her son’s rocking, running non-attentive body in the documentary, signals disorder, failure and grief for Ellen, despite her current delight. Through Ellen’s narration, autism is accomplished as a non-viable “standpoint,” an unnatural, disruptive, non-congruent and undesired form of life that disrupts the ground of normal development and sociality (Schutz, 1962). After her failed attempts as a ‘warrior mother’ to produce a cure for her son, Ellen’s only “hope” is that scientific research will yield future treatments for her son.

Viewers also meet Adar Hassan, a westernizing, Third World autism mother introduced as a Somali immigrant with two autistic sons she cares for full time. Unlike her privileged, white Western counterparts in the documentary, who have extensive advocacy experience and are fierce movers of scientific agendas, Adar is still learning what to make
of autism. We watch, listen and learn along with her as she seeks medical help, engages services and searches for answers about autism. Autism is virtually unknown in Somalia, Suzuki tells us, but it is being identified in the Toronto Somali community to such an extent that Adar and other families have been asked to participate in genetic research studies at the University of Guelph and University of Western Ontario. Both she and Suzuki name the shift to an industrialized country and the loss of “simple foods” as a possible cause for the apparent rising incidence in the Somali community. Adar is depicted as a ‘developing’ subject alongside her autistic sons. Along with Suzuki’s narration, viewers are shown images of the so-called simple autism-free life Adar left behind in Somalia, and are in this way directed to a romanticized picture of a more pure, natural, pre-industrial, autism-free world from which Adar came and to which we must return, but this time on the ground of Western scientific, capitalist production and intensive mothering. In a sense, Adar is depicted as a westernizing subject by virtue of bearing, and learning how to bear, the pathologizing effects of late modernity – autism diagnoses for her sons, intensive scientifically informed expert ‘warrior’ mothering, advocacy, the impulse toward cure and engagement of normalizing treatments. The *Autism Enigma* ties a mother’s love in the domestic realm to the ‘return’ to a healthier and more ‘pure’ state, where we see Adar preparing raw foods, for example. However, a mother’s fight to find a cure for her autistic child is also tied to the consumption of products and expertise in the public realm. We watch as Adar attends the annual Autism One conference held in Chicago, for example, where parents, scientists, celebrities, and capital collide in the search for and promotion of treatments and cures. Indeed, the very “duty and urge to act” that Bauman (2004a, p. 20) ties to the accomplishment of modern forms of identity composes Adar’s new westernizing
selfhood, as she learns to consummate both herself and her sons into being through Western neoliberal scientific versions of the human and racialized discourses of development delivered through autism industry. Adar’s story demonstrates a key shift in governance of autistic populations during the years 2000-2015. Autism’s expert ‘mother warrior’ as epitomized by Ellen Bolte, has become a westernizing cultural phenomena, one that is now encircling and governing subjects – autistic child and the good/bad mother - beyond Kanner (1943) and Bettleheim’s (1967) white or Jewish bourgeois North American or Western European subjects whose mothers work (on autism and culture see Jimenez, 2009; Kim, 2012).

A second set of everyday texts of interest are Autism Speaks’ website pages that describe different aspects of their Global Autism Public Health Initiative, and its implications for the meaning of mother (Autism Speaks, 2012). This initiative aims to export Western scientific understandings of autism (particularly genetic ones), treatment practices and health policies to developing nations, where autism is beginning to be diagnosed, tracked and traced. Members of the initiative were involved in the First World Health Organization Conference on Autism, for example, where delegates from around the world agreed that autism now poses an “urgent global challenge” (Rosanoff, 2013, para. 3). Delegates adopted the recent resolutions on autism of the United Nations General Assembly and World Health Assembly (Autism Speaks also helped author these resolutions) to urge world governments to implement a Western scientific understanding of autism along with conventional Western models of research, diagnostic and treatment practices, and public education (Rosanoff, 2013, para. 8). What is noteworthy, like Adar’s story in the Autism Enigma, is that autism no longer appears as a white, Western bourgeois
phenomenon. Rather, through such initiatives from Western advocates, the scientific governance of bodies and minds alongside autism industry is now exported globally, as an “urgent global challenge” for developing nations. Given heightening class and gender inequities that continue to cast women as primary care-givers globally (Ringrose & Walkerdine, 2008), the campaign also inserts a gendered version of care that enlists a particular kind of mother – autism’s mother warrior - in the achievement of the rational, neoliberal, self-interested, autonomous, productive Western consumer-subject as the unquestioned standard of the ‘normal’ human. This is a moment in which we might glimpse the complex intertwining of the identity ‘mother warrior’ in contemporary Western capitalist colonialist projects.67 I turn now to an in-depth consideration of one ‘mother warrior’ - the feminine warrior – within an autism mother global recruitment campaign in order to take a closer look at the interpretive processes tied to this new identity and her exportation, as well as what else might be “behind” today’s warrior mother. My work suggests that the exportation of new contradictory subjectivities like the ‘mother warrior’ – a developed and developing (of herself and others), aggressive and nurturing, scientifically self-governing and experientially grounded mother – and scientific understandings of autism regulate the good/bad mother anew, and invite compulsory participation in increasingly violent and globalizing frames of gendered and normative human identity for us all. I begin with two descriptions of the campaign, and then move to explore these descriptions phenomenologically.

67 For further reading on such global initiatives, see Titchkosky & Aubrecht (2015), who draw from disability studies and post-colonial theory to trace and disrupt the World Health Organization’s dissemination of “mental health” discourse as a “colonizing force in postcolonial times” (p. 69), one that arises from and sustains Western colonial relations, exports “restrictive and exclusive versions of the human” (p.69) and oppresses diverse bodies and minds in order to sustain exploitative colonial relations.
Autism Mothers Global Recruitment Campaign: Part One

I sit with laptop on knees and browse the Autism Mothers Facebook page, one of the first few ‘hits’ when I google ‘autism mother’. It is affiliated with the autism media channel (http://www.autismmediachannel.com/#!about/cuxm), where founder and autism mother Polly Tommey invites viewers to “join us in the movement to change the lives of people living with autism.” The media channel offers information and advice from a team of autism experts (including siblings and parents, but from all appearances, not autistic persons), particularly those who support biomedical interventions. I follow the link to the The Autism File, an online magazine (now with its own media channel, Facebook page and twitter following) founded by Tommey in 1999, and now the official publication of the UK advocacy organization Autism Trust. The cover of Issue 33 (2009), which I find on the Facebook page, appears to be the first in a captivating, repeating series of mothers posing in black evening gowns. Thirteen photos of mothers in black gowns, and a headline in the bottom left corner reads in bold “AUTISM MOTHERS UNITE WORLDWIDE” (“Autism Mothers Unite Worldwide,” 2009).

The most prominent photograph on the cover of Issue 33 (third row, second from the left) features six figures who appear white and female with long brown or blonde hair standing posed in a line, most angled in and toward one another, one facing away. Each wears the same uniform of long, black evening gowns with low necklines and high heels. Their stance is wide, like they are ready for action. They appear slim and ‘fit’ and stand tall, their necks long, bare shoulders thrown back. No one smiles. Hands are on hips, and one gloved hand holds its partner, presumably just taken off. The silky, elbow-length gloves are vibrant red, green, purple, silver and yellow. The image appears as part of the
photographic archives on the Autism Mothers Facebook page alongside similar images of groups of autism mothers from England and the United States, though there are groups from South Africa, Dubai and New Zealand too. I come across a similar image of the same mothers featured in a newspaper article, and learn that the photo shoot was done for the first United Nations World Autism Day (O’Brien, 2009). Something stirs in me. Grief? Guilt? Recognition?

**Autism Mothers Global Recruitment Campaign: Part Two**

In my searches, I find images from the photo shoot in two different versions of an *Autism File* video, the most recent of which is linked to the same newspaper article (O’Brien, 2009). The newspaper article calls the campaign a “global phenomenon” (these images also appear in an *Autism Mothers* calendar, on tote bags, keychains and mugs). I am beginning to ‘get the picture’ of a far reaching, multi-media campaign “…to bring mothers of autism together across the world,” as the description of this ‘autism mothers’ video informs us (“Autism Mothers: The Final Cut”). I find similar videos made in other Western countries with similar stories, as well as other campaigns that use this feminine warrior image. The most recent, an image of mothers in black gowns and red boxing gloves, appears on the cover of the 2014 advocacy issue of *The Autism File*, where parents are urged to use the Internet as a source of information to become “citizen scientists” – parent-experts on the environmental causes and cures of their child’s autism (Uram, 2014).68 In the original *Autism File* video of the photo shoot for World Autism Day 2009, dozens of

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68 The term “citizen scientist” was introduced by freelance writer Sara Solovitch (2001) in *Wired* magazine, where she argues that the Internet has been instrumental in the advocacy movement of parents of disabled children, changing the shape of medical research, “United by the Net and emboldened by their numbers, parents of desperately ill children are funneling millions into research, building vast genetic databases, and rewriting the rules of the medical industry” (p. 1).
images of mothers in some version of the black gown pose ready to run, and ready to fight: some have boxing gloves on or hold racing flags, others pose in “Charlie’s Angel’s” style or stand with motorcycles, ready to race. A forceful statement follows the images: “Autism mothers, a powerful alliance. Standing together, fighting for our children. We will win. We will win.” The images are set to the Leona Lewis (2007) version of the pop band Snow Patrol’s song Run. The song starts slowly. Its haunting progression builds to inspirational peaks with lyrics that might very well have been written from this warrior to her autistic child:

To think I might not see those eyes, makes it so hard not to cry… Light up, light up, as if you have a choice…Even if you cannot hear my voice, I’ll be right beside you dear…Louder, louder, and we’ll run for our lives. (Lightfoot, 2003)

I watch the video over and over again (and continue to return to it), mesmerized by its drama. The words, images and music haunt me and return to me at unexpected times – driving in my car, walking up the stairs in the home where I live, shopping for groceries. I search these images, looking for something, scanning the poses and determined expressions. These mothers know something, I think, and part of me knows it, too. It is the secret of our shared, violent and irremediably ethical lived contradiction as ‘autism mothers’ to fight against autism even while loving our unique and different child in front of us these mothers seem to keep that binds them together, and them together with me (on uniqueness see Arendt, 1998/1958, pp. 175-181; on alterity and ethical violence see Levinas, 1969, pp. 33-52, 72-81; on identity see Stiker, 1999; on the meaning of the human
see Titchkosky & Michalko, 2012). I struggle with grief at this figure, and with outrage. I find the campaign exhausting.

I now have two descriptions of my experience with two different iterations of a global autism mother recruitment campaign. One appears on the cover of a popular UK autism magazine, the other takes the form of a YouTube video produced by the same international autism advocacy organization. Both use language and images. Both are widely available through virtual worlds. The campaign is global in reach – and globalizing - as it makes the now familiar, almost taken for granted call to join the fight against autism. The call emanates from autism mothers of the US and UK, summoning mothers “across the world” to join the fight (“Autism Mothers: The Final Cut”). Like the World Health Organization’s resolutions and reports that would follow campaigns such as this (see, for example, World Health Assembly, 2013; World Health Organization, 2013), the Autism File campaign globally exports Western scientific understandings of autism as only and always a problem body/brain and worse, as a threat to the well-being of children, homes, families, nations, and indeed, the world. Within its Western scientific frame of autism as threatening disorder, the recruitment campaign involves a call to mothers that is also a duty (Bauman, 2004a, p. 20) After all, according to Western frames, a mother’s nature – her calling – is to bear, love and protect her child in a particular shape of care as we saw above. This mother’s “because-of” and “in-order-to” motives are clear (Schutz, 1967, pp. 86-96). That is, given our Western scientific cultural ground of sameness and certainty that yields autism as disorder, a non-standpoint, unnatural, a withdrawal, a threat and more, it makes sense to us that a mother would grieve the loss of her ‘normal’ child because of autism, and fight against autism in-order-to secure her child’s future well-being. This mother’s child
has been taken by autism. Telling a different story about autism and mothers requires a reorientation away from depictions of autism as a problem or threat, and toward autism as a cultural scene – a background upon which the troubling and contradictory ‘mother warrior’ – here as feminine warrior - is emerging.

**Autism as a Cultural Scene**

The Merriam-Webster dictionary online defines a campaign as “a connected series of operations designed to bring about a particular result” (Campaign, 2013). The global autism mother recruitment campaign, which began in 2009, consists of a widely distributed video and images linked to Facebook pages, twitter and magazine issues that continue to be virtually accessible. It was and is similar to other global autism mother campaigns like those of *Generation Rescue* (2013). And it continues within regular features on advocacy (news from the front!) and “biomedical updates” in *Autism File* magazine, suggesting that this is an ongoing fight, one with duration, one in progress, one that needs particular types of mothers in order to make a particular kind of progress toward an autism-free future that will allow for individual and collective well-being and economic flourishing. Mothers, clearly, are the campaign’s operatives, its subjects and actors. Indeed, the campaign needs mothers to act in this new warrior-like way to succeed. The sought after result is clear: “…to bring mothers of autism together across the world…a powerful alliance standing together fighting for our children…we will win.” With the massing of warring mothers “across the world” who now uniformly orient to autism as a threat, this most powerful force “will win” the fight. We are “fighting for our children,” the campaign declares. The

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alternative, it suggests, is the tragic loss of our children and the failure to make the right kind of progress toward a future free of autism.

**Moved Through Affect**

The campaign orients its viewer – mothers and allies - through *affect* and the play of powerful and now familiar Western cultural narratives – a terrifying threat to a child’s well-being, the loss or withdrawal of a child, a mother’s love and grief, and the courage of a hero-warrior. Despite myself, I found myself ‘captivated,’ ‘mesmerized’ and even ‘exhausted’ by the video. The words, images and music ‘occupy’ me. I ‘search’ the images for ‘something’. I remember my own struggles with my son in the everyday and feel bound to these mothers. The campaign is personal and it betrays urgency: “Even if you cannot hear my voice…we’ll run for our lives” (Lightfoot, 2003), sings Lewis. Hundreds of mothers abandon their ‘natural’ place as proximate to their own child so that they might promote the campaign and be proximate to normal development and an autism-free world. We know that they will return home, alone in the face of this terrifying threat. How do these narratives operate on and with viewers here?

Within the campaign, an orientation of affect – love, grief, fear and blame - *moves* and implicate viewers (mothers and allies) in the fight against autism, and toward Western scientific versions of the human. Indeed, the campaign makes its ‘impression’ through affect, reshaping the very shape and direction that our embodied subjectivity might take (Ahmed, 2004). In other words, affect operates in the campaign in *making us subject* to, and subjects of this new contradictory feminine subjectivity. “There are two meanings of the word ‘subject,’” Foucault states, first, “subject to someone else by control and dependence; and [second] tied to his own identity by a conscience or self-knowledge”
Let us leave Foucault’s first meaning aside for the moment, and instead concentrate on his second meaning (perhaps in a way he may not have intended) - “tied to his own identity by a conscience or self-knowledge.” This implies that we come to know ourselves as subjects through identity as a particular, and embodied, historical possibility. Like the tie that binds us to the autistic life we bore, mothers are paradoxically tied to this historical identity by a so-called nature given duty to protect our child from threats like autism. This duty is understood as outside of time even as it shapes time through particular actions toward the achievement of normalcy in our child, all for their purported well-being. Who decides what shape this well-being takes? How do mothers turn away from the unique autistic child in front of them and toward working to make them the same?

To press the point of becoming subject further, I suggest that the orientation of affect within the campaign invites and even compels – mothers and allies - to take a “backward glance” of perception of our own. It turns us toward memory and the familiar, taken for granted cultural ground of the everyday life-world that includes particular understandings of a mother’s care and autism, as we have seen in detail through the genealogical work of this dissertation. We are called to ‘know again’ a particular type of mother and a particular type of threat – a mother warrior hero in the shape of the feminine warrior fighting against autism as not only the loss and withdrawal of her child, but also an environmental illness and biological defect. Ahmed describes this interpretive move of perception in reference to Althusser’s (1971, p. 163) notion of the ideological recruitment of subjects, “The subject is recruited by turning around…” (Ahmed, 2007, 157). What’s more, Ahmed says, such “Recruitment functions as a technology for the reproduction of whiteness” and by extension, in our case, for the reproduction of neuro-normativity (2007,
Recruitment, through powerful narratives and compelling affect, operates (now globally) within the campaign to re-orient mothers and allies toward Western scientific understandings of love and the normal human that necessarily work for the elimination of autism and the installation of Western, white bourgeois ways of being.

In her work on gender constitution, Judith Butler suggests that it is through repetition – knowing/doing ourselves, and knowing/doing ourselves again – that identity becomes an historical, embodied possibility (1997, p. 403). Through the campaign’s various iterations (alongside the discursive explosion in everyday text and talk), autism mother, this time as feminine warrior, becomes a familiar embodied identity. Ironically, it is through Foucault’s first meaning of subject as an historical situation of constraint - “subject to someone else by control and dependence” - that we might become a particular type of autism mother who knows herself, recognizes herself, and turns to act in the world. My freedom to act – my subjectivity - is paradoxically formed in this situation of discursive constraint and authority. To loosen the grip of the feminine warrior subjectivity and the natural attitude a little further, and to open possibilities for other historical iterations of autism mother, I turn next to the role of language in world-making, both within my description and within the campaign (Butler 1997a, p. 402-4).

The Role of Language

Fleshy words saturate my description and discussion of the campaign thus far – words like captivate, secret, stir, haunt, touch and outrage. What might this disclose about subjectivity and my activity here? How might this help me to tell a new story? First of all, my activity of description is much more than the doing of ‘mental image-making’. An object cannot be familiar, grieved, stirring, outrageous, or captivating without ties to the
background - some kind of proximity to or touch of bodies, culture, histories and language. These words elicit a living, touching, feeling experiencing body-subject. They betray an intimate relationship of body/subject and word/world. As Butler phrases it, this relation to and knowledge of the world is one of “kinship” steeped in language. She says, “Consciousness is always consciousness of its object, it is nothing without its preposition, and its preposition marks its kinship with the world that it interrogates” (Butler, 1998, p. x).

Description, and subject-making, involve acts of consciousness that attempt to build up a knowable world, yet know this world intimately as one that can only ever be done through the instability and openness of language. Body-subjects do not “stand alone” but become, “gearing” into the world as well as being moved by it (Schutz 1970) in a relation of touch and proximity to and with their inseparable object.

Furthering my point, and moving now more directly toward the ‘feminine’ and ‘warrior’ language of the campaign, I want to think about how the viewer is presented with campaign language that appears in direct correspondence with the ‘real’ of the world. For example, body and world are separated in the campaign’s images: autism is a threat external to history, and mother its natural warrior. The interpretive schemes surrounding autism and mothering (i.e., western, genetic, biomedical) that tie us to particular, and embodied, understandings of “types” of people, in this case of problem types, simply become part of the scenery. They fade away into the background. But objects – campaigns and identities - cannot be recognized or oriented to without these already constituted, and constituting, interpretive schemes. There is nothing natural about the ‘natural attitude’. As Schutz tells us, language is “a treasure house of ready-made preconstituted types and characteristics, all socially derived and carrying along an open horizon of unexplored
Language is integrally implicated in world-making, the making and undoing of selves, identities and lives, and the recognition of others. We are all caught by a language that renders invisible the processes that make the ‘real’ (autism, feminine warriors) appear as an empirical given. It is the threat of autism and its corollary, the heroic feminine warrior that is ‘real’ here, rather than the loss of a different, pedagogic form of care, for example, that might orient us to the ‘difference’ of our autistic child differently (Michalko, 2002). Taken for granted interpretive schemes keep this mother’s ‘secret’ – her irremediable ethical paradox to care through cure; the fundamental alterity of us all; autism as culturally produced, rather than essential biological difference - well hidden, tucked away in a background that easily fades from ‘view’. Through its language, we are oriented to the campaign’s meaning as a closed matter, and to consciousness as separate and internal, a disembodied, unremarkable thing in and of itself.

If we stay with the idea that language is a world-making activity, then what might the images and language of the autism mother campaign itself teach us about the feminine warrior as a ‘reinvented’ femininity? First of all, this autism mother is no longer Bettleheim’s refrigerator mother. This mother is ‘hot’. Her uniform is not that of the soldier, but a softer, feminine, sexualized one. Her feminine curves and flowing hair are accentuated by her black gown and high heels against a white background. She is exposed, vulnerable, even physically compromised in her evening gown and heels. She could not “run for her life” here, as Leona Lewis sings in the background of the autism mothers video. What’s more, the very strangeness of the formal black gowns suggests something extraordinary is going on here. By Western significance, this autism mother is very
formally, and publically, grieving. At the same time, she is courageous, strong and independent. Head held high and shoulders thrown back, she stands not delicately but proudly. She is empowered. Unlike the hesitant feminine corporeality that Iris Marion Young (1980) has depicted as shrinking in space, the feminine warrior occupies and even extends into space. Her hands are on hips and her stance is wide. She does not smile or look away but looks straight at the camera as if she might spring into action. Her gloves are literally, coming off. Yet even this gesture of strength and aggression is encased by softer, nonthreating, sexier qualities. Her gloves are silky and long. Her bare shoulders meet cleavage. Here, characteristics of the feminine and the masculine mingle. They contradict and more.

The violence of the campaign’s language and images is ironic given Western notions of bourgeois, white femininity and motherhood as caring, sensitive and nurturing (Ringrose & Walkerdine, 2008). The campaign seems to contain some contradictory messages not only about gender but also about that most sacred, loving and close of bonds: that of mother and child. A (birth) mother carries and must cut free the infant she births. She is that close to her child. This tie, one that binds mother to child/child to mother is understood as timeless, situated in biology and therefore ‘natural’. It is only natural then, that mothers are protective and nurturing of the life they give. This certainly appears to be true of the feminine warrior. Her willingness to protect her child and family from the supposedly hostile threat of autism is unsurpassed. She is willing to go to war and by implication abandon her child (indeed, no children appear in the campaign) and even lay down her life or the life of her child to win this fight. Witness the murders and murder-
suicides of autistic children by mothers over the past fifteen years (also see McGuire, 2011b, pp. 275-86). Below are just a few that occurred within Canada between 2000-2015:

**Scarlett Cheng**, murdered, July 12, 2004. A 4 year-old autistic girl was drowned by her mother, Xuan Peng, in a bathtub in the family’s home in Toronto, Ontario (Small, 2007).


**Robbie Robinson**, murdered, April 3, 2014. 23 year-old Robbie was murdered by his mother, Angie Robinson, who also took her own life. “Angie loved him more than anything on earth,” a relative said (as cited in Boesveld, 2014, para. 3).

When it comes to autism, the closeness of the mother/child bond, paradoxically, demands distance, even violence. A mother’s ‘coldness’, aggression and hostility toward autism (she is, after all, fighting a war), qualities more commonly associated with masculine subjectivity, and thus contradictory ones, remove her from the close and loving bond of the feminine. So while she operates in the feminine and affective (she is loving and nurturing), she also operates in the masculine, instrumental, logical and hostile. Here, she brings ‘all’ of motherhood, the human, and Man to wage her war against the partiality and trouble of autism. Her fight must be waged, at least in part, through a coldness and hostility toward autism, one paradoxically, and disturbingly, borne of her love for her child: “I miss my
daughter everyday. I still love my daughter. I hate autism,” says mother Xuan Chen, who drowned her autistic daughter in 2004 (Friday, 2010, p. A11; also see above). This mother is fighting against a threat that is personal, one located in her home and even closer, in her child’s body (McGuire, 2011b, p. 99). Failure to shore up the resources to eliminate autism in her child is met, for some mothers, by murder. There is no “backward glance” here (Ahmed, 2006, p. 570), or hesitation at the ‘loving’ and paradoxically violent, unethical duty of eliminating autism with which she is charged. The images of the campaign, and the media reports of murder, betray only determination and finality.

**The New Feminine**

Today’s autism mother subjectivities (feminine warrior, mother warrior, mother expert, Westernizing autism mother) are reinventions and intensifications of neoliberal and postfeminist discourses of the empowered feminine. Ringrose and Walkerdine (2008) argue this is a contradictory neoliberal subjectivity in which qualities of the masculine and the feminine combine and contradict, as we have seen with the feminine warrior above. Success and independence outside of the home meet success in the achievement of innate feminine qualities: beauty, allure and nurturance. Notions of beauty adhere to Western bourgeois standards: this warrior is slim, fit, white and flawless. There are no drug-store bleach-blonde dye jobs here, no fatigue from domestic labour and no shortage of resources, whether financial or temporal. She is liberal feminism ‘all grown up’. Like the neoliberal, postfeminist ‘yummy mummy’, the feminine warrior ‘has it all’ – kids, career, beauty. But more, this mother has all the strength of the ‘masculine’ to fight disability by going to war. She is not only the alluring feminine object but also an exaggeration of the masculine
agentive subject. She must be both distant and proximate simultaneously. The feminine warrior autism mother thus not only intensifies the culpability of autism mothers in terms of ‘cause’ and ‘cure’; through love and proximity, she intensifies Ringrose’s and Walkerdine’s empowered feminine subjectivity (2008).

Neoliberal discourses (whether as ideology, policy or forms of governance), articulate and incorporate the marketization of every aspect of human life, whether the governance of the market, social institutions or indeed, how we understand and do our selves (Larner, 2000). Under neoliberal governance regimes, the ideal self is the self-entrepreneur. In a globalizing consumer capitalist society, this means that owning the “means of consumption” as a way to “consume ourselves into being” has become the route to humanness and our freedom, well-being and happiness (Ringrose & Walkerdine, 2008, p. 230; also see Rose, 1999). We have become our own experts. What does the feminine warrior consume? Beauty products, fashion items and items of fitness, to be sure. Perhaps websites, parenting books or therapies, too. But there is more. The feminine warrior must not only consume herself into being as sexy object/commodity, and agentive mother/career subject. She must also learn to be an effective, successful warrior, and as such she must consume her autistic child into being as non-autistic. Bio-medical interventions, behavioural therapies, gluten-free casein-free diets, autism therapies and endless information (scientific, bio-medical, environmental or otherwise) must be on her list too. They are her weapons and her instruments of war. She is the ideal feminine and more, an intensification of “…an intensification of the feminine as (both subject and object) of commodification and consumption” (Ringrose & Walkerdine, 2008, p. 230). Hers is an impossible task to negotiate: she orients through love and hostility simultaneously to
eradicate the autistic child *who persists* in front of her. Failure haunts this contradictory femininity (it is impossible to achieve). Yet when failure inevitably occurs, or ‘progress’ is slow, it is cast in the individual, psychological and pathological terms of neoliberal discourse (Rose, 1999). More therapies are needed! More rallies of empowerment! Reinforcements! Ringrose and Walkerdine tell us that the ideal feminine is “bourgeois yet coded universal, normal and attainable for us all” (2008, p. 228). In this way, neoliberal discourses masquerade as our ‘freedom’ while gender and class inequities deepen and intensify, leaving transgressive bodies to fail in the achievement of the normal human, let alone in its exaggeration: an autism mother who is responsible for ushering in a future of individual and global well-being that is autism-free.

Through the movement of my chapters, the dire need for something other and more than dominant depictions of ‘autism’ as a defect, and ‘autism mother’ as the expert engineer of its elimination, has presented itself. We have caught ‘glimpses’ of different possibilities for being together along the way in autism mother memoirs and blogs, where care grounded in maternal authority and embodied difference identified as autistic began to rupture the problem/solution dialectic of disability. I have called this pedagogic care. It is to an in-depth exploration of the question of pedagogic care that I finally turn through my focus groups dialogues with autism mothers.
CHAPTER SIX

Autism Mothers’ ‘Pedagogic Care’

This chapter explores the focus groups I conducted with Toronto autism mothers as a unique part of the ‘autism mother’ archive gathered for this dissertation. Through this exploration, my key theme of constraint/pedagogic possibility presents itself in a new light, along with the meaning of ‘autism’ and my consideration of the manifold ways ‘autism mother’ has emerged and shifted as a key cultural contradiction. To organize my discussion, and to understand these transformations, I borrow from Ricouer and his understanding that “mimesis is poesis” as articulated within his paper on interpretation, text and metaphor. Ricouer says,

Indeed, the Artistotelian concept of mimesis involves already all the paradoxes of reference. On the one hand, it expresses a world of human action which is already there…But, on the other hand, mimesis does not mean duplication of reality; mimesis is poesis, that is fabrication, construction, creation. (1974, p. 109)

This understanding of mimesis as poesis, which will be explored in more depth below, imaginatively captures how constraint and possibility was lived by the mothers I spoke with about everyday text and talk in two focus groups during the fall of 2013, set in Toronto. Mothers spoke about forms of care that both mirrored dominant cultural representations of

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70 I employ scare quotes to indicate that I understand ‘autism’, and ‘autism mother’ as culturally produced subjectivities rather than ways of being grounded in the biology of different brains or bodies, for example, or as things in and of themselves. I use scare quotes the first time the terms ‘autism’ and ‘autism mother’ are introduced, and intermittently, to remind the reader of my orientation.
'autism’ and ‘autism mother’, and at once gestured to and constructed something beyond them. I call this pedagogic care - a way of being that mimetically mirrors, resists and transgresses the bounds of our ‘real’ about autism, mothering and care. As I described in my conceptual framework, the conversations I had with mothers integrally shaped the way I gathered texts and shaped my approach within my previous chapters. Here, I offer an in-depth description of these groups as ones that were pedagogic: mothers and I worked toward new, communally created understandings of autism and mothering that begin to gesture to how the meaning of embodied ‘difference’ is not only lived and negotiated, but potentially resisted and transformed within the powerful scientific regimes that regulate mothers, at least in part through everyday text and talk. I begin below with a description of how I went about organizing my two focus groups with Toronto autism mothers.

A Unique ‘Autism Mother’ Archive: Speaking with Mothers

Like the everyday text and talk gathered for my archive in chapters three, four and five, I understand my dialogue with mothers within my focus groups as sites of social action mediated by everyday understandings of autism and mothering (as they appear in text) and the interactional processes between them that produce a sense of self and other. I shaped my focus group dialogues by asking moms to reflect together on, and interact with ‘autism mother’ collages of everyday text and talk I composed from my archive (see Figures 6.1, 6.2 & 6.3). My focus groups thus represent a unique way to critically and interpretively explore the ground of our own archive as it is lived within interpretive processes of meaning-making and articulations of power, as well as in moments in which alter – possibility kinder - ways of caring appear in our midst (Van Manen, 1990, pp. 20-4),
a form of consciousness-raising as knowledge production. I approach focus groups a little differently than conventional social scientific qualitative approaches grounded in humanist assumptions about the subject as a source of ‘truth’ and knowledge (see, for example, Morgan, 1997, pp. 4-6; also see St. Pierre, 2014). The idea of conducting focus groups in this alternate manner, and including them in my archive, was not as much to collect empirical data from subjects as sources of knowledge or truth, or to achieve representative samplings of mothers that might be extended into a larger study and generalized as knowledge about autism and mothering. Rather, I wanted to explore, with mothers, how dominant, and constraining, modes of identity and care as they appear in everyday text are lived and negotiated interpretively, and how this living and negotiating of identity and care through text might also contain new possibilities - the outlines of creative disruption, resistance and new constructions and understandings of autism and care grounded in love and embodiments identified as autistic. Living these realities as an ‘autism mother’ shapes my research direction toward imaginative ways of opening into novel possibilities beyond normalcy.

Through this unique approach to the inclusion of focus groups in my archive, this chapter shows how mothering and care can be something more than a mirror image of the dominant biological, developmental sense of autism as a problem, or expert sense of the solution as ‘mother warriors’ fighting against autism. Within my dialogues with mothers - even as mothers also negotiated dominant culture through text - care appears, in moments, in an alternate form, as pedagogic. Pedagogic care means a form of care that is responsive to the ‘different’ and unique autistic child in front of me, a form of care emerging in a

71 For a current, local example of this more conventional qualitative approach to autism and mothering see http://www.yorku.ca/nkhanlou/documents/InfoSheetVoicesofImmigrantMothersofChildrenwithDisabilities,2013_001.pdf
mother’s everyday in self and world in transforming ways, as a mother attempts to bring forth a place in the world in which her ‘different’ child might feel at “home” (Van Manen, 1990, 59-60, 102-3). My discovery and description of pedagogic care helps open up my focus groups beyond their particularity into a site from which future research directions and recommendations for what is necessary to practice ‘pedagogic care’ might be gleaned. The point then becomes not a quantitative measure of how many mothers participated in my focus groups, but qualitatively that some mothers some of the time find the capacity to resist and respond differently from within the constraints and exclusions of dominant discourse.

Max Van Manen (1990) articulates phenomenologically the tension between particularity and universality that I attempt to bridge in my approach to focus group dialogues, by suggesting that research might orient to “…mediating in a personal way the antinomy of particularity (being interested in concreteness, difference and what is unique) and universality (being interested in the essential, in difference that makes a difference)” (1990, p. 23). From this orientation, my use of focus groups becomes a way to explore and describe the cultural ground of a world that, on the one hand, gives the identities ‘autism’ and ‘autism mothers’ their meaning, as a worthy pursuit that might make a difference to how we understand these phenomena; while on the other hand, attending to the particularity of the meaning of difference (Van Manen, 1990, p. 5; on the difference of disability making a difference, also see Michalko, 2002). To state the matter differently, I work to disrupt the “gaze from nowhere” of the Cartesian knowing subject and resist the opposite “god-trick” (Haraway, 1991, p. 191) of relativism that imbes subjugated experience with truth (Scott, 1991). I also attempt to remain open to how embodied difference ‘exceeds’ any attempt to
categorize or understand as central to an orientation to care that is pedagogic, gesturing to the fundamental alterity of us all and ethical call to respond to the other without reducing them to the same (Boler, 1999; Levinas, 1969).

As I worked toward an interpretive phenomenological understanding of my focus groups for this chapter, I found the genealogical work of my previous chapters also coming to mind. This continuation of the dialogue between my focus groups and genealogical work has meant that for this chapter, I have ‘slipped’ between the edges of interpretive phenomenological and critical approaches in disability studies and feminist philosophies of science as ones that understand the meaning of human subjectivity, knowledge and being quite differently (Dehli, 2008; St. Pierre, 2014). I continue to attempt to use this space generatively, as one in which new meanings and understandings of care emerge.

**Organizing my Focus Groups**

After receiving approval of my research protocol from the Office of Research Ethics at the University of Toronto (see Appendix A), I posted flyers at the University of Toronto and sent flyers and letters of introduction to mothers in my own autism mother networks, as well as a number of Toronto advocacy and service organizations (see Appendices B and C). These organizations include: The Asperger’s Society of Ontario – Toronto Chapter, Autism Ontario, The Geneva Centre for Autism, Griffin Centre, The Redpath Centre, Surrey Place Centre and Community Living Toronto. While not all organizations responded, several of them enthusiastically published information about my study in their newsletters and on their websites, and many mothers passed flyers along to other autism moms they knew, creating the sense of a ‘buzz’ that was moving through
autism mother networks in Toronto about my research. After a mother emailed or called to indicate she was interested, we spoke by phone. During these conversations, I described my research in more detail, and inquired about a mother’s interest to confirm her awareness that my focus groups would concentrate on how mothering and autism are represented by popular media (popular science and popular representation). This was important to clarify, as most research advertised by autism organizations is grounded in science and the promise of better treatments or progress toward a cure. I had an enthusiastic response from approximately twenty-five mothers, many of whom expressed they were intrigued by research that was investigating mothers’ broader reflections about autism and care, rather than asking about coping, or recruiting for more scientific studies from which promised results that were seldom delivered. Once I confirmed a mother’s interest, I sent an invitation letter by email describing the study in more detail and explaining informed consent and confidentiality. My main challenge was finding times that could accommodate as many mothers as possible, given the reality of mothers’ paid work and primary caregiving roles (all but one of my participants, who shared caregiving tasks with her husband, was the primary caregiver to their child and also worked). To do so, I offered one group during the day in my east Toronto home, and another at the University of Toronto in the evening. Along with the homemade banana bread, coffee and tea, this was a successful way to get mothers out for my groups!

I met with eight Toronto mothers in total in two separate groups. Each group began with the collecting of informed consent forms (sent to participants ahead of time, this included the permission to digitally record the group) and casual conversation with one another while we waited for other mothers to arrive. This occurred while mothers perused
the collage of everyday text and talk displayed on the table where we would sit and talk, and while I fixed coffees and teas and served treats. The collage included autism mother memoirs, documentaries, novels and a display of newspaper and magazine cuttings that depicted the popular science as well as popular representation of autism mother subjectivity (see Figures 6.1, 6.2 & 6.3). There was a general sense of anticipation during our initial

Figure 6.1: ‘Autism mother’ texts displayed at focus groups.
gathering for both focus groups, as if something very special was about to take place, and perhaps it was. Gathering autism moms together in a group has significant practical challenges and barriers, including finding childcare and time amidst paid employment, care and advocacy demands in mothers’ lives. Even more distinct was that these mothers were gathered together to reflect on and talk about something quite unique within a landscape dominated by scientific research – their own understandings of how autism mother identity and care are represented in dominant culture, along with their reflections on what it means to live such dominant understandings of identity and care. Once mothers had all arrived, we gathered at the table together where I briefly summarized my larger dissertation research.
and reviewed the topic of the focus group. I then posed two key questions: 1) What are the popular understandings about autism, mothering and care? 2) What is your understanding? The collage remained on the table while we spoke. Each group met for about an hour and a half, and engaged these questions deeply.72

![Collage of ‘popular science’ displayed at focus group](image)

Figure 6.3: Collage of ‘popular science’ displayed at focus groups.

My role in the groups was that of facilitator-participant. As such, I join other feminist and community-based researchers who aim to share power with participants in shaping research, to disrupt power relations between researcher/researched and to challenge the problematic notion of researcher ‘objectivity’ (see, for example, Kirby, Greaves &

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72 For another example of the use of collage in focus groups see Thomson, Kehily, Hadfield & Sharpe (2011).
Reid, 2010; Matthews, 1983; Nielsen, 1990). This was particularly important for my
groups, as I knew one of the mothers through other involvements in Toronto autism mother
networks, and because many mothers (and autism mothers more generally) articulated
histories of being subject to paternalistic research and encounters with professionals. My
insider status and commitment to autism acceptance also helped ameliorate power
differentials. I both drew from and shared my experiences as an ‘autism mother’ during the
groups, while also consistently guiding the discussion back to my research focus through
prepared prompts, and by holding open the possibility for unexpected directions in the
conversation. The groups were semi-structured and open-ended in this way. Mothers not
only spoke about everyday text and talk and its meaning in their everyday lives with their
children, but also spoke about the manifold ways that the cultural meanings everyday texts
impart both circulate and are lived within various sites of Toronto autism mother networks.
In this way, and working from how mothers helped shape the direction of focus group
discussions (and indeed, this dissertation), this chapter extends the meaning of everyday
text and talk to other sites in Toronto autism mother networks including domestic space,
schools, medical appointments, public spaces and autism service agencies.

I met mothers from a variety of backgrounds who identified as immigrant and non-
immigrant, single and partnered, birth and adoptive mothers, white, Jewish, and Asian -
with diverse offspring ranging from eight to twenty-eight years, and with autism
identifications including Aspergers Syndrome, high functioning autism, pervasive
developmental disorder-not otherwise specified (PDD-NOS), autism and regressive autism.
As such, some mothers described offspring who communicated verbally with them, while
others described different, ‘nonverbal’ communication with their child through music
or typed communication, for example. In addition, some mothers described adult offspring who relied on mothers and personal supports for dressing and toileting, for example, and who participated in sheltered workshops, while other mothers described young people who relied on moms and social supports to attend university and work in paid employment.

What these mothers shared was the identity of ‘autism mother’ and the experience of living with, and caring for an autism-identified child within autism mother networks in Toronto. Beyond the brief description above, I did not formally collect demographic data for mothers and their offspring. I made this decision because the purpose of my project is interpretive, descriptive and exploratory – I am not researching the truth of an empirical ‘real’ that can be known with certainty, explained and generalized. Rather, within my discussion I note how mothers themselves articulate their differences and their child’s way of being as meaningful within their everyday lives and our discussion together.

I engage in identifying ‘types’ of mothers and autism with some care and caution here, as an activity that is related both to the broader Western milieu of typification (through which we know ourselves, our world and one another; see, for example, Schutz, 1970, pp. 116-122), and to the activity of distinguishing some ‘types’ (of mothers, autism, people etc.) as significant within particular contexts (like research) rather than others (i.e., the racial identity of the mothers in my groups, rather than urban/rural background). With this milieu in mind, and noting I did not set out to recruit some types of autism mothers and not others, I briefly note the presences and absences in my focus groups in relation to ‘autism mother’ as a culturally produced identity. The appearance of immigrant, single, adoptive and Asian moms is notable, since these moms have been historically excluded from the identity category ‘autism mother’ (recall that this identity emerged as a white or Jewish, bourgeois and Western identity - see chapter 3). The question of whether this is reflective of the widening boundaries of autism diagnosis and the increased regulation of populations poses itself here. It is also notable that Black and queer mothers (at least none who identified as such) were absent from my focus groups, as ‘types’ of mothers who have also been historically excluded from the identity ‘autism mother’. The absence of these moms may be both reflective of this historical exclusion (although recall the increased diagnosis of autism within the Somali community in Toronto – see Sumpton, Bender & Gruner, 2011), as well as reflective of my own dominant positioning in relation to the identity ‘autism mother’ as a white, cisgender and middle-class researcher recruiting within autism mother networks in Toronto. These absences may, too, reflect these mothers’ resistance and “strategic disengagement” from dominant autism mother networks (on working class mothers, developmental disability and strategic disengagement see Sousa, 2015, for example). As a final note, the range of autism identifications and age of the children of the mothers, and thus the implication of sustained activism of the mothers in my groups is also of note, and possibly indicative of which mothers have access to participation within research, as well as the sustained level of involvement for autism mothers (see Ryan & Runswick-Cole, 2008, for example). All of these notes are suggestive of future research and further theorization of the ground of a world that gives us ‘types’ of mothers and autism as an orientation device to research.
I followed up each focus group with an email invitation to mothers: “I am really interested in the stories that were emerging in the group. Is there something in your story prompted by our discussion that feels important to share? If so, please feel free to email me about it.” Several mothers responded to this follow-up with post-group reflections (which I include in my discussion) as well as invitations to take part in mother’s groups and community art events, some of which I have attended over the past two years. I also extended invitations to mothers (some of whom attended) in my groups to attend a public talk where I presented my initial analysis of their stories. This is one way I have attempted to share power and incorporate feedback from mothers during the analysis and writing stages of my dissertation. It has been invigorating to receive positive responses from mothers throughout my focus group process and follow-up. Here, I share mothers’ stories and the ‘secrets’ they reveal as ones that might contribute to a different way to care about being human together within the late modern world that we share. This means that rather than engage the “backward glance” (Ahmed, 2006, p. 570) of genealogy, I take a backward glance perceptually instead, and peek behind the identity ‘autism mother’ and the disruption of ‘autism’ a little differently. In this way of proceeding, we might ‘glimpse’ the “secrets and intimacies which are constitutive of the world, and which bring the world as world into being for us and in us” (Van Manen, 1990, p. 5), yet remain so seamlessly concealed from us in our everyday. To do so, I do not survey all that was said during my focus groups but instead depict those comments that help me reveal the ‘secrets’ I am after – how identity is forged, how the problem of ‘autism’ is recognized via interrelations, and how caring moves beyond either a developmental (scientific) sense of the problem or an expert (mother warrior) sense of the solution.
Analyzing my Focus Groups

The method (as opposed to technique or procedure), or “way,” I use to thematize, describe and make meaning from my focus groups is both phenomenological and interpretive (see Van Manen, 1990, p. 27-8; also see Husserl, 1970; Merleau-Ponty, 1962). This means that I attempt to “bracket” the natural attitude and provide a “rigorous” description. This is a description that aims to both get at the background of this mother’s appearance, and reveal the nature of her experience in a way that might ‘get at’ the meanings it relies on and reproduces. The aim of this method is to name the deeper, lived meaning structures of autism and mothering as ones that have value in terms of understanding the meaning of care and being together for us all, while also holding open the excess of meaning. Van Manen (1990) articulates the “impossible” nature of such a method as follows:

To do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the lifeworld, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal. (p. 18)

To begin, I transcribed focus group dialogues in full, while also noting my participation, times when mothers spoke over one another, emotional expression (as much as this is possible) and mothers’ responses to one another. I note such moments in square brackets throughout my discussion. I also kept a journal of my immediate reflections immediately following each group. To maintain confidentiality, I kept my data recorder in a locked filing cabinet and transcripts on a password-protected computer. In my descriptions, I use
pseudonyms for mothers and their children to protect their anonymity. I read and scratched over my transcripts closely, and listened to my recording of the groups as I worked to understand their meanings. What will be encountered here is how such focus group discussions open clear beginnings, especially as this relates to how mothers are represented and how they felt compelled to make something out of these representations that moved beyond dominant understandings of autism and autism mother.

Working in a circular fashion, I thematized my focus group transcripts in three ways, with each ‘turn’ deepening toward the phenomenological: first, I noted the topics of conversation that emerged, secondly, I identified the key thematic and lived tension that emerged within our discussions, and finally, I discovered the deeper existential theme of pedagogic care. I work with the themes of identity/difference and pedagogic care phenomenologically, approaching them as “knots” of meaning in the lifeworld that might capture something of the spirit of lived experience for autism mothers, and perhaps yield lessons for us all (Van Manen, 1990, pp. 78-80). In terms of topical themes, my focus group dialogues in both groups covered diverse ground. To provide a sense of the breadth of topics touched on, I list them here: diagnosis, genetic testing, types of interventions, the meaning of autism, the meaning of normal, refrigerator mothers, genetic mothers, warrior mothers, guilt, mother blame, public education, medical appointments, service agencies, lack of services, moms as educators, advocates and experts, gender and care, immigration, privilege, isolation, coping, stigma, stereotypes, bullying, gifts and lessons. While the constraint of biomedical discourse bound the topics possible, our discussion suggested new possibilities such as ‘lessons’ and ‘moms as educators’. These topical themes weave their way through the two sections that follow below. Secondly, I identified the key thematic
tension and contradiction that emerged from mothers’ reflections on their lives together with their autistic child vis-à-vis everyday text - identity/difference. This theme captures how mothers grappled with the gap and seemingly irremediable contradiction between loving their ‘different’ child within their everyday, and the dominant cultural sense of the identity of ‘autism’ as a problem of development gone-wrong, and ‘autism mother’ as a solution steeped in Western scientific expertise and remedial treatment. I explore the theme of identity/difference in my section on mimesis below. Finally, I identified the deeper existential theme of ‘pedagogic care’ (Van Manen, 1990) as one that describes mothers’ way of being together differently with their autistic child that breaks open the constraints and contradictions of identity/difference and the problem/solution dialectic of disability in their lives. Pedagogic care gestures to what else might be possible in terms of caring for and about ‘difference’ within our late modern life together. I explore the theme of pedagogic care in my second section on ‘mimesis is poesis’ below.

The separation of ‘mimesis’ and ‘mimesis is poesis’ in my discussion is a helpful heuristic device, yet these are not separable imaginative and interpretive processes. Mimesis, as the imitation or reproduction of a ‘real’ to which it refers but can never duplicate, is as such itself a “fabrication, construction, creation” (Ricouer, 1974, p. 109), one that also contains within its fabrication, therefore, the creative and productive outlines of the possibility of something new. This is a particularly productive way to engage the dialogues I had with mothers, as mothers’ engagement with dominant depictions of the identity ‘autism mother’ reflect yet transgress what is ‘real’ and produced socially from dominant discourse. Rod Michalko’s (2002) work on “passing” (imitating sightedness) as a
blind professor, which he explores through the idea of mimesis in *The Difference that Disability Makes*, is particularly helpful as I explore my themes below.

**Mimesis and Living Constraint: Identity and Difference**

I begin with an exploration of the theme of identity/difference, and with how mothers spoke about their contradictory experiences with the identities ‘autism’ and ‘autism mother’ as they appear in everyday text and become meaningful within a variety of sites within autism mother networks and through the problem/solution dialectic of disability. If, as Bauman has suggested, that the idea of identity, born as a fiction within the emergence of modern Western forms of social life as an “as-yet-unfulfilled, unfinished task, a clarion call, a duty and an urge to act” (2004, p. 20), then it is, as the work of chapters 3-5 also brings vividly into relief, a “duty and an urge” that is also extended to mothers as the ‘expected parent’ within and beyond everyday text and talk. Mothers in both groups spoke about how the dominant sense of autism as a biological problem in need of ‘warrior’ and ‘expert’ autism mothers as the solution was bodily and practically expected of them within different sites of Toronto autism mother networks - schools, domestic space, autism service agencies and medical appointments, for example. In many ways, mothers articulated how they imitated, through their everyday practices, both this expert mother warrior and her achievement of a ‘normal’ child that dominant renderings of these identities articulate. However, through this discussion, the disruption and excess of autistic as well as mothers’ own differences within the constraints of living identity mimetically rupture the expected and open a space, gesturing to the creative possibilities for new constructions and
understandings of difference and care contained within mothers’ mimetic embodiment of ‘autism mother’.

After the initial collecting of consent forms, perusal of my collage, fixing of drinks and treats, and brief introduction and welcome, both focus groups began with an anticipatory hush, followed by introductions. We quickly became known to one another as ‘insiders’ through the introduction of our child’s autism identification, as well as through our autism stories, ones that were remarkably similar in how they closely imitated dominant cultural narratives - from the moment mothers ‘knew’ there was something wrong, to doubts about what she might have done to cause her child’s autism, to the process of diagnosis and the navigation of medical, educational and governmental systems, to the articulation of a different sense of the meaning of autism and mothering. Mothers were rapt while others spoke, interjecting only with brief questions or affirmations - “I know,” “Yes,” “It’s hard” – and shared their stories liberally during their introductions. However, in the dialogue that emerged from these rounds of introductions and identifications, it was not only the gendered, scientifically ordered linear narratives of diagnosis and progress (Fisher & Goodley, 2007) that became the topic of our conversations or that was embodied in the group. It was also a different sense of autism and care – something more like reflective love and autism acceptance that was also pedagogic – that began to emerge as I probed: Why do we pursue all of this treatment anyways? What do you think autism means? What does it mean to care? Dialogue within both the groups surged at this point and was sustained for over an hour. Mothers talked over one another at many points, and there was a lot of laughter. There was a sense of excitement in the groups when shared – and ironically contradictory - aspects of this intensive identity were
discovered, and a kind of familiar recognition occurred around deeper questions of the meaning of care. As ‘Julie’ described in her follow up email to me, “My brain was buzzing by the time I left the focus group, and it wasn't just the coffee! So many questions came to mind…” This layered engagement by mothers typified my focus groups, and complicates any straightforward notion of autism and mothering. I begin below with an exploration of how mothers articulated identity as a lived imitation forged through dominant renderings of autism and autism mothers within and beyond everyday text and talk, and how, ironically, this opened them to the embrace of what is identified as autistic difference.

First of all, mothers spoke candidly about the gendered nature of the ‘expected parent’ in their child’s lives and how a mother’s “duty” to achieve identity with the ‘normal’ human– an autonomous, productive, self-fashioning, independent, rational being - for her different child is part of the unquestioned ground of her everyday life. After twenty years of workshops and programs, for example, ‘Julie’, the mother of 19 year-old ‘Kyle’, observed, “Most of the care that is given to our kids is given by women.” Julie was the only mother who mentioned a father’s involvement in a caring role, “My husband is very involved…but he is almost always, when he goes to a workshop over the years…in the strong minority.” Only one other mother, ‘Esther’, mentioned her male partner, “Well, my husband’s an engineer…He’s convinced that Ryan can access parts of the brain that we can’t access. He’s smarter than all of us…” This perhaps reflects Jack’s (2014) observation about gender and autism, “Whereas narratives written by mothers tend to take on a quest for recovery, narratives written by fathers tend to take on a quest for understanding – not simply of the child in question but of the father’s own character and identity” (pp. 157-8). Julie’s observations also reflect the very global reality that the bulk of caring labor
continues to be done by women, and that care is presumed to be the ‘natural’ duty and clarion call of mothers (Walkerdine & Lucy, 1989). Indeed, many of the mothers framed their ‘hunch’ that led to their child’s diagnosis, despite dismissals from ‘experts’ that it was nothing to worry about, as a kind of mother’s intuition, or knowing grounded in their identity as mother: “We’ve always known it’s something. Me especially,” was how ‘Helen’ framed it. For ‘Esther’, “I’m a first time mother. I know nothing about being a mother, but I know there is something wrong with this kid.” This ‘knowing’ did not require expertise or even experience, as Esther put it, but was based on something closer and more immediate, implying she understood how she ‘just knew’ as a kind of ‘instinct’, perhaps even a bodily one, about her child that emerged from within the closeness of a mother’s ties to her child.

Already identity has become not only about identifying ‘autism’ (many mothers also spoke about knowing, and watching for, the ‘signs’ of normal development), but also about knowing bodily, that “there is something wrong.”

More was at stake for these moms with the “unfinished task” of identity than hunches. The “urge” and “duty” to fashion an imitation of normalcy in her child had at some level come to bodily inhabit their maternal identities and practices as guilt and blame for their child’s autism. In response to a clipping about refrigerator mothers I included in one of my collages (see Figure 6.3), for example, two mothers spoke about the direct blame they had experienced and continued to inhabit through psychoanalytic vocabularies. These mothers lived the ‘bad’ mother identity of refrigerator mother. As ‘Rosa’, mother of 26 year-old ‘Elizabeth’ described it, “I thought she [the psychiatrist] was diagnosing my daughter but she was really observing me…and because of that, the mother’s cold, [it was] not about my husband but the mother.” ‘Anna’ also experienced direct medical blame. She
spoke about the impact on her life, “I never had, could have another child…I mean emotionally… because I always had it [the blame] in mind.” Rosa agreed, “Neither could I.” The damaging scientific blame, regulation and oppression of mothers in the ‘past’ is embodied in our present within mothers’ lives within autism mother networks in Toronto. Mothers in my focus groups also lived a more implicit form of blame, one reflected in their search for reasons their child is autistic. ‘Julie’, mom of 19 year-old ‘Kyle’ wagered that “every mom…felt some degree of responsibility for their child’s condition, however illogical.” ‘Anna’, mother to 29 year-old David’, shared her experience of her decision to vaccinate, “…I remember he was a little bubbly baby…I thought that he would be an early talker…And then after the booster shot he completely stopped…he stopped speech…” For ‘Esther’, mom of 10 year-old ‘Ryan’, it was, first, her struggle with nursing that she returned to as the possible cause of her son’s autism “…it’s always been in my head…he would get better if I nursed him. If I nursed him, the autism would somehow go away.” Esther also struggled with the invitation she accepted from her doctor while pregnant with son Ryan to undergo genetic testing, which would eventually reveal that both she and her children had a “deletion” on gene 16:

We don’t have the bigger deletion, it’s the smaller deletion. The smaller deletion is linked to developmental delay and possibly autism, but there are also people in the normal population who have it and don’t have any issues at all…What do I do with that information?… Ryan’s a great kid. Would I have not had him knowing that there’s a 50% chance he was going to have that genetic variation…you would erase the population…
While this “newer” version of “genetic motherhood,” as Ester phrased it, was a “relief” in some ways – she did not do something that directly caused her children’s autism – in other ways it meant an agonizing lived contradiction between her love for, and the possible scientific elimination of children like her son through a mother’s own “choice” (Landsman, 1998, pp. 2-3). Here, in addition to knowing that something is ‘wrong’ with your child, maternal identity also becomes about how mothers identify with how ‘what is wrong’ is articulated or lived (Is it my fault? What did I do wrong? Should I participate in genetic research? What do I do with this information?). These impossible situations – holding the care of your unique child together with intense scientific blame to remedy your child, one that instrumentalizes human life - are moments in which space begins to open beyond that of imitating the ‘good’ mother who achieves an imitation of normalcy in her child.

The “compelling seduction” of normalcy (Michalko, 2002, pp. 172) for mothers in their lives together with their autistic child was also a topic of conversation. Mothers urgently pursued both conventional and alternative normalizing treatments for their child, an implicit form of mother-blame in terms of their success or failure in achieving a child who could imitate normalcy (Sousa, 2005). It was, at least in part, through everyday text and talk that the “urge” to treat and find such therapies entered mothers’ lives: the movie Sonrise: A miracle of love (Rosenbloom, 1979), online articles about gluten and casein-free diets, popular science reviews of ABA (applied behaviour analysis), genetic testing and more. When I asked, “What are we doing all the interventions for?” Esther replied, “It’s for us, to make them be more normal. I don’t think it’s for them at all.” Having a ‘normal’ child is compelling, even desirable, for Esther. This “making” of normalcy in her child – or at least as close of an imitation as possible - reveals normalcy’s seduction and power, as
well as its fabricated nature. What is understood as ‘normal’ rests upon Western culture’s ‘natural’ body. But this mythical ‘natural’ body is, too, a fabrication, constructed through scientific and political vocabularies that shift over time, as my previous chapters have shown (also see Michalko, 2002, 170-2). Ester recognized normalcy as a fabrication and instrument of alteration that she wielded in her son’s life in her statement that we live the constraint of normalizing interventions “for us” rather than for our child. In this recognition of her impossible ethical choice, she also opened a space for a different kind of care. This space, one where autism ‘just is’ and requires no explanation or alteration, was lived as a contradiction alongside the urge to treat that mothers also bodily and affectively inhabited, a point I return to in more detail later in this chapter.

Mothers also described the “duty and urge” to imitate identity for their child, so richly detailed in everyday text and talk, as an intense and very real contradiction they lived within their everyday lives. Here, the expected parent was not only gendered, but also the bourgeois, autonomous, productive, healthy and non-alter neoliberal Western subject. This mother must have access to unlimited resources – financial, temporal and personal – and make herself constantly available to educate and train herself, attend professional appointments, work intensively with her child, closely monitor her child’s development and advocate for their needs (Hays, 1996; Sousa, 2005). ‘Helen’, mother to newly diagnosed 7 year-old ‘Hannah’ said this about attending an autism service agency for the first time, “It’s funny, cause I went to the orientation evening…and it’s like, “We’re going to simplify it…here’s 10 000 pages!” On the same topic, seasoned autism mom ‘Julie’ shared the following in the midst of laughter and much talking over one another, “It’s a wonderful reality that you live in [as if to the service agency professionals]…Can I make supper? I
mean, that’s gotta be in here somewhere!” Mothers who fall outside the bounds of the expected parent – immigrant mothers, mothers of colour, single moms and working-class moms, for example – encounter multiple forms of exclusion. A single immigrant mom, ‘Carol’, described her experience this way, “Being a parent is hard. Being a single parent of a special needs child…it’s very difficult”. ‘Jennifer’, mom to 7 year-old ‘Eric’ and founder of an autism organization in a South Asian immigrant community in Toronto, articulated the exclusions that marked the lived reality for immigrant moms, “Because of language barriers, there’s lots of other things…we immigrants, we are all busy, struggling, surviving.” In the same focus group, mothers paused during an exchange about challenging experts to ask about the mothers who are absent:

Julie: I am always curious about all the people I don’t meet, the parents who…don’t have a degree in science…and are they going to say to someone [i.e., are they going to challenge an expert]. I don’t think so.

Helen: No, they’re not! People get mowed over…by the system.

In part, it was the classed, gendered and raced nature of the intensive ‘good’ mother, and her duty to achieve an imitation of normalcy in her child, that these moms spoke of and at times poked fun at. Even more, in mothers’ ironic recognition that the ‘mother warrior’ identity is impossible to imitate, yet nevertheless must be imitated as a ‘good’ mother who works to achieve normalcy in her child, mothers’ imitations of her became a kind of comedic mimicry. Mothers’ parody of the mother warrior exposed the constructed nature of her instrumental aim to remedy autism, and revealed, too, the constructed nature of
normalcy. Space for a different way to care about autism, mothering and care was opened through these moments of laughter together.

Mothers articulated, too, how they had become their own “experts” about their child’s autism and treatment. Autism mother ‘Jennifer’, for example, mom to 7 year-old ‘Eric’, explained, “I got all kinds of opinions, like, oh he’s fine, he’s severely autistic…[laughter]. They are all professionals. And oh my goodness, now I just, I’m the expert.” Jennifer went on to describe how she had studied all the articles, books and treatments she could find, and had opened an information and support network in her South Asian community in order to address the limits of conventional medical knowledge and autism agencies. Another mom, ‘Anna’, with 29 year-old ‘David’ who lives with her, put it this way,

They [autism service agencies] tried to counsel the parents, not help with the behavior of the children. If you…do your own research, I mean, I’m sorry, I don’t need to be told what to do…It’s educating the parent…they won’t even help you to advocate…they sit in meetings and won’t say anything.

While mothers shifted the ground of expertise away from science and professionals as part of their identity, this can also be read as mothers embodying implicit blame – the responsibility to recover her child through developing her own expertise - that emerged in the everyday text and talk for the years 2000-2015 as described in chapter five. That is, through neoliberal rationalities of freedom and choice and a range of market options, as well as genetic and biomedical scientific regimes and ideologies of natural and intensive
mothering, a mother is expected to re-educate herself, merge her love with science, and treat her child with the goal of recovery.

However, unlike the recovery hero/warrior stories in everyday text, the mothers in my focus groups did not articulate the goal of recovery for their child, but acceptance of their child’s difference, and, as Anna put it for her son David, “working with him to make his life better.” Rosa, too, stated that she “wanted to help” her daughter Elizabeth, not treat her. Even while mothers governed themselves into dominant expert mother warrior identities, and engaged their child in “therapies,” they simultaneously opened, albeit just a tidge, space for a different ground of authority and form of care (Sousa, 2005, p. 229-30). In their challenges to paternalistic experts, their initiation of organizations, appraisal of which therapies to use and criticisms of intensive mothering and of autism industry, mothers gestured to a different way of being together with their different child. Helen articulates her challenge to experts this way,

I started doing my own stuff…You’re telling me this is what it is, and that’s not what I’m seeing, so maybe you’ve got a PhD in it but I’m living with her every day and it’s not working…a lot of it comes down to “I’m an expert, this is how it works…it’s not working it’s because you’re doing it wrong.”

Another mother Julie with son Kyle, aged 19, summed it up this way about autism professionals, “I mean, they’re questioning your ability to parent your child in some ways by telling you you have to parent differently.” During a conversation about alternative therapies, this same mother wondered,
It’s interesting though, all the interventions we haven’t talked about…it crosses into the ‘mother’ domain, so anything to do with food and things, even in the most liberated families probably tends to fall more on that side, and you’ll see discussion groups [online] where they will say you are harming your child by not doing the diet or chelation, or whatever. So I’m curious about that when the evidence-based ABA, which is more scientific and systematic, somehow that’s not the mothers’ thing…Do we [mothers] veer toward things that sit right…that fit within how we want to be with our kids…rather than the more scientific and systematic approaches like ABA or other conventional therapies?

Such ‘maternal treatment’ (only this time, not on mothers but by mothers), while operating in some ways on the same gendered and neoliberal terms as intensive mothering, and from the same urge to treat and normalize their child, begins to disrupt the ground of scientific and professional authority. As Julie went on to say, “You wonder if the rise of things…the RDIs [Relationship Development Intervention] and the Sonrise’s and the diet and things is a way to take back…some control over the situation.” Jennifer added, “I think there should be a balance, on the one hand the parent, you already coped for several years and there is for sure something you know, but…you have to be open to learn different kinds of things.” This mother also criticized costly therapies that offer “big improvement.” Here, mothers begin to articulate another aspect of maternal identity forged through life with their autistic child that begins to veer away from the impossible imitation of the ‘warrior mother’ and her intensive, instrumental urges and scientific treatment of her child. Aspects of the devalued maternal realm – love, relationships and
domestic practices like cooking – begin to open a space of being together that has 
acceptance and love as their goal.

Within their lives together with their autistic child, mothers’ mimetic parody of the identity ‘mother warrior’ is merged with the realm of the maternal and becomes something more. Mothers embodied a contradiction and “liminal space” (Titchkosky, 2007, p. 21) between the expected parent and ‘normal’ child on the one hand, and a lived reality of autistic and maternal difference on the other, that began to challenge the authority of paternalistic science and professional expertise about the meaning of autism and care, and shift it toward something new.

For the mothers in my focus groups, embodied difference identified as autistic included different learning styles, different modes of being social, different ways to love, different modes of communication, even different forms of what we know as real. As Joy shared about her 16 year-old daughter Anya, “She has a totally different learning style.” Engaging in playing music by ear, for example, was a way that Anya gathered her focus for more academic tasks. Advocating for this within a public school meant the exhaustion of educating others about her daughter’s difference. Anna spoke about an ‘autistic’ form of love, “I remember when he was little, the first time understanding that he really has this deep feeling… He put this song on about mother… We don’t get [the spoken]… ‘Mom, I love you’.” Esther had a similar experience with her son Ryan expressing himself through music on a CD instead of verbal language, “He knew what song was what number [lots of “ya’s” and “mhmm’s”] when he was two and a half…we didn’t know what he knew.” Both mothers had been given very severe assessments of their child’s developmental trajectory. And while I do not wish to imply that there is a hidden autistic “intelligence,” as Kanner
originally suggested (1943), or that we should therefore value and prioritize remediation and training for autistic children, these are moments where alter modes of communication and meanings of autism outside of dominant perspectives appeared within mothers’ lives. Here, ‘autism’ does not appear as a withdrawn child damaged from disordered mother-love, nor as defective brains lacking Theory of Mind and materialized in deficient social skills, but as an alter way of being and relating that opens up and humanizes non-normative forms love, sociality and communication. Anna continued about her son David, “They see life in a different way. They tap us into a different real if you are able to kind of pull down the mask.” In other words, if we orient to what is identified as autism not as a pathology but a different and viable way of being human, the naturalness or façade of normative and conventional modes of being human, communication and of caring for one another fall apart. Rosa shared a glimpse of her daughter that challenges notions of non-normative sociality identified as autistic, “We used to call her a social butterfly, even though she’s nonverbal. She liked to interact with people…they’re social [autistic people], they’re really social.” Other aspects of her daughter’s way of being she called “exploring” – “She’s going over here, she’s going over there. She’s too busy to give you attention.” Anna communicated with her son through typing (facilitated communication).

For these moms, pedagogic care was the central feature of a good life together, as they learned one from the other, embodying a new shape of “home” together with their child. New possibilities emerge, possibilities in terms of understanding what it means to live a good life together. “My son is my teacher, and no matter how people make fun of that it is because he shows me…little ways can sometimes be very big,” Anna also shared. Here, Anna echoes disability studies approaches that learn from the experiences of persons
who occupy non-normative subjectivities identified as disabled in ways that might transform dominant and exclusionary ways of being, knowing and caring in the world. Disability becomes a “unique teacher of human alterity within a culture committed to maintaining a singular sense of the ordinary and normal as unexamined values” (Titchkosky, 2003, p. 233 Titchkosky & Michalko, 2009, p. 6). Rather than seeking to cure or remedy embodied difference through treatment, the identity ‘autism mother’ and the meaning of care begin to take on the pedagogic.

**Mimesis is Poesis: Pedagogic Care**

Before I consider the ways that mothers’ imitations of the ‘good’ mother warrior already contain the creative outlines of a different kind of care outside of dominant renderings of identity, I pause for a moment in case I am presenting the reader too romanticized a picture of mothers’ lives together with their autistic children. Within current configurations of care, scientific understandings of being human and the biomedical imperative to remedy difference (Michalko, 2002), mothers in my focus groups described lives that were difficult. In many ways, some of the experiences articulated by mothers reflect dominant depictions of autism and mothering in the everyday text and talk I analyzed in chapters three, four and five, as well as key findings reported within dominant social scientific research on autism and mothering within medical sociology, social work and other fields. Mothers described sharing the stigma of difference with their child, the stress of coping, struggles with depression and resilience, grief, as well as a lack of autism services in Ontario, particularly for immigrant families, autistic youth and adults (Goffman, 1963; Gray, 1993; 2002; 2003; Khanlou & Haque, 2013; Stoddart, 2013, p. 44). In response
to one of the everyday text and talk collages that included mental health struggles I made for my focus groups (see Figure 6.2), Anna, mother of 29 year-old David, to a chorus of “mmhmm’s” from other mothers, reflected, “What I’m saying is our path is extremely hard. I think we have these issues with…being depressed…and we’ve all been there.” Other moms spoke of the stigma and isolation that comes with this life. Helen commented about stigma, “She does stuff and people are like, oh, what’s she doing that for? Why is that gigantic kid having a tantrum? And it’s like well, we’re on the subway and there’s a lot of stuff going on, and then they look at you…” Here, Helen shares some of her ‘different’ child’s stigma through a public event infused with blame and reliant on the cultural ground of normal ways of acting (Goffman, 1963). Julie spoke about the systemic isolation of mothers and caregivers, “We’re all in silos…when we go drop our kids at a workshop and I ask the facilitator could you maybe have a parent group and it is no, we’re not funded for that.” Julie was expressing how difficult it is within the current system to find other families to share driving and the cost of a support worker, for example. You are “on your own” described Jennifer, an immigrant mother who had started an information-sharing group to fill the gaps in services and information for her community.

Many mothers also spoke of the exhausting advocacy work required to gain access to very limited problematic services and even diagnoses. “I would argue that every mom who wakes up every day and faces life with a child with ASD is a ‘warrior mom’,” wrote Julie in a follow-up email to me. Here, the Western biomedical imperative to remedy difference was an urge that was tenacious for these moms. These mothers pursued diagnoses, treatment options and services with resolve, even as they lived the contradiction of a stubbornly autistic child. Anna, for example, shared her intensive engagement with the
Sonrise approach to “reach” her son, for example, when he was young, “I never left him longer than fifteen minutes at all, so when he was playing I would just kind of pull him back.” Given our current configuration of care, the stresses and “duty” to achieve normalcy, particularly for mothers who fall outside of the ‘expected parent’, are very real. Yet even in the midst of mothers’ depictions of stress, depression, isolation and the compulsion to treat their child, mothers redefined the meaning of the ‘warrior mother’ identity. Mothers re-visioned the ‘war against autism’ as depicted in everyday text and talk and described in chapter five. This ‘war’ is no longer solely a war to eliminate autism (or at least achieve an imitation of normalcy). The mothers in my focus groups also reimagined the ‘war against autism’ as warring with services to gain access to the world for their child. Here, there is a hint – an outline - of the making of a different kind of care that embraces rather than expels embodied differences understood as autistic.

Amidst mothers’ descriptions of the constraints of dominant depictions of autism, mothering and care, as well as mothers’ descriptions of the impossibility of imitating these dominant depictions, a very different configuration and meaning of autism, mothering and care appeared, one that was both a critique of dominant depictions and constraints, and pedagogic rather than ‘remedial’. In a phenomenological sense, ‘pedagogic care’ describes the “lived structure of meaning” in which mothers embodied care with their different autistic child (Van Manen, 1990, p. 4). For mothers, what made care pedagogic was the nature of her response to the ‘call’ of the alterity and uniqueness of the child in front of her.

The final paragraph of the above section, in which I describe how mothers learn from their autistic child’s ‘difference’ and extend the meaning of the human, begins to describe this pedagogic orientation to care as one that embraces and learns from, rather than expels the
difference of autism. The vocation of pedagogic care, in which mothers are deeply engaged in reflecting on and fashioning what is best for their child, can be understood as shaping lived space where her different child can be at “home,” facilitating the being and becoming of her child and their “safekeeping” in a hostile world, as well as reshaping the meaning of autism, mothering and care (Van Manen, 1990, p. 59-60, 102-3). This is an orientation, like the moments of ethical narration described in chapter four that begins to gesture to the alterity of us all. I turn to a more in-depth exploration of pedagogic care below, as well as to the ways in which mothers’ imitation of the ‘good’ expert mother warrior identity already contains the creative tracings of pedagogic care and a different meaning of the identities autism and autism mother that move beyond restrictive Western neoliberal capitalist scientific understandings.

Even as mothers articulated their understanding of autism and care through the language of intensive mothering, Western science and alternative views like Sonrise, they simultaneously pushed against dominant meanings of the identity ‘mother warrior’ and her role as the “regulator” of normal development (McGuire, 2011b, p. 82; also see chapters 3-5). “What is normal?” Anna asked, “We keep missing it… We only see it to pull them on our side and make them normal,” she continued. Anna was speaking about her decision to shift from a search for remedial therapies and working with professionals to “cure” her son of autism, towards ways she might work alongside her son to “help him out” in ways that also learned from his way of being. “I’m getting something out of it. He’s getting something too,” she shared. For Anna, autism had become “something to think with” (Michalko, 2002, p. 168), both a “mirror” that reflected society’s artifice in constructing the ‘normal’ out of the ‘disorder’ of autistic bodies and mother’s “regulator” role, and a valued
identity grounded in difference that expanded the meaning of being human, the lessons and potential rewards of which we were all at risk of “missing” if we continue to pursue treatment and turn away from a relationship with our ‘different’ autistic child (Michalko, 2001, p. 168-171). In forging this alternative meaning of ‘autism mother’, Anna, too, became a kind of “mirror”. She embodied a different way of negotiating the central contradiction in these mothers’ lives – to love her different child in the face of the irremediable cultural imperative to normalize them - where what’s ‘normal’ is always already shaped through our Western cultural ground of science and intensive mothering.

Another interesting exchange between mothers about the limits of autism mother identity and the meaning of ‘normal’ occurred while Julie was reflecting on having a child very different than herself. She said, “I honestly don’t recall thinking…I didn’t have any grand plans to fall apart.” In the midst of enthusiastic responses to this statement and a lot of talking over one another, Helen sarcastically quipped, “And your dream of a normal life was shattered with a diagnosis of autism,” to which Julie replied, “Who’s got one of those normal lives anyways [group laughter]?” Julie and Helen, who attended a different focus group than Anna, nevertheless extended Anna’s critique of ‘normal’ to include a critique of dominant narratives about the devastating impact of autism on ‘normal’ family life so ubiquitous within everyday text and talk (see Figure 6.2, for example; also see chapters 3-5). Their quick exchange was its own mirror, humorously reflecting back both the dominant narrative itself, as well as a critique of its fabricated nature - a grief-stricken mother who has lost her ‘normal’ child, her dreams shattered; a family torn apart; an unimaginable life of stress and self-sacrifice. For the mothers in my focus group, autism became an occasion to rethink the meaning of ‘autism’ and ‘autism mother’ even while dwelling within
dominant vocabularies. Indeed, Julie also articulated her limits of understanding identity and difference, stating, “Maybe a kid who was gurgling and doing [normal things]…and then the classic, you know, head banging, flapping, rocking. I think I’d think they were withdrawn from the world…” Despite limits, the descriptions these mothers offered embodied a living critique and alternative to normalizing regimes. Here, we can see that at least for some mothers, some of the time, something other than being the “mirror” of dominant culture’s ‘autism warrior’ identity who must remedy autism in her child as body/brain “gone-wrong” (Michalko, 2002, p. 22) and cope with autism’s tragedy within her family, is possible. Titchkosky captures this relationship between mimesis and poesis when she says that disabled people, “embody alternative ways of being-in-the-world and act as living depictions of the possibility that things could be otherwise” (2003, p. 237). For mothers, who lived an alternative maternal identity grounded in everyday experiences caring for a child who embodies difference identified as autistic, this depicted the possibility that we might care and live otherwise. Here, mimesis is poesis.

Mothers also questioned Western cultural understandings about the meaning of the difference of autism. Many mothers articulated an understanding of autism that was radically different from that of a tragic or threatening biological defect that can and should be remedied. One mother, Julie, poked fun at the psychoanalytic understanding of autism as a withdrawn or imprisoned self still present within everyday text and talk. She quipped sarcastically, “He seems to be in his own world.” In the midst of laughter she added, “Whose world should he be in? I never got that. Wouldn’t it be a problem if he was in someone else’s world?” And in this quip she undermined the very notion of autism as an exception or otherworldly phenomenon. Instead of the withdrawal of an otherwise normal
child, an inhuman difference, or development of self and brain gone awry - as articulated within psychoanalytic, cognitive psychological and genetic approaches – Julie opened space for caring about her child differently. Here, not only ‘autism’, but also ‘mother’ begins to mean something different. The identity ‘autism mother’ moves into the realm of the pedagogic where she is learning from her child’s difference, and pressing for the lived shape of care and being human to change, to create a home for her child in the world.

Carol, mother to 10 year-old Jason explained it this way, “Not just seeing all the wrong things…Just accept who they are is the least I can ask.” Indeed, most mothers were unambiguous that autism just is. “She will always have it,” Helen said in response to questions about a cure for her daughter from curious parents. Autism cannot be fixed or cured. It is part of the human condition. These children were not taken or stolen. Rather, autism is a different and viable way of being human. As Julie again contributed, “The whole issue of the separation of the condition from the child or from the individual…there is no non-autistic Kyle.” And in this, Julie undermined scientific descriptions of the ‘natural’ body and ‘normal’ human as mythical fabrications that compose the unquestioned ground of our lifeworld and mothers’ care, and opened space in which we might glimpse how the creative possibility of something new had already appeared in mothers’ relationships with their different child. This revaluing of autism also begins to break open the problem/solution dialectic of disability, and embrace autism as a viable way of being-in-the-world. These are important contributions toward understanding a form of care that is ‘pedagogic’ and a revaluing of autism, contributing, too, to telling the “disability story of parents” (Avery as cited in Ryan & Runswick-Cole, 2009, p. 43; also see Panitch, 2008) a
little differently than dominant depictions within everyday text as well as feminist and
disability studies scholarship on care.

Revaluing autism as part of a pedagogic orientation to care also animated mothers’
stories about how the challenges of living in a world that is hostile to difference and
disruption recognized as autistic taught them about relationships, and turned them toward
the world in a stance of compassion, openness to difference, tolerance for ambiguity,
protectiveness of others and humility about their ultimate lack of control over the
uncertainties of being human. This was a different orientation; a new, and disruptive, place
to begin to care from the standpoint of maternal experience and autistic difference (Smith,
1999). Esther, for example, spoke about a transformational moment with her husband about
her son Ryan’s repetitive bedtime routine, “We feel like he’s being selfish but he’s really
not [no, they’re not, no]. He has this routine in his head…he doesn’t know how to do it any
other way…” Here, a re-orientation to the difference of autism as viable, meant a self and
relational transformation that intimately tied a mother, through a more critical and
conscious intentionality, in new kinds relationships to the world and each other, ones that
undermined dominant scientific depictions of autism and care. Rosa also articulated how
learning from the non-normative autistic embodiment of her daughter opened her to self-
transformation and towards the world, “I’m just more open, more understanding, more
protective” of those who appear as different in the world. In response to the depiction of
autism treatments in one of my collages (see Figure 6.2), Rosa described how she sought to
understand autistic difference from autistic adults themselves, and expressed her solidarity
through visiting autism self-advocate’s blogs and speaking out against normalizing
treatments publically, “…this was a fundraiser for Autism Speaks…and I quoted [an
autistic blogger] that said “I don’t want to be doggy trained” because that’s what it [ABA, as promoted by Autism Speaks] is.” Through attending to the disruption of autistic difference differently, mothers and their relationship to self and others, as well as to a world grounded in scientific conceptions of the normal human, was transformed. Mothers’ critical and creative re-orientation to the disruption of autism as a mirror reflective of dominant cultural perspectives - along with their redefinition of autistic difference as a viable and even valuable way of being human - began to disrupt the meaning of ‘normal’ sociality as tied to an assumed reciprocity of perspectives in knowing the other. Rather than Schutz’s “glance of attention” (1967, p. 84) to the ground of the known, these mothers disrupted the ground of the known about difference and identity, revealing glimpses of its ‘secrets’ that began to insert not only a living critique of the modernist values of sameness, certainty and scientific control over nature and the human body (Stiker, 1999), but to embody and live new and creative understandings of care that learned from difference identified as autistic and reshaped the world.

Pedagogic care also meant mothers engaged in caring pedagogic relationships that aimed to re-fashion the world in more “homey” ways for their autistic child. Based on their research with families of children with disabilities, Rapp and Ginsburg (2011) suggest that such intimate, worldly transformations are a “new kinship imaginary”:

…parenting with a difference first reverberates through family life, creating new understandings and orientations of what one author has aptly described as “life as we know it” (Berube 1996). Over time, many use the idioms available to them to reach out beyond the world of kinship to forge a new arena of public intimacy where atypicality is the norm. (2011, p. 406)
For mothers in my focus groups, this intimate world-changing activity involved careful attention to their children’s embodied differences in a world that does not reflect their child’s way of being or doing, for example, and to teaching others along the way. Helen spoke of seeking out helpful metaphors to use in teaching others to appreciate autistic difference, “I think it helps people, I find, to put it in concrete physical terms.” Other moms described the persistence required to introduce understandings of autistic difference that might help shape small corners of the world for their children and others to live and learn in difference. “I kept pushing and pushing,” Joy shared about her journey to get an appropriate school setting for her daughter. She described the same persistence when it came to teaching her children about how to live in a world that does not incorporate their way of being: “I want them to have strategies for dealing…confidence, self-esteem,” she shared. This mom explained that such strategies were not only a way to shape the world in more ‘autistic’ ways, but a way also to “[let] the world come in.” Carol, too, described how she worked to find a daycare, and then to educate staff in order to make space in which her son might be at home: “Jason learned a lot from them but they also learned a lot from him…they can really see, you know, the inside.” Above, I described how Jennifer started an information sharing organization in her community. Julie, Anna and Rosa also initiated educational and artistic events that advocated for rather than against their child’s autistic difference as a viable way of being human.

In many ways, as described above, mothers’ vocation to “safekeeping” their child’s being and becoming, as well as attending to their child’s uniqueness and making space in the world in which “home” is possible, mimics the ‘typical’ parent vocation to love and care in such ways (Van Manen, 1990, 59-60, 102-3). As parents, we want what’s best,
including belonging, for our child. And yet, mothers pursued this vocation for their autistic child in a world that is hostile to this difference, and expectant that a mother will gather expertise and skill in order to ‘work on’ achieving at least an imitation of normalcy in their ‘disordered’ individual child. In their imitation of ‘normal’ and ‘natural’ parenting (Michalko, 2002, pp. 167-75), the mothers in my groups creatively embodied an alternative way to care about autism that becomes a kind of disruptive ‘mirror’, critically reflecting back to us dominant culture’s interpretations of both ‘autism’ and ‘autism mothers’ (Michalko, 2002, p. 168). It was not the power of normalcy, but mothers’ pedagogic orientation to the unique child in front of her as a life she cannot help but attend to in ways that puncture the mastery of normalcy that shaped her imitative vocation. In this creative approach fashioned by mothers, practices of care rupture the compelling nature of the ‘normal’ life as what is ‘good’, and reveal a glimpse of the ‘secrets’ of its exclusionary ground. Care becomes a radical pedagogic, loving vocation that ruptures the problem/solution dialectic of disability and opens new ways of being human together.

The care practices mothers described in my focus groups were radical in the sense that they began from a different location, that of the lived experiences of autism mothers and difference identified as autistic, as well as the realm of the maternal and feminine – love, care, relationships, the domestic – along with the scientific and professional (Smith, 1999). Even when faced with paternalistic science and intensive expectations of ‘good’ mothering, mothers alternatively pursued what they perceived would best facilitate teaching and learning with their different child. Anna shared the story of a recent medical assessment she had approved for her 29 year-old son David, for example, in order to gain access to resources within the mental health system. Through this process, Anna was
labeled a “crazy” mother who “may have a problem with the diagnosis of mental retardation,” when she communicated to the assessors they may be missing some practical know-how about how to relate with non-verbal individuals like her son. Anna spoke about the importance of “a knowledge about working with [autistic people] and their strengths and abilities and sensitivities,” as well as different ways of being social, such as using longer wait times between questions, that helped her son gain access to tests. Here, Anna attempted to meet scientific paternalism and authority, and the historical coupling of femininity with madness, with a pedagogic stance grounded in experience with her different autistic son (Thomson, 2001). Mothers also paid attention to what their children were telling them about how they learned and interacted differently with the world. And as I described above, many mothers shared stories about the way they discovered their child knew more than doctors were telling them was possible through music. Rosa, for example shared this about her daughter, “She would pay attention if I sang to her instead of spoke.” Anna also shared this from her son David, who types with her to communicate, “Music is…where I am calm and peaceful. It touches every single atom in me and sends me good feelings. I understand this world and people from music.” For mothers, the vocation to care meant attending to and coming to know the ‘difference’ and uniqueness of their child while negotiating the difficult, contradictory and sometimes anguishing demand of the ‘good’ autism mother identity and its duty and urge to achieve a normal identity for her child (Bauman, 2004a; Van Manen, 1990, p. 147). A radical form of care that begins in the disruption of autistic and maternal experience, mothers embodied pedagogic care as a vocation that attends to and values difference in ways that move beyond a mirror image of dominant discourses and transform our understanding of the human, autism, mothering and
care. Chapter seven now turns to conclude the journey of this dissertation, one that began with my desire for reconciliation and an ethic of disruption, moved through a critical and interpretive disability studies engagement with dominant scientific regimes, and worked to release creative forms of resistance and imaginative alternatives to autism, mothering and care grounded in non-normative ways of being identified as maternal and autistic. I also consider the contributions that this dissertation has made.
CHAPTER SEVEN

Conclusion

I began this dissertation with a narrative of disruption and desire for reconciliation. As the mother of an Asperger’s identified son, I experienced a sense of fracture, or space between mother blame and everyday violence and exclusion toward ways of being identified as autistic on the one hand; and the vocation, as a parent, to care for the child in front of me in all of his uniqueness and particularity on the other. My aim was to reconcile, through critically and creatively understanding, this stark yet ‘ordinary’ lived contradiction (Arendt, 1994, pp. 307-27). I wanted to show how the identities ‘autism’ and ‘autism mother’ are socially and relationally produced phenomena, and disrupt any sense that they are ‘objectively given’ or ‘just there’ as objects available for scientific or social scientific study or professional treatment, while also making room for the ‘excess’ of difference.

I started with a simple methodological goal: to “enlarge the understanding that we already have” (Stiker, 1999, p. 18). Given the dire need for alternatives to dominant scientific approaches and autism mother memoirs that rely on a universalizing “god-trick” implicated in normalizing care practices and extreme forms of maternal governance, I turned away from scientific certainty and its totality of “vision” and toward the disruption and situated knowledges of autistic and maternal standpoints for methodological and theoretical direction (Haraway, 1991). My focus group dialogues were key in fashioning this approach. My ethic of disruption, one that recommends a constant questioning of the ground of a world in which violence against alter embodiments is ordinary, and that seeks to open critical and interpretive space to imagine alternative possibilities from within the
disruption of difference, became the guiding principle and one of the key contributions of this thesis. The detailed work of my chapters shows there is generative possibility in attending differently to moments of disruption by bodies marked autistic, and in the disruptive “backwards glance” (Ahmed, 2006, p. 570) of the ‘bad’ mothers who embrace and learn from their autistic child’s way of being human. Disruption can be attended to epistemologically, ethically and pedagogically as a call for something beyond the ordinary, that is, beyond dominant regimes that pose difference as a problem and mothers’ embodied practices of care, as shaped by science and bourgeois mothering, as the necessary and natural solution. An ethic of disruption reveals and de-naturalizes the problem/solution dialectic and the ‘normal’, ‘natural’ human it presupposes as one that regulates all embodied identity and difference, and opens space for other, more humane possibilities of being in the world for us all.

I have argued that autism mother subjectivity emerged as a key cultural contradiction through which a Western scientific, white, bourgeois understanding of autism and contradictory femininity came to regulate the good/bad mother and what it means to be human in new ways for us all. I pursued this argument through a critical and interpretive disability studies engagement with everyday ‘autism mother’ text and talk, including focus groups. We met the ‘cold’ refrigerator mother of psychoanalysis who causes autistic withdrawal in her otherwise normal child; the ‘heroic’ mother therapist of neuropsychology who must rescue her child from disordered biological development; and the expert mother ‘warrior’ of biogenetics who must save her child through her own expertise and resources. Within these shifting scientific regimes, mothers have not only been blamed and pathologized but held responsible for bringing all of the contradictions
of motherhood, the human and Man - the natural, scientific, loving, violent, hot, cold, proximate and distant, instinctual and instrumental - to eliminate the trouble and partiality of autism. The radical contingency of identity and mothers’ creative mimesis is revealed through the analytic work of my chapters, recommending further investigations of maternal care and resistance as an important site of learning about how human beings both complexly comply with and “refuse what we are” (Foucault, 1982, p. 216) under dominant scientific, capitalist, patriarchal regimes. My thesis is thus an invitation to the academic fields I engage in my work - disability studies, philosophical sociology, maternal theory, feminist philosophies and histories of science, cultural studies and poststructuralist and phenomenological philosophies - to pursue questions of the meaning of autism, mothering and care further.

My goal has been to expand the understanding of autism and mothering already circulating in our world and open space to imagine new and more humane possibilities for care. This objective has been both the strength and the limitation of my work. I do not offer any resolutions to the central contradiction and ethical paradox I introduce. Rather, my work has embraced contradiction and opened new questions and ways of proceeding in knowledge production that have yielded both contributions and challenges to the scholarly fields I engage, as well as recommendations. I have already mentioned my ethic of disruption as a key recommendation. The link of powerful scientific regimes of governance to neoliberal capitalism and the marketization of all arenas of life, including knowledge production (Mallet & Runswick-Cole, 2012), and the urgency with which non-autistic identity is sought through research and private markets shows the dire need for such an ethic. Unlike the disruption, innovation and change that drive capitalist
accumulation in research and autism industries, an ethic of disruption recommends ways of proceeding that open alternative ways to care by turning to mothers’ understandings of the fundamental value and humanity of persons identified as autistic. My focus groups demonstrated this vividly through an exploration of pedagogic care. Within mothers’ lives together with their autistic children, the outlines of a different way to care constantly open to learning from the disruption of autism already appears. This suggests further exploration with mothers and autistic children of future recommendations that can be made about what is necessary to practice care that is ‘pedagogic’, particularly within education and health care practice, for example, a recommendation I plan to explore in my postdoctoral research project on mothering, autism and digital story telling as an ethics of disruption and educational intervention.

This thesis also contributes to the “emergent landscape” (Block, 2015) of autistic studies as a developing area of academic scholarship by and for autistic persons with an emancipatory aim linked to the neurodiversity and self-advocacy movement. As a mother-ally, my project contributes a little differently to this emerging area of study through an ethic of disruption and pedagogic care. I not only contribute critical autism and mothering histories and ways of doing research grounded in the disruption of ways of being identified as ‘autistic’ as valuable, viable and pedagogic. I also demonstrate the radical contingency of ‘autism’ and ‘autism mother’ identity, a provocation to “autistic studies” to constantly disrupt its own ground even as it emerges. The claim of the neurodiversity movement of an autistic identity grounded in biological difference is limited in its ability to challenge normal/abnormal and us/them binaries, as well as the commodification of difference, whether positive or negative (Runswick-Cole, 2014). As
a basis for knowledge production, such claims limit the purchase of critical scholarly work to understand the histories of the meanings and governance of autism, or to rupture the problem/solution disability dialectic. These challenges are urgent ones given the ‘ordinariness’ of violence against persons identified as autistic. Proceeding from an ethic of disruption promises to care about autism differently, holding open these critical, creative and vital possibilities for this emergent area of study and suggesting alternative ways to be an ally that move beyond understandings of autistic identity grounded in ‘differently wired’ brains.

My dissertation also offers a new “disability story of parents” (Avery as cited in Ryan & Runswick-Cole, 2009, p. 43) to disability studies, maternal theory and feminist studies of science that moves beyond dominant social science and biogenetic depictions of autism and mothering as stigma, coping, biomedical disorder or tragedy. The work of my chapters shows, first, mothers’ leadership in advocacy and activism against the oppression of autistic persons and their families, as well as mothers’ “refusal” of dominant depictions of autism and mothering and (re)valuing of autistic difference as both viable and pedagogic. This is an important disability and feminist history that is only beginning to be told, suggesting further study. At a deeper level, this new “disability story” of mothers makes an important contribution to disability studies, maternal theory and feminist studies of science, showing not only how autism mothers “are made subjects” (Foucault, 1982, p. 208) within dominant scientific regimes, but also how they negotiate, resist and refuse such subjectification within situations of extreme scientific, capitalist and patriarchal governance. Mothers both comply within regimes that demand identity – by participating in normalizing treatments, for example – and they creatively
resist, turn toward difference and relationality as a teacher about human alterity and imagine care anew grounded in maternal authority and interpretive experience. One convergence I discovered that calls for further interrogation is how extreme modes of governance turned autism mothers’ gaze toward their own inner lives and embodied practices, which not only became new spaces of governance but the ground of autism mothers’ resistance. This new “disability story” of mothers suggests that it is in (re)turning our gaze toward these spaces of incomplete governance and the shared yet disqualified ‘autistic’ and maternal knowledges that “hover” (Park, 1967, p. 121) at the edges of scientific discourse yet exist centrally in autism mother’s lives that we might “bridge” (Kelly, 2013) different academic disciplines and engage forms of resistance that embrace the maternal as well as autistic difference.

My project has also been, more broadly, epistemological insofar as I have been interested in knowledge production as its own site of inquiry. While I have not sought to create a new theory of knowledge, I have worked to value a ‘disruptive’ alter gaze in knowledge production grounded in previously marginalized autistic standpoints and the pedagogic care of autism’s ‘bad’ mothers who have resisted the “god trick” in dominant scientific regimes. This approach recognizes the partiality of all knowledge production, and values ‘evidence’ outside of empirical facts and scientific rationality; namely, the philosophical, imaginative, interpretive, critical, affective, relational and maternal. It is my hope that this project has offered new and possibility transformative ways to proceed in knowledge production as one political, ethical and pedagogical site from which to enlarge our understandings about mothering, care and being together in difference, differently.
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Continuum.


Appendix A: University of Toronto Ethics Approval

UNIVERSITY OF
TORONTO

OFFICE OF THE VICE PRESIDENT, RESEARCH

PROTOCOL REFERENCE # 29180

July 19, 2013

Dr. Tanya Titchkosky
DEPT OF SOCIOLOGY & EQUITY STUD. IN
EDUC.
OISE/UT

Ms. Patricia Douglas
DEPT OF SOCIOLOGY & EQUITY STUD. IN
EDUC.
OISE/UT

Dear Dr. Titchkosky and Ms. Patricia Douglas,

Re: Your research protocol entitled, "Mothering and Autism: Rethinking the limits of the human"

ETHICS APPROVAL

Ethics Approval Date: July 19, 2013
Expiration Date: July 18, 2014
Continuing Review Level: 1

We are writing to advise you that the Social Sciences, Humanities, and Education Research Ethics B has granted approval to the above-named research protocol under the REB's delegated review process. Your protocol has been approved for a period of one year and ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Sarah Wakefield, Ph.D.
REB Chair

Dean Sharpe
REB Manager

OFFICE OF RESEARCH ETHICS
McMurrich Building, 12 Queen’s Park Crescent West, 2nd Floor, Toronto, ON M5S 1S8 Canada
Tel: +1 416 946-3273 • Fax: +1 416 946-3763 • ethics.review@utoronto.ca • http://www.research.utoronto.ca/for-researchers-administrators/ethics/
PROTOCOL REFERENCE # 29180

July 4, 2014

Dr. Tanya Titchkosky
DEPT OF HUMAN, SOC SC & SOC JUSTICE
EDUCATION
OISE/UT

Ms. Patricia Douglas
DEPT OF HUMAN, SOC SC & SOC JUSTICE
EDUCATION
OISE/UT

Dear Dr. Titchkosky and Ms. Patricia Douglas,

Re: Your research protocol entitled, "Mothering and Autism: Rethinking the limits of the human"

ETHICS APPROVAL

Original Approval Date: July 19, 2013
Expiry Date: July 18, 2015
Continuing Review Level: 1
Renewal: 1 of 4

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) delegated process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Sarah Wakefield, Ph.D.
REB Chair

Dean Sharpe
REB Manager

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Tel: +1 416 946-3223 ● Fax: +1 416 946-5763 ● ethics.review@utoronto.ca ● http://www.research.utoronto.ca/for-researchers-administrators/ethics/
Dear Dr. Titchkosky and Ms. Patricia Douglas,

Re: Your research protocol entitled, "Mothering and Autism: Rethinking the limits of the human"

ETHICS APPROVAL
Original Approval Date: July 19, 2013
Expiry Date: July 18, 2016
Continuing Review Level: 1
Renewal: Data Analysis Only

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) delegated process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Sarah Wakefield, Ph.D.
REB Chair

Dean Sharpe
REB Manager
Appendix B: Invitation and Informed Consent Letters

November 5th, 2013

Dear Participant,

This letter is an invitation to participate in a focus group conversation about your views on popular understandings of and approaches to autism, mothering and care. The group is being held at the OISE building, 252 Bloor Street West at 7 pm in Room 12-272. The focus group is part of my larger doctoral research project on autism and mothering that I am completing in the Department of Humanities, Social Science & Social Justice Education, at the Ontario Institute for Studies in Education, University of Toronto, under the supervision of Dr. Tanya Titchkosky. I am inviting you to participate because I think your experiences and insights about mothering an autism-identified child will make a valuable contribution to this study.

The study uses a feminist and disability studies approach that understands mothers’ experiences as an invaluable source of knowledge. In addition to focus groups, my project traces the emergence of popular understandings of and approaches to autism, mothering and care in the Greater Toronto Area. It is hoped that the focus groups will offer a way for you to speak with other interested mothers as well as to contribute to new research directions supportive of mothers’ and children’s experiences and needs around care. As the mother of an autism-identified child and former special education teacher, I bring practical and professional knowledge of these issues with me, and am I very excited to speak with you.

Between three and five other mothers of autism-identified children will attend the group with you. As a starting point for our conversation, I will bring a collage of common media representations of autism and mothering to the group, along with coffee and treats! We will meet and talk for about an hour. Any participant is free to withdraw at anytime. You will have the option of giving feedback after the group by email, though are under no obligation to do so. I will also invite you to comment on how I am using your statements in my dissertation, and will send you an electronic copy of my project once it is complete.

The focus group and all correspondence about the study will be kept secure and confidential, and no personal information that can identify you or your child will be included in my research. I will have an informed consent form available at the focus group for you to review and sign, and will ask permission from the group to audio-tape our discussion. Should you wish to withdraw from the study, you may do so at any time without any consequence by contacting me, and any statements made by you will be excluded from my research immediately.

I hope that your participation in the focus group might be an occasion to speak with other mothers about your impressions of popular approaches to autism, care and mothering outside of a school, service agency or medical context. Please do not hesitate to contact me if you require
Further information at 647-221-1721 or patricia.douglas@utoronto.ca. You can also contact my supervisor, Dr. Tanya Titchkosky at tanya.titchkosky@utoronto.ca or 416-978-0451 and/or the Research Ethics Board at the University of Toronto at ethics.review@utoronto.ca or 416-946-3273 for more information.

I look forward to speaking with you!

Sincerely,

Patricia Douglas

PhD Candidate
Department of Humanities, Social Science and Social Justice Education
Ontario Institute for Studies in Education of the University of Toronto
252 Bloor Street West,
Toronto, ON, M5S 1V6
patricia.douglas@utoronto.ca
November 6th, 2013

Dear Participant,

This letter is an informed consent letter for your participation in the focus group conversation about your views on popular understandings of and approaches to autism, mothering and care. It reiterates the invitation you already received, and provides additional information about what you are consenting to. The focus group is part of my larger doctoral research project on autism and mothering that I am completing in the Department of Humanities, Social Science & Social Justice Education, at the Ontario Institute for Studies in Education, University of Toronto, under the supervision of Dr. Tanya Titchkosky.

The study uses a feminist and disability studies perspective that understands mothers’ experiences as an invaluable source of knowledge. In addition to focus groups, my project traces the emergence of popular understandings of and approaches to autism, mothering and care in the Greater Toronto Area. It is hoped that the group will offer a way for you to speak with other interested mothers as well as to contribute to new research directions supportive of mothers’ and children’s experiences and needs around care. As the mother of an autism-identified child and former special education teacher, I bring practical and professional knowledge of these issues with me, and am I very excited to speak with you.

Because I am interested in what mothers have to say, the focus group is open-ended. As a starting point for our conversation, I have brought a collage of common media representations of autism and mothering to the group along with coffee and treats. We will meet and talk today for about an hour. You will have the option of giving feedback after the group by email, though are under no obligation to do so. I have invited you to participate because I think your experiences and insights about mothering an autism-identified child will make a valuable contribution to this study.

Audio Recording and Confidentiality

The focus group and interviews will be confidential and no personal information that can identify you or your child will be included in my research. I will audio-record the focus group. I will stop taping any time you request and you may withdraw from the focus group or study at
any time. Audio recordings and research notes will be anonymized during transcription and kept in a locked and secure file in my home, along with consent letters. They will be securely destroyed within five years of my dissertation defense. You can withdraw from this focus group at anytime. Should you withdraw, I will remove your statements, related research notes and signed consent form immediately and securely. I will also invite you to comment on how I am using your statements in my dissertation, and will send you an electronic copy of my project once it is complete.

**Forseeable Risks and Possible Benefits**

I will be asking you to speak on popular understandings of and approaches to autism, mothering and care. It is hoped that the group will offer a way for you to speak with other interested mothers as well as to contribute to new research directions supportive of mothers’ and autistic children’s experiences and needs in this climate of “unmet need.” While it is unlikely you will experience discomfort during the group, you may leave or withdraw your participation at any time.

Should any further publications become possible from this research, I will ask your permission before proceeding. I am also happy to facilitate continued communication between participants should this wish be expressed. It is my hope that the focus group will be an occasion to reflect on your experiences and knowledge with other mothers in different and positive ways.

I am very excited about this study as one that places priority on mothers’ experiences and knowledge in shaping an autism-positive world. Please do not hesitate to contact me if you have any further questions at patricia.douglas@utoronto.ca or by telephone 647-221-1721. You can also contact my supervisor Dr. Tanya Titchkosky at tanya.titchkosky@utoronto.ca or 416-978-0451. If you have further questions about the informed consent process you can contact the Office of Research Ethics at 416-946-3273 or ethics.review@utoronto.ca.

Thank you,

Patricia Douglas
PhD Candidate
Department of Humanities, Social Science and Social Justice Education
Ontario Institute for Studies in Education of the University of Toronto
252 Bloor Street West,
Toronto, ON, M5S 1V6
patricia.douglas@utoronto.ca
October 30th, 2013

Consent Statement

The purpose of the study and focus group has been explained to me, and all of my questions about the study and the informed consent process have been answered to my satisfaction. I agree to participate in this study, and I agree to the focus group being audio-recorded.

__________________________________________  __________________________
Signature                                      Date
Appendix C: Other Focus Group Materials

Focus Group Flyer

Are you the mom of an autistic child or adult, and interested in discussing how mothering and autism is represented by the popular media?

Please come to a focus group discussion at the University of Toronto as part of my PhD research on autism and mothering...

- Take part in a discussion with other moms
- Contribute to new research directions
- Choose from a group on popular science, popular representation, or both
- Meet a mom-researcher (that’s me) interested in telling new stories about autism and mothering
- Enjoy some coffee and treats!

All information shared will be kept confidential, and participants can withdraw from the study at any time. Contact Patty Douglas at 647-221-1721 or patricia.douglas@utoronto.ca to find out more.
Focus Group Questions/Probes

Guiding Questions: Views on Popular Representation

1. How do you feel about the popular representation of autism and mothering? What’s missing?
2. What do you think autism is?
3. What do you think mothers and autistic children need?
4. Where have you turned to learn how to be an “autism mother”?

Guiding Questions: Experiences Mothering

1. What does it mean to be “this kind” of mother (an autism mother)?
2. What are some of your best memories? Hardest memories?
3. How did you know your child is autistic?

General Guiding Questions:

1. Can we talk more about…?
2. Can you clarify what you meant by…?
3. Do you have anything else you would like to add?
Appendix D: Copyright Acknowledgements

A version of Chapter 3 has been published under the title “Refrigerator Mothers” in *Journal of the Motherhood Initiative*, volume 5, number 1, pp. 94-114 (Douglas, 2014). It is included with the permission of the journal’s editor, Dr. Andrea O’Reilly.

A version of Chapter 5 has been published under the title “As If You Have a Choice: Autism Mothers and the Remaking of the Human” in *Health, Culture and Society*, volume 5, number 1, pp. 167-81 (Douglas, 2013). It is included with the permission of the journal’s senior editor, Dr. David Reggio.