Abstract

This thesis brings interpretive disability studies together with a governmentality approach and feminist methodology to think through the meaning of autism, Asperger’s and maternal care. I examine how Asperger’s is articulated as a problem of individual governance through what I call the care complex, an array of practices, knowledges, technologies and institutional locales that attempt to scientifically know and manage alterity under neo-liberal rule. I focus on discourses of inclusion that seek to normalise the movements of alterity through a mother’s care, and reveal how direct and authoritarian forms of power are integral to the accomplishment of this paradoxical version of inclusion and care. The aim of this thesis is to “take care” of autism differently. Thus I also consider how maternal care is lived out and felt, opening analytical space to ask critical questions about power, embodiment and human vulnerability.
If you knew when you began a book what you would say in the end, do you think you would have the courage to write it?

-Michel Foucault, Truth, Power, Self: An interview with Michel Foucault, 9
Acknowledgements

I began this thesis not knowing what it was I wanted to write about caring for an Asperger’s identified son, just that I wanted to do so. Through the mentoring of my committee members, I have ended, gratefully, with questions that captivate me, and that may occupy my thinking for a very long time. I want to thank Tanya Titchkosky, my supervisor, who has unfailingly supported and encouraged my thesis as a work of care. Her deeply provocative and creative feedback called upon me to grow as a thinker and writer. I also want to thank Kari Dehli for suggesting that I embrace this place of “not knowing” and simply begin. Kari’s influence and feedback has been instrumental in the shaping of my approach and questions. She has also challenged me to be more incisive in both my thinking and my writing. I have been fortunate to work with these immensely knowledgeable and talented scholars who are also wonderfully supportive and fun. Any failings are my own.

Thank you to my friends and family along the way who told me “you can do it” as “life happened” – the loss of my dad, a fractured vertebrae, the return to full-time work – and to my co-parent Chris, who gave me many extra hours of child-free time. I have been constantly grateful as my sons Brennan and Jesse cheered me on even as my writing meant less time for us. This thesis is for them. And to Tom, brilliant scholar and beautiful friend, thank-you for everything.
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Introduction

Encountering Asperger’s: The Governance of Embodiment and Maternal Care

The first time I encountered the term, “Asperger’s Syndrome,” was when my son was eight years old. By that time, my care for my son had failed to shape his behaviour to meet social expectations. Wanting to be a ‘good’ mother, I had tried hard to teach my son and cared very much that he learn to ‘behave,’ but he continued to display ‘odd’ behaviours that others found confusing or bizarre, and I continued to fail. For one thing, this meant ‘trouble’ at school. Situations involving transitions in the classroom or busy social scenes on the playground often escalated into confrontation, as school officials enforced rules and my son responded in unexpected ways. Concern was expressed by principals and teachers, and suspensions occurred more than once. The school board eventually suggested that I move my son to a small primary gifted/behavioural program where intensive interventions to re-form his behaviour could be programmed. The end goal of these programmatic efforts was ‘successful inclusion’ back in the mainstream classroom. Up until this time, I had lived with the surprise, perplexity and even joy of my son’s quirks and difficulties, consulting parenting literature and devising strategies as I went. A part of me felt that he simply moved through the world ‘differently,’ but I was also tired of the worry and struggle. I wanted clear answers that would help my son ‘fit in.’ I agreed to the educational intervention along with a psychological assessment. Thus began our encounter with what it means to live with and care about Asperger’s.

1. I use single quotations the first time some words are introduced to invite the reader’s critical attention to foundational assumptions I am attempting to unsettle here.
2. I consulted with my thesis committee and the University of Toronto Centre of Ethics to ensure that my work meets the ethical requirements of the Tri-council Policy Statement: Ethical Conduct for Research Involving Humans: 1) I do not identify or criticize individuals, 2) I did not practice care with the intention of performing research, 3) I frame Asperger’s as a teacher. I return to the issue of ethics in more detail in Chapters 3 and 4.
During the assessment and educational intervention, the authority of psychology and ‘brain science’ loomed large, constituting Asperger’s as an individual problem of development-gone-wrong, one located within lone brains. During the process I was asked to recall facts about my son’s development, putting my thoughts in chart-form (see Figure 1). Interestingly, I organized my chart in the language of developmental psychology, in terms of “What Seems Normal,” and “What Does Not.” I identified, among other things, my son’s alternate mode of facial expression as evidence of ‘abnormal’ development, as if development should unfold according to a universal and ‘natural’ process, one that had simply ‘gone wrong’ for my son.

Figure 1. Excerpt from Chart for Asperger’s Disorder Diagnostic Process, 2006

<table>
<thead>
<tr>
<th>What Seems Normal</th>
<th>What Does Not</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Facial Expressions/Emotions</strong></td>
<td><strong>Facial Expressions/Emotions</strong></td>
</tr>
<tr>
<td>• Expressive voice and smiley when not under stress</td>
<td>• Directly taught through daily practice and drawing how to make and respond to facial expressions and the feelings associated with them</td>
</tr>
<tr>
<td>• Makes happy and angry faces</td>
<td>• Flat face and affect when sorry or remorseful or sad</td>
</tr>
<tr>
<td>• Can readily identify facial expressions when asked and can intellectually explain what emotions mean</td>
<td>• Awkward looking smile/laughter when scared/nervous</td>
</tr>
</tbody>
</table>

Together with observations made by our psychiatrist, my observations formed the basis for a diagnosis of Asperger’s Syndrome, a mental dis-order on the autism spectrum involving ‘deficits’ in social communication. My desire to shape my son’s behaviour normatively through pedagogy and care (e.g., I engaged him daily in cartooning to teach him facial expressions), alongside the social act of chart-making, implies that I took for granted that maternal care, as a practice informed by popularized notions of development, is somehow central to the
accomplishment of normalcy. The solution to development-gone-wrong, then, was equally individual: the guidance and shaping of an individual child’s conduct not only through individual educational interventions, but through a mother’s scientifically informed and finely attuned care.

Programmatic attempts to re-form my son’s behaviour at school integrally involved my care. Indeed, I secured the involvement of an autism agency and learned to ‘see’ and respond to my son’s behaviour anew, through scientifically informed grids of perception. For example, I learned new therapeutic techniques such as applied behaviour analysis, attempting to align my practices in the home with educational ones. Social skills, self-control and autonomy – norms of development defined by cognitive psychology - were identified as key goals, understood to be necessary for a happy and productive life. But my son’s alter modes of embodiment persisted, and programmatic attempts to re-form his behaviour failed. Alongside my intensified efforts to ‘care,’ the disciplining of his continued transgressions at school heightened. We were caught within a paradoxical version of maternal care that was to achieve ‘inclusion’ on the basis of exclusion, and that had become enforceable by coercive means.

It is this paradoxical inclusion-exclusion problematic as it pertains to the meaning of Asperger’s, embodiment and maternal care that is the central concern of this thesis. Rather than use an approach that defines Asperger’s as a problem of individual body/brain gone wrong and care as somehow the ‘natural’ realm of mothers, I argue that maternal care is a modern form of governance. Indeed, this thesis is an attempt to care for autism and Asperger’s differently in at least two related senses: 1) by offering alternative understandings of alter embodiments, and 2) by re/thinking care and inclusion as relational phenomena. As Foucault proposes:

There are times in life when the question of knowing if one can think differently than one thinks, and perceive differently than one sees, is
absolutely necessary if one is to go on looking and reflecting at all. (1990, 8)

I understand care not as something ‘natural’ that individual mothers ‘just do.’ Rather, a governance frame approaches maternal care as forms of practices and thought constitutive of Asperger’s as a particular kind of problem located within lone brains. Practices are organized through the family and work of mothers in particular institutional sites such as schools, and animated by the expert knowledge of neuroscience and cognitive psychology. They recruit a mother’s ‘private’ work and desire for normalcy in the political task of nation-making through the production of self-regulating, enterprising, ‘normal’ citizens. Nikolas Rose says the following about the governance of childhood:

Childhood is the most intensely governed sector of personal existence. In different ways, at different times, and by many different routes varying from one section of society to another, the health, welfare, and rearing of children have been linked in thought and practice to the destiny of the nation and the responsibilities of the state. The modern child has become the focus of innumerable projects that purport to safeguard it from physical, sexual or moral danger, to ensure its ‘normal’ development, to actively promote certain capacities of attributes such as intelligence, educability, and emotional stability. (1999, 123)

Thus my emphasis of analysis will be on the complex of practices, knowledges, identities and technologies that govern Asperger’s and care.

The Approach

To do the work of fashioning an alternative approach, I bring an interpretive disability studies approach together with an analytic of governmentality to reveal Asperger’s and practices of care as socially and politically assembled phenomena, and therefore contingent in character. 3 I contrast my approach with cognitive psychology and neuroscience as they have been popularized

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3. I am using the term ‘interpretive disability studies’ to refer to an interdisciplinary approach influenced by hermeneutics and phenomenology, as taken up within a variety of fields: feminist post-structuralism, disability studies and interpretive sociology, for example. See Titchkosky (2003, 2007) and Michalko (2002) for key examples of this approach. Also see pages 21-3, Chapter 1, for a more general discussion of the field of disability studies.
within fields of teacher education, advice literature and parent guides. These more mainstream and established approaches strip autism and Asperger’s of history and interpretation, and thus mask its contingency and embeddedness in social and political fields of power, fixing it instead within lone defective brains. I work to recover autism from psychological and scientific discourses and to animate new approaches that prise open analytic space from which to ask questions about embodiment, power and human vulnerability.

First, I draw from governmentality literature, inspired by the work of Michel Foucault, especially his later work. Governmentality approaches ask questions about the complex operations of power that govern the constitution of self/other as well as practices. While a genealogy or tracing of the historical emergence and specificities of this autism/Asperger’s regime is beyond the scope of my thesis project, I consider some of the contemporary conditions around which autism and care are assembled today. Foucault says the following about such regimes:

...to analyze regimes of practices means to analyze programmes of conduct which have both prescriptive effects regarding what is to be done (jurisdiction) and codifying effects regarding what is to be known (veridiction). (1991c, 75)

I call the regime of practices that surrounds autism and care today the care complex. Already alluded to in the above discussion, the care complex can be understood as a ceaselessly shifting, sometimes contradictory yet increasingly organized assemblage of practices, expert knowledges, institutional locales (i.e., the family, the school, the autism agency, the medical institution, the market, the state), identities (such as Asperger’s), and technologies that work to govern autism and care, and to accomplish rule through self-governing subjects (Dean 1999, 21). I perform an analysis of a number of aspects of the care complex utilizing a governmentality approach.
Secondly, a disability studies approach provides a space from which to ask questions about how the governance of Asperger’s and care is lived out in various sites within the care complex at the messy, ambiguous and nebulous level of meaning, embodiment and subjectivity. Here, I draw from the phenomenology of Maurice Merleau-Ponty (1962) within a disability studies frame to examine how care is experienced in the everyday.\footnote{See Crossley (2004), who engages a dialogue between the work of Michel Foucault and Maurice Merleau-Ponty.} Within this frame, I conduct a phenomenology of the care complex through autoethnographic reflections as a mother. I ask how it feels and what it means to live out all of this organization in our current historical moment and locally situated contexts. I allow these two distinct analytic frameworks to reveal different understandings of autism, Asperger’s and care, ones I hope will constitute the beginning of a generative dialogue that might have something to offer in terms of challenging dominant and restrictive modes of governing embodiment and maternal care.

**The Way Forward**

Through a discussion of the predominance of cognitive psychology and neuroscience in autism research, Chapter 1 suggests the need for an alternative approach to Asperger’s and care. I suggest that governmentality and interpretive disability studies offer a generative way to unmask and critically analyze what is being accomplished by scientific claims to ‘truth’ about the body in our time. In Chapter 2 I discuss my theoretical and methodological approach in more detail. I argue for a situated and multivocal account of autism and care as opposed to a total or official one. This is an approach that attempts to open analytical space to care about Asperger’s differently through alternative understandings of Asperger’s and care as ethical, social and political phenomena. This is also an approach that acknowledges itself as a practice of knowledge production, one in which I am inextricably implicated. In Chapter 3, I turn to the
context of schooling as a key institutional site through which caring practices around autism and Asperger’s are organized and lived out in the life of mothers, children and families. I focus my analysis on educational policies of inclusion and how their paradoxical logic governs disability in our time. This logic recruits mothers and families into the work of normalisation, organizing interpretive relations to embodiment, vulnerability and alterity as that which must be made knowable and governable. I discuss more direct and coercive forms of power in Chapter 4, as ones that are integral to the government of disability and embodiment through mentalities such as inclusion. I analyse applied behaviour analysis as an example of progressive discipline, an ascendant practice of authoritative power that attempts to make inclusion practicable, one that weaves between various sites within the care complex: the family, schools and autism agencies. In Chapter 5, I conduct a phenomenology of care, focussing on the lived-out-ness of knowledges, practices, technologies and policy by reflecting on some of my own experiences as a mother within the care complex. The distinction between policy, practice and experience as I have made them here cannot be made at the level of embodiment, where they are instantiated simultaneously. It is my hope that this division will help provide clarity and provoke generative dialogue as I make the hermeneutic shift from governmentality approaches to discussing how it feels and what it means to live-out policies and practices of care.

The central concerns of this thesis - governing embodiment and attending to the ‘rub’ of power and subjectivity – inform an animating question for the project to which I return to along the way: How might care be re/imagined as a way of practicing and embracing alterity? This implies that the aim of my project is not only to reframe practices of care in ways that learn from and are responsive to alterity, but also to rethink the meaning of autism in situated and relational terms. As such, my earlier chapters utilize critique as a means to open analytic space for
alternative understandings, while Chapter 5 engages a deeper and more creative meaning of critique, moving toward understanding my own implication as a mother in practices of power and the creation of alternative approaches to doing Asperger’s and maternal care (Butler 2004). I conclude by considering implications for further research. Chapter 1 defines some terms we will need along the way, turning to a critique of dominant understandings of Asperger’s and care.
Chapter 1  Assembling Asperger’s Disorder: Toward an Alternative Approach to Asperger’s and Care

On World Autism Day, April 2nd, 2009, the World Health Organization (WHO) released a communication entitled *Need to Address Mental Disorders in Children* to its member nations and the media. It included the following statement, made by Dr Ala Alwan, Assistant Director-General for Noncommunicable Diseases and Mental Health at WHO:


Within the shifting economic, political and cultural relations of the past forty years, new and intensifying practices of caring for the mental, social and emotional life of the child – our “youngest citizen” - have emerged (Rose 1999, 123).5 The rise of the expert knowledges of cognitive psychology and neuroscience, increasingly conjoined in their effort to understand the human brain and unlock the ‘mysteries of the mind,’ have re/articulated the boundary between normality and abnormality according to new ‘truths’ about so-called normal and abnormal cognitive and social development: the achievement of autonomy, social competence and self-control. These new truths have dispersed widely, animating diverse institutional locales and practices. For example, advice literature popularizes scientific versions of maternal care in the home, and re/formed educational practices draw from neuroscientific and psychological research as the new ‘truth’ about autism. Prevention, treatment and a cure is considered of utmost

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5. Nikolas Rose uses the term “The young citizen” as a chapter title in his work *Governing the Soul* (1999, 123). He adopted the term from Donald Winnicott, who shows how the project of public education has attempted to cultivate qualities of citizenship in children, ones whose subjectivity and bodies align with western capitalist rule.
importance if individuals, families, communities and nations are to avoid the threat to happiness, productivity and citizenship this “global burden of disease” purportedly poses.

In the face of this global regime of care, this chapter works to unravel its authority. I first spend time defining and discussing a few technical terms that will be needed to proceed, reframing the argument of the thesis in the language of governmentality and interpretive disability studies. Secondly, I provide a brief overview of the assembling of Asperger’s as a new identity category in the late 20th Century. I discuss and critique dominant approaches to autism and Asperger’s – cognitive psychology, neuroscience and normative social science – that have been integral to assembling the disorder and that continue to animate the care complex. Next, I introduce the fields of disability studies and governmentality as ones that counter dominant understandings of Asperger’s. I describe current work on autism and disability to lay the groundwork for Chapter 2, where I present my theoretical and methodological approach.

**Discussing Terms**

Let me begin by restating the central argument of the thesis in more technical language. I then take some time to clarify my use of this language so that we can proceed. Inclusion and care comprise an ascendant form of *neo-liberal governmentality*, a form of modern power that circulates together in complex ways with more coercive forms to bring mothers and families into the project of “making up” young citizens on normality’s terms (Dean 1999; Davis 1995). I use the term governmentality in two senses, following Michel Foucault. First, I use the term to describe a form of political reason. Political reason refers to the “intellectual machinery” and practices that “render[s] reality thinkable in such a way that it is amenable to political

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6. This term comes from Ian Hacking. In an article that appeared in the *London Review of Books* he states: “Sometimes, our sciences create kinds of people that in a certain sense did not exist before. I call this ‘making up people’” (2006, 23). I use the term here to flag autism and citizenship as historically and socially assembled phenomenon.
programming” (Rose 1996, 42; also see Foucault, 1991a). Political rationalities have moral forms that shape the ideals of government, as well as epistemological forms that define both the “objects to be governed – nation, population, economy, society, community – and the subjects to be governed – citizens, subjects, individuals” (Rose 1996, 42). Neo-liberalism as political rationality seeks to govern through self-regulating, “free” consumer- subjects, and at a distance, degovernmentalizing government and resituating expert knowledge within market relations (Rose 1996, 40-1). Thus one of the things that is new today in the context of neo-liberal governance is how citizens are prefigured in increasingly restrictive, abled and normative terms as autonomous, productive, enterprising subjects of freedom and choice. Further, while the child and the mother have been a target of governance over the past century at least, the intensification of ways that inclusion and care enlist the participation of mothers and children in their own self-governance is key to this emerging mode of governance. Self-governance can be thought of as the work, suggested or prescribed, we come to do on ourselves, including the ways in which we practice care and fashion our self-understandings. Regimes of neo-liberal governance like the care complex compel mothers into self-governance through love, desire, a sense of responsibility and moral obligation to take up the work of care (Dehli 2004).

Secondly, Foucault uses the term governmentality to describe the various modes of thought and action meant to regulate, shape and guide the conduct of not only others but also ourselves (1991a). These modes of thought and action become governmental when they are expressed technically and programmatically through various procedures and mechanisms that effect them as practices. Mitchell Dean describes the modes of thought involved in governance as mentalities of government, a term that “…emphasizes the way in which the thought involved in

7. See Rose (1999) and Donzelot (1979) for genealogical accounts of the governance of mothers, children and families over the past century.
practices is collective and relatively taken for granted” (1999, 16). Inclusion and care are forms of governance that involve scientific and neo-liberal *mentalities of government*, a “way of seeing” Asperger’s and care so ‘natural’ that it has become virtually unquestioned and unquestionable (Hill 2009). This “way of seeing” means, for example, that pedagogical and therapeutic practices meant to enhance the cognitive and social development of our young child align with western capitalist rule within procedures and apparatuses that appear to us as ‘obvious’ (Griffith and Smith 2004; Dehli 2004). Further, as interpretive disability studies helps elucidate, this “way of seeing” means that mentalities of government practically animate a particular interpretive relation to embodiment within western cultures, one in which the mystery of the brain - in which lies a deep vulnerability - is understood as something that is and should be made both knowable and governable. This insight is key, as it underlies the organization of lived experiences of care, as well as the more systemic systems of governance of autism and care today. Having defined my use of a few key terms, I turn now to a discussion of the emergence of Asperger’s Disorder as a way to begin to disassemble the ‘obviousness’ of this category.

**Assembling Asperger’s Disorder**

The interpretive identity category I am interested in studying, Asperger’s Syndrome, has recently emerged in the midst of other new and so-called mental disorders such as ADD, ADHD, conduct disorder and oppositional defiance disorder, to mention just a few. I offer a brief consideration of the conditions at the close of the 20th Century within which Asperger’s was assembled as a new category of mental disorder identifiable in childhood. In *Governing the Soul* (1999), a genealogical study of the links between political rationalities (liberalism and neo-liberalism), subjectivity and the expert knowledge of psychology, Nikolas Rose says the following:

> Since World War II...Psychology has played a key role in establishing the norms of childhood, in providing means for visualizing childhood
pathology and normality, in providing vocabularies for speaking about childhood subjectivity and its problems, in inventing technologies for cure and normalization. (133-4)

Under the neo-liberal rule of the past thirty to forty years, cognitive psychology and neuroscience have emerged as dominant paradigms, establishing new truths about and boundaries between normality and abnormality in childhood. More specifically, within these paradigms, cognitive and social development and the achievement of normalcy has become tantamount to the capacity to fashion an autonomous, productive and enterprising self. Mothers, particularly middle-class mothers, are recruited into the role of monitoring their child’s development for any sign of abnormality as defined by these knowledge regimes. These new truths fuel the establishment of re-formed programmes of early identification, intervention and normalization (Nadesan 2005, 110; Rose 1999; Griffith and Smith 2004; Walkerdine and Lucy 1989). In the context of Canada and the United States, autism research agendas, mothering practices, the development of treatments (including pharmaceutical and therapeutic), parent advocacy agendas, professional practices (educational, medical, service agencies) as well as popular culture are animated almost entirely by these dominant understandings of autism. Partnerships and relays have been established across and between a diversity of institutional locales in an effort to establish research priorities, a national autism strategy, treatment programmes and autism awareness, all efforts supported by the ‘technicians’ of cognitive psychology and neuroscience – doctors, scholars, researchers, psychologists, teachers, social workers and so on.  

8. The specifics of some these partnerships and relays will be taken up further in Chapters 3 and 4. For the interested reader, I mention just a few within the Ontarian context. Relays and partnerships are emerging between health institutions, autism agencies, parent advocacy organizations, research institutes, school boards and government departments, for example: The Geneva Centre for Autism, Bloorview Macmillan Centre, Autism Ontario, Autism Speaks Canada, Toronto District School Board, Ontario Public Health, Centre for Mind and Brain,
Along with psychometric testing (which began to emerge in the late 1800s as the arbiter of the boundary between the surface of the body and inner mental and emotional states), new technologies of science (i.e., Magnetic Resonance Imaging) have allowed cognitive psychologists and neuroscientists to construct an ever-deepening gaze into the unknown realm of brains and the genetic workings of individuals. These technologies have opened neurological and genetic structures and processes to government, providing scientific explanations of and solutions to the ‘problem’ of alternate modes of sociality and embodiment, ones which seem to spring from “life itself” (Rose 1999, 130). Scientific explanations and practices seek to eliminate the appearance of human difference, delimiting possibilities in terms of viable ways to be human. Whether ‘true’ knowledge of the mind can ever be revealed or not, the mind as an entity in and of itself – a knowable object - is made real through the operation of these discourses and technologies, which orient to the mystery, and therefore the openness, of the human condition as something that can and must be identified, known and managed.\(^9\)

It was within this context of heightened surveillance over the life movements of the mother and child, ever-restricting and refined psychological and scientific understandings of normality, and new technologies within bioscience, that Lorna Wing was able to describe and classify a new category of mental disorder – Asperger’s Syndrome - in her influential 1981 article entitled “Asperger’s Syndrome: A clinical account.” This was the latest refinement of categories of autistic mental disorder, beginning with Hans Asperger’s work on autistic psychopathy and Leo Kanner’s work on early infantile autism in the early 1940s.\(^{10}\) Both Kanner and Asperger identified a new disorder in children which involved core impairments in social

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10. See Nadesan 2005 for an in depth discussion of the emergence of these categories.
interaction and non-verbal communication. While Kanner considered autism to be genetic, and classified early childhood autism as a type of psychotic disorder, Asperger classified autistic psychopathy as a personality disorder, and seemed to be describing a less severe disorder caused in part by problematic mothering practices. Asperger noted characteristics that seemed to distinguish his disorder from Kanner’s: ‘normal’ spoken language development, a high degree of creativity and intense and enduring special interests (Nadesan 2005; Wing 1981). Lorna Wing and her colleagues worked to refine understandings of autistic disorder, particularly as developed by Asperger, adding “impoverished” speech, literal thinking, and “lack of the intense urge to communicate” from birth to Asperger’s observations (1981, 117). In the context of scientific disagreement over the aetiology of autism, Wing argued for the utility of a distinct category – Asperger’s Syndrome – to describe a seemingly less severe version of autistic disorder in which language is present. At the same time, Wing hypothesized an “autistic continuum” (commonly known today as the autistic spectrum) with a common and core triad of impairments: social interaction, social communication and social imagination (Wing 1981, 1988; Nadesan 2005, 9-28). In this way, autistic spectrum disorders were assembled as distinct yet related categories which have at their core a social impairment, made distinguishable from other mental disorders such as psychotic disorder, neurotic disorder, schizophrenia or conduct disorder. In this way, the absence of so-called normal social functioning in children is subject to heightened surveillance through these new categorizations and the work of mothers within various sites of the care complex. Debate around whether the various autistic disorders are distinct continues today, however, autism spectrum disorders are now generally understood as developmental disorders arising from a myriad of possible brain dysfunctions (see below). Formal classification of Asperger’s Syndrome, a new type of individual and population, within North America was made
in 1994 in the 4th revision to the *Diagnostic and Statistical Manual of Mental Disorders* published by the American Psychiatric Association.

**Dominant Approaches to Understanding Autism and Asperger’s**

In the next two sections, I offer a brief overview and critique of dominant forms of knowledge production – the expert knowledges of cognitive psychology and neuroscience, and secondly that of normative social science – which have come to animate our interpretive relation to autism, Asperger’s and care as practiced and understood today. These approaches refuse autism any social, political or historical significance, orienting instead to disability as an objectified condition of an individual-body-gone-wrong (Titchkosky 2000). Dominant approaches have weight, in the sense that they are embodied and organized in and through institutional locales, policy and practices. Further, they are linked through various technologies to modern political rationalities – organized ways of thinking about and administering governance - and indeed, to our very understandings and practices of normality, abnormality and ways of being human.

Titchkosky puts it this way:

> ...The most authoritative representations of disabled persons arise from medical and/or therapeutic disciplines, and the social sciences...

What Smith (1999: 73-95) calls the “official text producers” of a society rely upon and enhance the ideological constructs of people and things that already circulate within a culture. These producers have more resources, institutional support, and authority to “put the word out,” and even claim to have the most important word to put out, more important even than the words of the subjects of these texts. (2000, 198)

In the face of almost totalizing dominant knowledges and practices around autism and care, ones which at times do violence in the lives of disabled and nondisabled individuals alike, I use my discussion as a way to animate the need for alternative approaches. Dyer tells us:

> ...representations here and now have real consequences for real people, not just in the way they are treated but in terms of the way
representations delimit and enable what people can be in any given society. (as cited in Titchkosky 2000, 198)

Alternative approaches have the potential to disrupt official versions of embodiment that underpin ever-restrictive notions of citizenship within our current Western neo-liberal capitalist context.

Dominant cognitive and biogenetic approaches to understanding autism and Asperger’s attempt to fix it in time and space by mapping its aetiology onto what are assumed to be universal and a priori cognitive structures, neurological processes, and/or genetic profiles. In brief, prevailing psychological research today seeks to identify autistic deficiencies in information and emotion processing using three key and related approaches: theory of mind, executive functioning and weak central coherence. While a detailed accounting of each of these perspectives is beyond the scope of this chapter, I briefly address Theory of Mind (ToM) as one of the more prevalent examples not only of dominant psychological approaches to understanding autism, but also as a prime example of the way in which cognitive psychology has become increasingly intertwined with biogenetics.11 These approaches locate the origin of cognitive difference within defective genes and/or faulty neurological processes. Building on the seminal work of Baron-Cohen within the Theory of Mind approach (see Baron-Cohen 1988, 1995, 2000), a leading Toronto psychiatrist and colleague in the field of Asperger’s research explains the link of Theory of Mind with neuroscience this way:

Theory of Mind (ToM) is the cognitive capacity to realize the uniqueness of one’s own and others’ beliefs, desires, and intentions, and is an essential component of perspective-taking abilities. Empirical evidence suggests that normal ToM is related to typical development of social understanding...and that children with AS have more difficulty with ToM tasks than controls... Neuroimaging studies have found deficits in the left medial prefrontal cortex of AS patients when performing ToM tasks. (Sloman and Leef, 1995, 254)

11. See Nadesan 2005 for further discussion of cognitive psychological and biogenetic approaches.
Theory of Mind locates sociality and empathy (perspective-taking abilities) within *typically developing brains* as a kind of natural-social cognitive capacity – mindreading. Deficiencies in ToM tasks, thought to be in a linear relationship with difficulties in sociality and empathy are attributed to “deficits in the left medial prefrontal cortex.” Further research attempts to link these faulty cognitive structures with genetic factors and brain chemistry (Nadesan 2005, 159). The taken for granted universality of normative cognitive structures and neurological processes underpins dominant approaches to understanding autism today, fixing autism as an objectifiable condition of an individual brain gone very wrong.

While dominant psychological and bioscientific approaches to understanding autism vary, at some level all of them are concerned with the elimination or alleviation of what have come to be understood within these interpretive frames as autistic ‘symptoms.’ Care and cure are sought through efforts to develop gene therapy, pharmaceutical interventions, cognitive/behavioural and other normalising interventions and therapies (Nadesan 2005). Certainly there are manifestations of the phenomenon of autism and disability which require intervention and care, as there are for all embodied beings. However, the push toward the normalisation of autistic individuals problematically attempts to *include* autistic persons within the project of “making up” citizens as what Titchkosky has called an “exclude-able type” (2007, 150). In other words, programmes of normalisation based on dominant forms of knowledge and knowledge production seek to reform alternate ways of being-in-the-world and bring them into line with social norms, at times by coercive and even violent means. Stiker puts it this way:

> There is no better way to escape the fear of strangeness than by forgetting aberrancy through its dissolution into the social norm...On to the negation of disability through adjustment, integration... Specificity and aberrancy are thereby forbidden and condemned...disability cannot be a confrontational position, a force for social change, a mutant or
revolutionary minority. In other words, the disabled should always adapt to society such as it is. (1999, 136-7 emphasis added)

Within dominant approaches there is a kind of “tyranny of the normal” (Silvers 1998, 114), a valorization of an unquestioned and unquestionable normal and so-called natural functioning. This forecloses the possibility that autism might also be a viable way of being-in-the-world, an alter mode of embodiment that might have something to teach us about the human condition (Titchkosky 2003, 2007; Michalko 2002). If we were to query Theory of Mind, for example, the positing of a priori, universal cognitive structures and typical development responsible for our sociability disallows any ambiguity in social communication, something we all experience from time to time. We have only to think about the number of uncertain interactions we negotiate on a daily basis and the ‘truth’ and clarity of ToM begin to unravel: What did that facial expression mean? Was she angry with me? Is this what he meant? Perhaps we all lack Theory of Mind at times. But what does this mean for the definition of autism? Are we all autistic at times?

Analytically opening ToM to question begins to recover autism and Asperger’s from scientific discourses. It reveals modern governance as an attempt to know and govern what I suggest through the work of this thesis is beyond the grasp of total knowledge and scientific governance: human mystery, vulnerability and alterity (Butler 2004).

Normative Social Scientific Discourse and Disability as Deviance

I turn now to a brief discussion of dominant approaches to autism within social scientific discourses as another site of “authoritative representations” of disability with the institutional support to “put the word out” about autism (Titchkosky 2000, 198). Given my situatedness in the discipline of sociology, I focus in particular on a brief overview and critique of traditional sociological approaches to disability as an issue of deviance. I reference Erving Goffman’s 1963 work Stigma: Notes on the Management of Spoiled Identity, as an example of a highly influential
approach that has been developed and integrated into normative sociological writings and practices around the study of disability, and within mainstream sociological courses (Titchkosky 2000).\(^\text{12}\)

Goffman’s work was concerned with identity and difference as social processes produced through social interaction, rules, roles and expectations. He distinguished a number of different kinds of stigmas, including “abominations of the body,” “blemishes of individual character,” and “the tribal stigma of race, nation and religion,” which he tried to demonstrate as being constructed in the interactional process between attributes (a marked difference that is undesirable such as tics, flapping hands or social disruptiveness) and stereotype (social norms) (1963, 4). He says the following about stigmatized individuals:

He possesses a stigma, an undesired differentness from what we had anticipated. We and those who do not depart negatively from the particular expectations at issue I shall call the normals...By definition, of course, we believe the person with a stigma is not quite human. (5)

Goffman’s work opens the possibility that disability and what counts as human is made in the interactional process between people. Yet, despite Goffman’s own recognition that norms of able-bodiedness, whiteness, heterosexuality, maleness and so on are an impossible achievement in any one individual, a mythic and naturalized norm of health and able-bodiedness remains unquestioned at times by Goffman himself, and particularly by some normal sociologists who have developed this approach in the study of disability as deviance (for an example related to autism, see Gray 1993, 1994). Normative sociological approaches often begin from the understanding that disability is an objective condition situated in individual bodies, outside of history and social interaction. In this way, autism has joined the ranks of other disability as

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12. It is important to note that some work within social psychology is beginning to take a more positive approach to the study of disability, acknowledging its historical, social and political nature. See Dan Goodley (2001) for an example of this important work.
deviance research, which inquires about disability as a spoiled identity, for example, and then moves logically to investigate coping, passing and management strategies, rather than the constitution of disability in the social spaces between us. In a study of how parents cope with the stigma and demands of having an autistic child, for example, David E. Gray states that the biggest problem parents faced was “the symptoms that arose directly from their child’s autism” (1994, 298). He goes on to list these problematic symptoms, purportedly located solely within defective brains: delayed language development and disruptive public behaviour, for example.

The interactional space in which these attributes become problems or stigmas, and through which social norms of comportment and sociality are produced, is collapsed within such an analysis. Interpretation, which draws on dominant discourses and cultural sensibilities, is forgotten. In many normative sociological approaches then, disability is made an ahistorical, apolitical and asocial problem of bodies gone wrong.

To sum up, dominant approaches to understanding autism - whether social scientific or bio-scientific - deny autism any social, political or historical location or importance, orienting to disability as a condition of individual bodies. Animated by biomedicine and cognitive psychology, dominant representations and approaches to autism and Asperger’s take perception and interpretation for granted, proceeding as if the perceiving subject and world exist in a relation of direct coincidence (Merleau-Ponty 1962). The scientific viewpoint that animates dominant approaches forgets the entangled space of autism and care as experienced in the lived and living everyday world of social interaction in which power also always circulates.

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Disability Studies and Governmentality Approaches

As previously introduced, interpretive disability studies and governmentality are approaches that provide conceptual and analytic tools with which to study autism and Asperger’s as social, political and historical phenomena (Titchkosky 2000). They provide an alternative to dominant understandings of autism and Asperger’s, orienting toward autism as something that is made – and therefore as something which might be remade - in the space between ‘us’ (Titchkosky 2003, 2007). Since at least the early 1990s, disability studies scholars have joined feminist, queer and critical race scholars in a critique of dominant and objectifying practices of knowledge production and representations, in this instance, of disability (Titchkosky 2000). Within the interdisciplinary field of disability studies, which spans beyond the interpretive approach I am adopting here, scholars in a wide variety of disciplines have utilized diverse theoretical and methodological approaches in order to unsettle dominant understandings of disability as a ‘natural’ category, and to inquire into the ways that disability is achieved in the social spaces between people (Titchkosky 2003; 2007). Tanya Titchkosky writes:

The defining feature of disability studies is establishing a tradition of inquiry that problematizes the ways in which disability is figured against an ahistorical, apolitical and even asocial background. (2007, 38)

Disability is never outside of time and space, rather, it is a political, social and historical phenomenon that has everything to do with the making up of the meaning of people, what Titchkosky calls our “interpretive relation to the human condition” (2000, 217). Establishing itself in critical relation to mainstream academic, professional/therapeutic, scientific and popular narratives which locate disability within the individual body-object, this new disability studies “appears to mark a movement...from a seamless unified concept of disability to disjunctive and
multiple conceptions of disability” (2000, 212-3). As an interdisciplinary field which pluralizes our understanding of modes of embodiment, disability studies “performs the understanding that disability is a social and not a natural category of persons” (Titchkosky 2000, 215). The need for alternative approaches is perhaps best illustrated by way of contrast with the language of bioscience itself. I include an excerpt from the Diagnostic and Statistical Manual of Mental Disorders-IV below, in which autistic symptoms are understood as signs of developmental delay and disorder, giving rise to a long list of impairments for this “new category of persons”:

Figure 2. Excerpt from Diagnostic and Statistical Manual of Mental Disorders-IV, American Psychiatric Association.

299.80 Asperger’s Disorder

(A) Qualitative impairment in social interaction
(B) Restricted repetitive and stereotyped patterns of behavior, interests, and activities...
(C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
(D) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)
(E) There is no clinically significant delay in cognitive development...

14. This approach to disability studies can be distinguished from the UK based social model of disability, founded in 1973 by Mike Oliver and Vic Finkelstein. The social model of disability was established in partnership with the Union of the Physically Impaired against Segregation as a way to counter hegemonic, medical, oppressive and exclusionary versions of impairment/disability/handicap as put forward by the World Health Organization (see Oliver 1996 for further discussion). The social model is built on a separation of impairment as a ‘natural’ biological (medical) condition, and disability, as the social barriers which oppress and exclude disabled people from citizenship (see also Titchkosky 2000, 212 and Titchkosky 2007, 213 for further discussion). This orientation to disability has helped secure important rights for disabled persons, and has been a source of knowledge about the experience of disability oppression (for numerous examples of this approach, see the Disability Archives UK http://www.leeds.ac.uk/disability-studies/archiveuk/). The ‘new’ disability studies in which I situate my work troubles the impairment/disability binary, and is more interested in understanding disability as an interpretive relation within matrices of power and social relationships. Synder and Mitchell (in Titchkosky 2007, 213) call this model the cultural model of disability to distinguish it from the social model of disability. See Lenard Davis’ work on the construction and enforcement of normalcy (1995), Rosemarie Garland Thompson’s work on representations of disability in literature and popular culture (1997), Henri Jacques Stiker’s work on the history of disability and rehabilitation (1999), Niramala Erevelle’s work on racist educational practice and disability (2000), Synder and Mitchell’s work on disability as narrative prosthesis (2000), Rod Michalko’s work on blindness as teacher (2002), Tanya Titchkosky’s work on the textual enactment of disability (2007) and Robert McRuer’s work on queering disability studies and compulsory able-bodiedness (2002) for key examples of this approach.
A disability studies approach is of vital importance in the face of these powerful and “seamless” representations and knowledges of autism and Asperger’s that have the power to classify individuals and populations in terms of “impairments” and “restrictions,” and change the shape of lives.

A governmentality approach unsettles some of our most fundamental and precious truths, including those about embodiment, autism and care. A number of scholars in diverse fields have increasingly developed governmentality approaches to understand diverse phenomenon and trouble the ‘obvious’ under liberal and neo-liberal rule. Kari Dehli (2008) identifies different threads within the field of governmentality studies, including studies which focus on the freedom and obligations of citizenship (Rose 1999), self-management and self-improvement (Cruickshank 1999), “consumption and media as sites of neo-liberal self-government” (Dehli 2008, 59), as well as the racialized nature of neo-liberal government that takes community and the “responsible citizen” as its target (Dehli 2004). Governmentality is an analytics. Mitchell Dean explains it this way:

An analytics is a type of study concerned with an analysis of the specific conditions under which particular entities emerge, exist and change....it seeks to attend to...the singularity of ways of governing and conducting ourselves. (2002, 20-1)

As an analytics then, governmentality provides a way to historicize the presumed ‘naturalness’ of impairment implicit in dominant approaches to understanding autism, as well as the impairment/disability binary explicit within the social model of disability (see footnote 13, pg. 22). This opens embodiment, subjectivity and the organization of caring practices as sites of historical and social inquiry, providing an analytic space from which to consider disability anew.

15. Also see Dean (1999), Barry, Osborne and Rose (1996); Burchell, Gordon and Miller (1991) for further examples of this approach.


Governmentality, Disability Studies and the Study of Autism

Finally, I offer a brief overview of current research on autism and disability within the fields of governmentality and disability studies, focussing in particular on work that has informed the development of my theoretical and methodological approach, which I take up in Chapter 2.

Within disability studies and governmentality, autism as a site of social inquiry/knowledge is just beginning to emerge. In a review of Shelley Tremain’s 2005 edited collection *Foucault and the Government of Disability*, Edward Comstock states the following:

> Given that Foucault himself dealt directly with the histories of ‘feeblemindedness’ and ‘idiocy,’ as well as medical, psychological, and biological deviation in general, some might be surprised that Foucauldian analyses of this kind are not already firmly entrenched in the study of disability. (2008, 112)

Tremain’s collection is notable then, addressing topics from community care, to educational inclusion and the government of public space utilizing an analytics of government. The collection makes a contribution to Foucault studies and challenges the unquestioned naturalness of impairment implied within the social model of disability (Tremain 2005). In particular, Nirmala Erevelles performs an analytics of government around the issue of facilitated communication, cognitive disability and autism, foregrounding what she calls the “crisis of the humanist subject” (46) that issues of competence and disability raise within discourses of modernity. Beyond Tremain’s collection, of key importance is Tanya Titchkosky’s work on the constitution of the “abled-disabled” citizen within government texts (2007). Titchkosky draws on phenomenological and governmentality approaches (among others) to articulate how disability is textually enacted as an “exclude-able type” within discourses of inclusion, the prevailing mode of the governance of disability under Western neo-liberal rule (2007, 150). Bernadette Baker addresses disability using an alternative approach, drawing from Foucault’s work on government, particularly in her work on dividing practices and normalization (2002). Important
work from an interpretive sociological perspective is also starting to emerge on autism specifically, as in McGuire and Michalko’s article that critiques dominant scientific conceptions of Theory of Mind. They propose an alternative focus on autism as a phenomenon that gathers in the social spaces between people (forthcoming). Finally, a major contribution to the study of autism is Majia Holmer Nadesan’s 2005 work *Constructing Autism*. Here, she incorporates elements of an analytics of government and Foucault’s genealogical method, tracing the historical emergence of autism and Asperger’s as new identity categories in the twentieth century. Her research, along with others described in this section, has been formative in terms of fashioning a multivocal rather than singular approach, and I am indebted to them.

Chapter 2 now turns to outline my theoretical and methodological approach in more detail. Rather than offer another ‘official’ account, I draw on governmentality, disability studies and feminist methodology to argue for a situated, multivocal approach that begins from women’s standpoint. This is an approach that begins to rethink the meaning of Asperger’s and care in terms other than those of neuroscience and cognitive psychology.

Chapter 2  Theoretical and Methodological Approaches: A Call to Dialogue

Having established the need for alternative understandings of autism and Asperger’s in Chapter 1, I now offer an overview of my theoretical and methodological approach as one that attempts to understand and care about autism and Asperger’s differently. In a sense, my struggle to understand how my/our modes of engagement with/in the world actualize understandings of autism and embodiment is itself a practice of care. Emmanuel Levinas states the relationship between understanding and care this way:

> To understand being is to exist in such a way that one takes care of one’s own existence. To understand is to take care. Exactly how does this understanding, this solicitude come about? *The phenomenon of the world,* or more precisely, *the structure of “being-in-the-world” presents the precise form in which this understanding of being is realized.* (1996, 18 emphasis in original)

As I work to understand autism and care, I also “take care.” I not only attempt to reflect upon the world, but also upon my own implication in caring practices, modes of knowledge production and potential sites of resistance. Rather than offer the certainty and authority afforded through dominant, ‘seamless’ approaches, I seek to provoke inquiry through a multivocal and situated account, one that remembers the agent of perception and interpretation as well as my own socially inscribed embodiment as researcher. This is a different way to care about autism and Asperger’s. It attempts to take seriously disability studies claim that disability is a social, political and historical phenomenon that always “appears in the midst of other people” and not just in isolated bodies or brains (Titchkosky 2000, 38). With this in mind, this chapter first discusses women’s experience and the experience of autism as rich sites from which to begin the work of social inquiry. This situates knowledge production in real bodies, and “discovers” systemic social relations in this way (Smith 1999, 4). Here, I also justify my methods – textual
analysis and autoethnography – as ones which provide a way to work toward alternate understandings of autism and care. Secondly, I establish the importance of approaches to social inquiry which pluralize understandings of disability. Finally, I identify philosophical influences that shape the way I engage with my two theoretical approaches, and provide more background in terms of their specifics and the critical purchase they afford. Though discussed as separate entities in this chapter, theory, method and methodology are interwoven through the body of my work, together providing a way – a method – to move toward a different manner of animating autism, and embodying and practicing care.

**Methodological Considerations I: Beginning from Women’s Experience**

My desire to understand autism and care began in the uneasiness and contradictions within my life as a single, working mom caring for and about an Asperger’s identified son. Asperger’s and autism is something I care deeply about, yet doing the work of care has meant facing practices which may at times be positive and necessary, but at others are dehumanizing and even violent. This was and is a struggle, not simply due to the difficulty of my son’s autistic ‘symptoms’ or being a single mom, but also in terms of understanding my own complicity in, as well as refusal or inability at times to participate in practices of care. In dispersed sites within the care complex – schools, autism agencies, at home and on the internet – I have struggled to negotiate and understand the invitations and demands to care about autism and Asperger’s in some ways but not others. Privileging the alterity of my son (i.e., challenging the dominant terms of care) or failing to care due to the real materiality of social relations in which our lives are entangled (i.e., an inability to take up care on terms that presume a two-parent family) become moments of transgression or failure that are lived out as a problem, an awkwardness, met with silence or even hostility. Over the course of my Master’s program, I have explored my desire to understand the
contradictions of my experience as well as to care for autism differently through an effort to articulate how my experiences are linked to more systemic and enduring ways in which governing practices are organized around autism and care. At the same time, moments of lived experiences of mothering and alter embodiments act/ed as constant reminders in my life of the tensions and gaps at what I have come to understand as the interstice of power and lived embodiment. Through many discussions in graduate seminars and meetings with Kari Dehli and Tanya Titchkosky, I have come to understand these contradictions and tensions as invitational, a provocation to inquiry and dialogue (Dehli 2008).

As a way to tease out the complexities of my own and other women’s lived experiences, I focus my analyses on textually mediated encounters with caring policies, practices and experiences within various sites of the care complex. According to the *Webster’s Ninth New Collegiate Dictionary*, the word ‘encounter’ has several connotations: to come upon unexpectedly, to engage with an adversary, and to meet face-to-face. This suggests that my attention to mentalities of government alone is not enough to understand autism and care. This project must also pay attention to how these mentalities come to be lived and felt in mother’s lives, at times through the different ways we encounter them, whether as policy, embodied practice or ‘direct’ experience. My use of the encounter is taken at least in part from Sara Ahmed’s work on encountering the stranger in post-coloniality. Though I do not use her analysis of the production of the ‘stranger’ to frame my encounters with autism, I learn from Ahmed that the figure of the stranger (and autism is certainly considered ‘strange’) is one that lurks on the edge of humanity, a threat known to us ‘normals’ (to use Erving Goffman’s term) as that which is not knowable (2000, 3). Indeed, Ahmed states:

> ...the stranger is not *any-body* that we have failed to recognise, but *some-body* that we have already recognised as a stranger, as ‘a body out of}
place.” Hence, the stranger is some-body we know as not knowing, rather than some-body we simply do not know. (55, emphasis in original)

Thus I attempt to describe how mentalities of government come to be lived and felt in mother’s lives through a variety of textually mediated encounters with autism as “body out of place,” and further, how the care complex attempts to make known and governable this “unknown” through science, maternal care and systems of administration, ultimately leaving “some-bodies” behind and re/constituting the normal through such exclusionary mechanisms.

To elaborate further, some of my encounters have been mediated by texts that are pivotal in organizing how care is governed across numerous sites, and in many women’s lives. Policy documents on educational inclusion for example, which I examine in Chapter 3, incorporate inclusion as a mentality of government, making it technical through mechanisms such as developmental history forms or special education placement decision sheets. These are parent forms that in the very act of completing organize a mother’s perception, her “way of seeing” (Hill 2009) autism through the frame of child development, thus organizing how inclusion comes to be lived and felt. Other documents examined in Chapter 4, such as Ontario Program/Policy memorandum 140 (2007c), a memo that universally endorses applied behaviour analysis (ABA) in schools, attempt to translate mentalities of government into lived practices in the lives of mothers and Asperger’s identified children. Still other texts, such as the introductory autism workshop and documentary trailer I analyse in Chapter 5, are more locally situated and specific to my experience, and I use them to consider the ways in which practices of care are experienced as the unending work of normalisation, failure or suffering, for example. Finally, I narrate a ‘direct’ experience of caring for my son at the end of Chapter 5. This ‘direct’ experience is also textually mediated, though perhaps less obviously so, through the many texts of government that define us, and the many textually mediated exposures to dominant understandings of autism and
care I have experienced as a mother. I use this encounter to examine the struggle of living care in the everyday, to animate the openness of the meaning of autism and embodiment, and to suggest there might be alternate ways to write texts and practice care. I use the idea of textually mediated encounters then, to talk about how mentalities of government are lived out and felt in technical, practical and experiential ways as modes of conduct and perception, moments of inclusion/exclusion, as well as suffering, work, failure, desire and care.

Though analytically distinct, I use two intertwining methods to examine textually mediated encounters with caring policy, practices and experience. First, I engage in a close textual reading of the types of documents detailed above. Through this method, I work to extract the “intrinsic logic” (Dean 1999) that animates dominant mentalities of government such as inclusion, as well as dominant understandings of autism and care. I do this through a close textual reading of the way in which mentalities of government are made technical, as well as through an examination of the effects, as opposed to the explicit rationality, of such technologies. Secondly, I engage in autoethnography, a method that works to extract cultural practices and understandings through the narration of lived experience. Aspects of a phenomenological method dwell here. That is, through description I attempt to draw near to care as a relational and embodied phenomenon. I engage this description in a hermeneutic sense in order to explore and disturb the meaning of autism, embodiment and care (Merleau-Ponty 1962, vii-ix). While each method is distinct, there are echoes of one through the other, since I have embodied all the texts I examine (i.e., I have lived them, changed them, fought them, complied with them, been subject to them and of them), as the texts have embodied me (Weiss 2003, 25). They are what Titchkosky calls “texts of embodiment” (2007, 28), the texts themselves as they are taken up (or

18. See Max Van Manen (1992) for a detailed description of this method.
not) through interpretation, and their discursive production sites of meaningful social action organizing, regulating and enacting – “acting on and living with at the level of embodiment” – the meaning of disability, Asperger’s and care (14).

Thus, my methods and methodology regard lived experience as a place to begin social inquiry. These lived experiences are always textually mediated and linked to more systemic and enduring systems of power, though are not reducible to them. Dorothy Smith calls this approach to inquiry “writing the social,” a sociology that begins in the actuality of women’s lived experience, which is always embodied, relational, spatially and temporally located. She says:

Women's standpoint as a place to begin an inquiry into the social locates the knower in her body and as active in her work in relation to particular others. In a sense it discovers the ruling relations. They come into view from where she is in the actualities of her bodily existence, as relations that transcend the limitations of the embodied knower. To explore them from women's standpoint is to recognize them as they enter her/my own experience and in her/my own practices as a knower, reader, and thinker. (1999, 4)

At the same time, lived experience exceeds “ruling relations” of power. We are never outside of interpretation and culture. It is from this embodied and textured entanglement within lived social relations, then, that my approach begins. This is an approach which argues for a situated, local, and always incomplete knowledge, one that recognizes its own participation in the power relations of knowledge production, as well as within the production of the phenomena of autism and care itself (Dehli 2008).

A Multivocal Approach

In this section, I discuss my rationale for drawing from multiple and at times seemingly oppositional approaches, both theoretically and methodologically, to examine autism and care. Each of the traditions I draw on – governmentality, interpretive disability studies, as well as
feminist methodology – afford a different critical purchase within my work to engage a
generative and critical dialogue about power and subjectivity. First, the subject is always
gendered, raced, classed and abled - social relations that are often forgotten in a governmentality
approach alone (O’Malley, Weir and Shearing 1997). I use a feminist methodology as well as
interpretive disability studies to embody relations of power and remember the gendered nature of
care. Further, governmentality studies fail to deal with the recovery of the subject in terms of
her/his interpretation as a source of knowledge – as something to be taken seriously. Thus
governmentality is an approach that does embodiment as something implicitly there, but never
taken into full account. Henri Jacques Stiker, a French disability studies historian and
philosopher influenced by Foucault’s work, teaches us that: “We are always other than what
society made us and believes us to be” (1999, 51). Recognition of the surplus of meaning of
lived experience, which potentially moves us between the discursive categories which fashion
our identities, is an important methodological move afforded by interpretive disability studies, an
approach that remembers interpretation and lived embodiment. In his article entitled “Between
Michel Foucault and Erving Goffman: Between Discourse in the Abstract and Face-to-Face
Interaction,” Ian Hacking argues for a similar approach:

> There is something missing in those [Foucault’s] approaches – an
understanding of how the forms of discourse become part of the lives of
ordinary people...Of course there is something absolutely missing in
Goffman too: an understanding of how the institutions he described came
into being, what their formative structures are...both are necessary. (2004,
278) 19

Between my chosen approaches then, there are moments of tension and resonance that act as
reminders of the complexity at the intersection of power and interpretive subject where I situate

19. I wholeheartedly agree with Hacking’s contention, however, turning to Goffman in particular as representative
of an interpretive approach, rather than also engaging a disability studies approach, may leave remnants of
impairment as something belonging to the realm of nature, while stigma and disability become social processes
made up between people. See my discussion of Goffman in Chapter 1, pg. 18-20.
my work. Each approach highlights different aspects of the phenomenon of autism and care, and together they provide an alternate way to understand and challenge the governance of lived embodiment.

Secondly, this is not to suggest that my approach might finally generate the ‘truth’ about autism, nor that I seek to create another authoritative account of autism and care. There is, indeed, no singular truth or understanding that might be revealed. We are faced today with “seamless” authoritative scientific accounts of disability as a problem of care. These dominant understandings animate our current neo-liberal Western capitalist context of massive ‘caring’ institutions and their antimony - practices of coercion and violence. This paradox may be one of the most pressing we face in our time (Foucault 1994b, 405). One has only to think of public educational systems, for example, which purport to embrace inclusion and equity for all, while simultaneously adopting systemic practices of normalisation which adhere to biomedical understandings of disability as bodies and brains gone awry. Or federal policies of inclusion in the face of publically funded genetic research meant to identify and potentially eliminate populations of disabled individuals. I have come to believe that pluralizing and provocative scholarly dialogue is of paramount importance. Such dialogue can work to disrupt totalizing and ever-restrictive understandings around ways to be human which today define our relation to embodiment and disability. Other scholars too, recognize the need to draw from a variety of perspectives. Feminist disability studies scholar Mairian Corker comments:

You may have noticed that in spite of my ‘self-definition’ as a post-structuralist feminist, I quite readily draw on work that is not part of this tradition. This is because I am uncomfortable with locating myself exclusively within the ‘authority’ of a single epistemological tradition,
as, among other things, I see this to be profoundly anti-feminist. (Corker and Thomas 2002, 27)  

A singular perspective, even a purportedly progressive or radical one, potentially reifies disability. A multivocal approach begins to release autism and care from the grasp of scientific discourse and point to the openness of the meaning of embodiment and care in the face of human vulnerability. It is here, at the intersection of power and the openness of embodiment that an interpreting, agential subject is implied, and new understandings and practices might be fashioned anew. It is here, too, in the face of normalising, exclusionary, and sometimes coercive and violent practices that hope and possibility reside.

**Theoretical Considerations: Philosophical Influences and an Overview of Approach**

In this section I briefly discuss the philosophical influences from which I draw sustenance within my theoretical frames, as well as provide a brief overview of each theoretical tradition. First, governmentality approaches have been developed out of some of the later writings of French philosopher Michel Foucault (see for example, 1982, 1991a, 1994, 1994a). Foucault describes his project as one in which he sought to “create a history of the different modes by which, in our culture, human beings are made subjects” (1982, 208). This was a radical project, as it opened up some of the most foundational truths of his/our time to historical investigation. Foucault’s practice of radical scepticism sought to historicize the rational autonomous subject of liberalism and the human sciences as both an “effect” and a “vehicle” of modern knowledge and power (1982). The interpretive subject was made suspect as the ultimate source of truth and knowledge, as were other “anthropological universals” and universals of humanism - progress, freedom, reason, and so forth (1998, 461; 1991b; also see Dehli 2008). More specifically, Foucault’s

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20. See Titchkosky (2007, 35-7), who also references Mairian Corker, for an excellent discussion on the need to draw from multiple perspectives, as well as Titchkosky (2007, 11-40) for another example of this approach in practice.
genealogies and work on governmentality traces the complex linkages between modern political rationalities (liberalisms), knowledges (human sciences in particular), practices and techniques – an example of which is what I have called the care complex - that make certain ways of being in the world possible, practicable and thinkable, and others unthinkable, in Foucault’s case within Western European culture (Rose 1996; Foucault 1991). This approach provides a way to think about the operation of power and modes of subjectification in our current context and time, disturbing the foundations of some of our most taken for granted practices and so-called truths (Dean 1999). In working to understand autism and care, some of the taken for granted truths I wish to challenge might be science as progress, the imperative of normality, the brain as a knowable object, or the biomedical imperative to treat, for example. In this way, governmentality not only opens up foundational questions, but also affords a space of disruption from which we might identify ways to “refuse what we are” (Foucault 1982, 216) and attend to what has been forgotten within our dominant ways of practicing and perceiving embodiment (Foucault 1980b; 1982).

In brief, governmentality approaches are concerned with regimes of practices, technologies, and tactics of government which think political rationalities into being in practical and programmatic ways (Rose 1996; Dean 1999; Dehli 2004). Foucault considered government to be an ascendant form of modern power, one which is both totalising and individualising, constituting subjects as both objects of knowledge (i.e., as populations), as well as self-governing subjects (i.e., identity as an effect of such power) (1982, 1991a). Foucault says the following about such power:

In itself the exercise of power is not violence; nor is it a consent which, implicitly is renewable. It is a total structure of actions brought to bear upon possible actions; 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. A set of actions upon other actions. (1982, 220)

Government is in this way concerned with the “conduct of conduct,” which “...consists in guiding the possibility of conduct and putting in order the possible outcome...” (1982, 221). It involves not only the shaping of the conduct of others but also what Foucault called “techniques of the self,” or the work of self-governance (1994, 87). To give an example, the expert knowledge of cognitive psychology and neuroscience make practicable the notion that the brain is to be regarded as a mysterious object that must be known. Touted as a rising threat to global health, researchers make every effort to solve the puzzling condition of autism, and work to identify individuals and populations whose brains must be more closely scrutinized. Teachers are invited to heighten their practices of observation and expertise around autism spectrum disorder. Given what Nikolas Rose calls the “gap” between their real child and the norm, mothers, too, are incited to care in particular ways. They are to observe, worry and teach their autistic child and struggle with their very identities as ‘good’ - or not good enough - mothers (1999). Autistic children are compelled into practices of self-governance through programmatic attempts at normalisation, at times meeting success in fashioning new ways of being-in-the-world (i.e., through applied behaviour analysis – see Chapter 4). Governance guides what is ‘possible’ in terms of caring for lived embodiment through the freedom of subjects who act, and equally makes alter modes of care, embodiment and sociality, unthinkable and impracticable – flapping hands, rocking bodies, the touch of alterity. It is important to note too, that for those who ‘fail’ in this game of freedom, more coercive forms of power work to separate and ‘improve’ populations, enforcing freedom through the enforcement of normality (see Chapter 4 for a discussion of the integral relation of practices of coercion and neo-liberal governmentality).
In this way, neo-liberal governmentality is a productive and strategic form of power, working through invitation, seduction and desire rather than coercion, which at times can empower, and at others “forbid” or “constrain” (1982, 220). It is a power which seeks to exercise power indirectly on specific targets (i.e., autistic children, families), through individual freedom and choice, and toward specific ends (i.e., the welfare of the population and the happiness of individuals). The State is understood as de-centralised and dispersed, as opposed to central and coherent, its power an effect of such practices (Foucault 1991a; Rose 1996; Dean 1999). Rather than the sovereign individual, the autonomous modern individual too, becomes the effect and instrument of power (Foucault 1982, 1991a, 1994b; Dean 1991, 2002). Within a governmentality framework, autism can be read as an effect of such power, and not read as simply existing in solitary, mysterious brains. This begins to historicize autism and opens embodiment to questions, one of the key critical strengths I draw on within this approach.

Regardless of how the government of bodies, minds and senses might operate or not, disability does not exist outside interpretation and social action. This understanding is at the core of my second theoretical approach. As I define it here, an interpretive disability studies approach draws on the work of scholars in a variety of fields who have been influenced by hermeneutics and phenomenology. In contrast to an analytic of governmentality, this is a return to the interpreting, relational subject as a key site of social inquiry. Phenomenologist Maurice Merleau-Ponty’s attention to perception and lived embodiment has particular relevance to an interpretive disability studies frame as I define it here. Phenomenology draws us near to “things themselves” (1962, viii), and in my more hermeneutic reading, to the making of meaning of people in the social spaces where body and world converge. The space of the subject incarnate, of lived and living body as it appears in Merleau-Ponty’s work, is inchoate, dynamic, creative and always
incomplete. Perception is reawakened as “the background from which all acts stand out” (1962, xi). That is, this is an approach in which reflection becomes conscious of itself through language as a creative, socially inscribed interpretive act. Here, consciousness is intentional and oriented – related in and to the world and no-thing in and of itself. As a way to notice perception and as a form of perception itself, a phenomenologically informed disability studies affords a way to proceed, a descriptive turn that might reveal something of dominant cultural narratives, and interrupt their implicit interpretive relation to dominant modes of embodiment and care.

Secondly, as a sociologist, my work draws on an interpretive tradition with a long history of understanding social action as a site of meaning-making. Max Weber, an influential theorist within interpretive sociology, and influenced by the phenomenological tradition, says “Action is social in so far as, by virtue of the subjective meaning attached to it by the acting individual (or individuals) it takes account the behaviour of others and is thereby oriented in its course” (1947, 88). We enter a social world not of our own making, our identities, choices and freedom already the effect of power. Yet we create meaning as interpretive beings. For example, my Asperger’s identified son appears before me. I take in his bodily stiffness, his facial tic, or tenacious request for more computer time. As I orient to this appearance of disability, I also orient to “ordinary regimes of sensibility and truth upon which all interpretive acts draw” (Titchkosky 2007, 30). I know this is Asperger’s Syndrome, a ‘disordered’ brain in need of a particular kind of care. I know the morality tale of the ‘good’ mother who must act and respond to this appearance of an alter embodiment in already determined ways. I am to make the disordered brain knowable through reporting what I observe, control the vulnerability of the mysterious brain through medication of his tics, refuse my son’s intense concentration and teach him to make transitions in a normative way. While I may indeed care in some of these ways, in the social space between my
son and I there is also interpretive openness and creative possibility. I might refuse dominant understandings and reorient to something new. Hannah Arendt, a political theorist writing against totalitarianism in post World War II Germany, calls this natality, and describes it this way:

With word and deed we insert ourselves into the human world, and this insertion is like a second birth, in which we confirm and take upon ourselves the naked fact of our original physical appearance...It may be stimulated by the presence of others whose company we may wish to join, but it is never conditioned by them; its impulse springs from the beginning which came into the world when we were born and to which we respond by beginning something new. (Arendt 1958, 176-7)

Meaning is ascribed to our bodies through our culture’s narratives. But we also take up those narratives and act. We begin something new through our actions as discursively constituted yet interpreting beings (Arendt 1958, 8-9). Within this embodied space where body and world converge, new understandings of autism and care are possible. If we accept Levinas’ assertion that “to understand is to take care” (1996, 18), then the multivocal approach which I have tried to fashion here is also a way to take care of autism and Asperger’s differently.
Chapter 3  Mothers and Schooling: Inclusion and the Making of “Young Citizens”

In this chapter I ask how the governance of autism and lived embodiment under neo-liberal rule is made technical, focussing on educational policies of inclusion in Ontario. In particular, I examine how the conduct of mothers as individuals and populations is regulated, governed and technologized by inclusion as a new way of thinking about disability. I examine policy and make use of some of my own textually mediated encounters with these technical forms of inclusion as they have shaped my practices of identity, perception and desire. Mothers are not only drawn into providing care as primary caregivers, but are also compelled to become experts in our own self-governance and the governance of our Asperger’s identified children. This implies that the “conduct of conduct” around lived embodiment is organized, in part, through inciting the desire and caring work of mothers within the family and other institutional sites. Thus inclusion comprises an emergent form of neo-liberal governmentality, one that circulates together with discourses of parental involvement, compelling mothers and families into the political work of “making up” young citizens.\(^{21}\)

To situate my work, I turn to that most salient of childhood contexts – schooling. Schooling has been a central site through which my caring work as a mother has been organized and embodied. It is in and through meetings and conversations with school officials, for example, that my failure to practice care ‘appropriately,’ or the suffering of a family – our ‘private’ journey of success and defeat – is made real. Here, I work to untangle some of the singularities and local specificities which assemble the school and family as part of the care complex in Ontario and Canada today - that ever-shifting web of expert knowledges, practices,

\(^{21}\) See Chapter 1, pg. 9 for an explanation of how I am using this term.
local institutional sites, identities, technologies and relays that organize the work of mothers as well as the meaning of autism and care. As ascendant mentalities of government, inclusion and involvement make explicit claims of empowerment, equity, parental choice and participation. These claims compose the rationality that drives policies and programs of inclusion and involvement. Yet this chapter shows that these claims are made in the face of an “intrinsic logic” that seeks to accomplish ever-restrictive, implied and normalised versions of citizenship – that of the enterprising, productive, autonomous citizen (Dean 1999; Rose 1996). This mode of governance is on one level about efficiency: opening systems of administration to the implications of alterity would mean costly and radical change. At a deeper and more existential level, this mode of governance also betrays western culture’s devotion to science as a way of knowing and our enduring distrust of that which cannot be scientifically known: embodied difference and the challenge of alterity (Michalko 2002).

It is important to note that the “intrinsic logic” of inclusion and involvement is intentional but not subjective, in the sense that it is not consciously intended by the actors who live it. In fact, there are countless caring professionals and families who are invested in the explicit rationality of inclusion – equity and justice - with the best of conscious intentions. In terms of autism specifically, the logic of inclusion seeks to normalise alternate modes of embodiment, communication and sociality, including autistic children as Titchkosky’s “exclude-able type” within the educational project. In other words, says Titchkosky:

...each and every programmatic attempt to institute inclusion is, at one and the same time, making disability materialize in particular ways, ways that perpetuate and support often unexamined conceptions of disability. (2007, 150)
To return to the case of Asperger’s and autism, the brain as a mysterious entity which can and must be known through the expertise of science, and ultimately governed, undergirds policies of inclusion as well as programmatic attempts at normalisation.

I focus my analytics on recently emerging Ontario educational policy as texts which attempt to think inclusion into being in embodied, material and programmatic ways. Policy is a key textual site through which the logic of mentalities of government is both embedded and bodily enacted (Titchkosky 2007, 28). In the case of autism, this entails practices of heightened surveillance over the mental, emotional and social life of the child through mothers’ participation in programs of inclusion, as well as in their own self-governance. For example, Ontario regulations such as O. Reg. 181/98 Identification and Placement of Exceptional Students (2005) are texts that attempt to make inclusion technical. They provide a way – a technology - to attach new identities to individual children and create new populations within the schooling context. These texts are integral in the organization and governance of autism and care at both a lived and more systemic level. Animated by cognitive psychology and neuroscience, regulations and policy like that of 181/98 govern how disability and maternal care are ‘thought’ in practicable ways, as well as what is possible – and what is not - at our historical juncture in terms of doing autism and care – living it out at the level of embodiment. My son’s non-normative way of negotiating school time, academic work and sociality, for example, were ‘flagged’ for early psychological assessment and identified as knowable types - ‘autism’ and ‘giftedness.’ He was placed within a special program meant to intervene in and normalise his conduct, his development gone awry. His alterity was to be reformed – a rather hopeful and utopian end of programs of conduct such as these - and to achieve it my mothering practices at home and in the

22. Also see Titchkosky (2007) for an analysis of inclusion as today’s ruling mentality, particularly as it is explicated in the Canadian context within federal disability policy texts such as In Unison.
school were to be brought into line so that my son could eventually be included back into the ‘regular’ gifted classroom, this time on normality’s terms (Griffith and Smith 2004). Here, the unknown of alternate ways of being in the world, which implies a deep and enduring mystery about ways of being human, is individualized and made knowable as a problem of governance, one located within solitary ‘defective’ brains.

This chapter first provides a context for the emergence of inclusion and parental involvement/maternal care as new mentalities of government within recent economic, political and cultural shifts, new intelligibilities of globalisation (i.e., competition, privatization) and global educational reform. Next, I trace some of the specificities in terms of the recent emergence of new educational categories as integral to neo-liberal governance. This is boundary work: an examination of how the very meaning of being human is one that is currently, and constantly, in flux. In particular, I concentrate my analytics on one new category of student – gifted/autism – within what is being called a special education “transformation” in Ontario (Ontario Ministry of Education 2005, 2006b; Ontario Minister’s Advisory Council on Special Education, 2005). As the mother of an Asperger’s/gifted identified son, this situates me in the phenomenon I study, as well as in the production of knowledge about Asperger’s and care. At the same time, it is reflective of my desire to offer alternate understandings of Asperger’s and care by revealing some of the linkages between local, situated experience and more systemic and enduring ways of organizing care and our interpretive relation to embodiment (Smith 1999).

Next, I perform an analytics of Ontario policy texts that attempt to think inclusion and involvement into being in programmatic and practical ways. Thus I study power as something that is productive, fragile, shifting and even contradictory at times (Foucault 1982). While the aim of this chapter is to reveal the intrinsic logic of inclusion as it operates within the care
complex, interpretive disability studies will return me to the way in which power is also always enacted at the level of embodiment. At the conclusion of the chapter I remind the reader of this key issue, one that echoes beneath the surface here: that of the interpretive subject as something that can never be completely “governmentalized,” or captured, by power’s reach (Butler 2004, 317).

**Inclusion, Involvement and Neo-liberal Governance**

Within the context of globalising imperatives as well as “…changes in the organization of contemporary economic, cultural and political relations” (Dehli 2004, 45), westernized nations have witnessed, among other shifts, educational reforms that have paralleled new intelligibilities of globalisation – competitiveness, productivity and marketization (see Rose 1999). This has effected programs of reform that draw from dominant understandings of child development in an attempt to “help students develop into highly skilled, knowledgeable, and caring citizens who can contribute to both a strong economy and a cohesive society” (Ontario Ministry of Education 2009; also see UNESCO 2000). At the same time, resources within classrooms have dwindled and the development of both academic and social curricula has increasingly come under centralized control. With this shift in governance, the capacity for autonomy, enterprise, competitiveness and “social competence” (Ontario Ministry of Education 2003, 30) has come to be understood as tantamount to the happiness, well-being and productivity of individuals, communities, families and nations (Dehli 2004).

In terms of the ‘problem’ of the rising incidence of autism in Ontario schools, the most recent Ontario Ministry of Education policy initiative, *Developing and Implementing Equity and Inclusive Education in Ontario Schools* (2009), clearly defines this shift in governance. Specifically, it gathers previous reform efforts such as parental involvement, character education,
anti-racist education, applied behaviour analysis or tiered approaches to school discipline within one framework (see Ontario Ministry of Education 2006b; 2007b, 2007c; 2008). The policy mandates inclusion as the preferred and increasingly global approach to human difference, one that “supports and reflects the democratic values of fairness, equity, and respect for all” (Ontario Ministry of Education 2009). Inclusion is to be achieved in partnership with families and communities and through scientifically informed programs of reform aimed to reduce “gaps in student achievement” and prepare students “for their role in society as engaged, productive and responsible citizens” (2009). In other words, given women’s continued role as primary caregivers, inclusion is to be achieved through the caring work of mothers and on normality’s terms. Exclusion – when mothers and children fail - is an unspoken presence beneath the surface here.

Since the 1990s, a government-initiated intensification of parental involvement in Ontario schools along with the move toward educational inclusion, have come to be understood by governors and governed alike as the preferred solution to educational problems like Asperger’s and autism. Indeed, the Council of Ontario Directors of Education (CODE), the professional organization for CEOs of Ontario district school boards, recently called for a system wide “refinement” of “system and school practices regarding parent engagement” targeted specifically at parents of “students with special needs” (2007). This initiative reflects shifts in the educational governance of disability under neo-liberal rule, including the marketization of education and new relations between mothers as primary caregivers, families, communities and schools:

Actively engaging parents of students with special needs increases opportunities to plan effectively for the student, creates successful pathways for academic success, and builds upon the community links and partnerships necessary for that child and his or her family. (CODE 2007)
In other words, new modes of neo-liberal power have emerged in schools for “special education” students and families in uneven, incomplete yet ascendant ways (Dehli 2004, 45). Inclusion and involvement are governmental, reconstituting educational identities and imagining into practice the improvable and autonomous gifted/autism student and the active, engaged caring special education mother, now an educational partner and consumer within the new education marketplace (Rose 1996; Dean 2002; Dehli 2004; Ontario Minister’s Advisory Council on Special Education 2005). While dominant understandings of child development continue to saturate pedagogic practice and educational space (Walkerdine and Lucy 1989; Walkerdine 1998), they have been resituated in distanitiated relations such as “school-family-community partnerships” (Dehli 2004, 46; Rose 1996). Thus, new relations under neo-liberal rule have emerged between mothers, families, expert knowledge, the state, the market and schools, as “...sites of governance that enlist the participation of individuals, families and local communities in their own regulation in new ways” (Dehli 2004, 47).

Importantly, feminist scholars and disability rights activists have demonstrated that the restructuring of social, economic and political relations post-welfare state (as touched on above) has also effected a (re)feminization and shift of care from state institutions and agencies (back) to the family and community. Thus there has been a return of care to the realm of the ‘private’ family, a shift that is both gendered and classed (Brodie 1995; Walkerdine and Lucy 1989; Walkerdine 1998; Rose 1999). While feminist scholars often emphasize the oppressive nature of care work and disability, or seek to grant the everyday work of care a more central place in academic research (see, for example, Allen, Klein, and Hill 2008), disability activists often emphasize the need for a consumer and rights-based approach in order to ameliorate oppressive and medicalized structures of care (see Boyle 2008; Ellis 2005; Gadacz 1994). Rather than
attempt to resolve the tension between these two approaches, I develop their insights to better understand how shifts in the governance of lived embodiment – inclusion and parental involvement - effect an intensification and reimagining of mothers’ caring work within families, schools and communities, and consequently a mother’s role in the enactment – and potentially in alternative enactments - of the very meaning of autism, embodiment and care (Brodie, 1995; Griffith and Smith 2004; Walkerdine 1989; Rose 1996; Dean 2002).

Like the middle-class mothering discourse revealed in interviews with mothers by Griffith and Smith (2004), inclusion and the parental involvement seek to align home-based practices with normalising educational practices, purportedly for the good of the child. For example, as the “good” and involved mother, I have been invited to support school efforts to shape my son’s behaviour through the practice of applied behaviour analysis. Applied behaviour analysis (ABA) has recently been endorsed as “best practice” in Ontario (Ontario Ministry of Education 2007c). From various sites within the care complex – autism agency-school partnerships, for example - I have been taught techniques of the approach. These are ones that ‘see’ behaviour through a perceptual grid of developmental and behaviourist psychology. As such, I have been instructed in a particular kind of maternal care: exacting observations and normative judgements of my son’s behaviour, along with calculated responses that align with dominant practice. Yet as a single mom of an Asperger’s identified son, I often fail at being this good mother. Certainly, my middle-class background and anxiety to help my son has found me uncritically practicing not only ABA, but also “sensitive mothering” - a fine attunement to my son’s so-called developmental needs, a transformation of power in the home into reason and play and domestic labour into pedagogy (Walkerdine and Lucy 1989). Despite this, my son and I perpetually fail to achieve the appearance of normalcy. What inclusion and involvement obscure
is not only the gendered and classed nature of care, but also the stubbornness of alterity and the regulation of mothers through moral imperatives about the “good” and “responsible” mother as one who is always financially and temporally available to support her child in ways that align with normative imperatives (Griffith and Smith 2004). For those of us who (inevitably) fail, exclusion, moral judgement, coercive practices and even violent actions result, a topic I expand on in Chapter Four.

Thus under neo-liberal governance, the “making up” of active and engaged citizens in schools has become synonymous with a mother’s care and moral regulation, as well as with her obligation to work for the economic well-being and happiness of individuals, communities and nations (Dehli 2004; Rose 1999; Walkerdine 1998). Long before school begins, mothers are instructed in this work of care, through parenting and autism literatures for example, as guided by cognitive psychology and neuroscience, and within a market of so-called free choice. In this way, mothers are charged with the task of “closing the gap” between the requisite of normalcy – a seductive image - and the real autistic child who stubbornly appears in front of us. Working to close what I would suggest is an unbridgeable gap elicits deep guilt and anxiety and fevered searches for expert help. More specifically, it elicits a deep desire to achieve the appearance of normalcy in our child, and perhaps more fundamentally, a desire to belong that is articulated on normality’s terms. Nikolas Rose identifies this “space” (1999, 153) for all mothers between actual children and dominant images of normalcy - Donzelot’s “regulation of images” (1979):

> The representations of motherhood, fatherhood, family life and parental conduct generated by expertise were to infuse and shape the personal investments of individuals, the way in which they formed, regulated and evaluated their lives, their actions, and their goals. (1999, 131)

This “regulation of images” is articulated somewhat differently in the matter of autism and Asperger’s. We – mothers of Asperger’s identified children – must achieve the appearance of
normalcy in our child through the *recovery* of a lost and broken child. This is to occur through practices of care informed by a particular market of expertise about the brain as a knowable and governable object. As for all mothers though, we are compelled through a desire for normalcy and within a market of ‘choice,’ as organized in and through the so-called natural and private family (Rose 1999). Both the family and mothers have become key instruments of neo-liberal governance in this way (Donzelot 1979; Rose 1999). Thus ascendant mentalities of government— inclusion and involvement - under neo-liberal rule link the ‘private’ caring work and desire of mothers in families and schools to the political and moral task of remaking the nation through the fashioning of productive, enterprising *normal* citizens.

**A Special Education Transformation**

Before turning to an analytics of Ontario policies of inclusion, this section elaborates the “transformation” in special education in Ontario as it relates to some of the larger issues of governmental power touched on above. Indeed, within the context of neo-liberal rule, the question of educating special education students, as well as the roles the governed and the governors were to play (i.e., students, teachers, mothers, schools), began to be “problematized” in new ways (Dean 1999). Advisory committees, working tables, and expert panels assembled in new instrumentalities of accountability (i.e., community partnerships comprised of nominated or appointed representatives from multiple disability groups), re/imagined inclusion within both educational policy and practice (Rose 1996; Ontario Ministry of Education 2005, 2006b, 2007a; Ontario Minister’s Advisory Council on Special Education, 2005). By the early 2000’s in some Ontario urban schools at least, children identified with multiple categorizations of neurological disability – Asperger’s Syndrome, Tourette’s Disorder, Learning Disability, ADHD – were increasingly being included within gifted classrooms. Historically, entrance to gifted programs
required that students meet a prohibitive and restrictive standard of intelligence (based on the expertise of cognitive developmental psychology), as well as meet restrictive definitions of student: high superior scores on traditional (gendered, classed, raced, abled) intelligence tests, and superior work habits (i.e., an ordered, docile body). Disabled youth are now accommodated during gifted testing, and changes have been made to gifted criteria (i.e., lower overall test scores for learning disabled and ESL youth, discontinuation of a work habits requirement, broader measures of giftedness, including parent input). Previously concerned with the creation of separate special education programs, which in effect contained this diverse population, new special education directions have sought instead to manage this population in new ways (Ontario Ministry of Education 2006b). Access has been redefined in terms of the inclusion of the special education population within academic and social targets and mainstream classrooms. As previously stated, academic and social targets are determined in reference to centrally controlled academic and social standards drawn from cognitive developmental psychology (Ontario Ministry of Education 2005, 2006b; Ontario Minister’s Advisory Council on Special Education 2005). Mothers are to take up the work of inclusion through forms of involvement that align with these new educational objectives and identities (Griffith and Smith 2004). Autistic individuals, too, are to do the work of inclusion through the development of capacities that align with new versions of citizenship as the autonomous, self-regulating, productive individual.

Inclusion and involvement are thus both a totalising and individualising form of power, demarcating new populations as well as attaching new truths and identities to individuals through the expertise of cognitive psychology and neuroscience, effectively “making up” new kinds of people (Hacking 1996, 1; Foucault 1982). They are a mode of governance that relies on the self-governance of mothers and autistic individuals in the achievement of a new kind of citizenship in
ways that practically effect the imperatives of neo-liberal capitalist rule. For my purposes in this chapter, I want to emphasize that this is a *fundamental shift* in terms of the modes and ends of government, technologies used, educational identities, as well as relations between the governors and the governed, within education in Ontario. While historically and locally specific in its modes of implementation, similar special education policy reforms, which seek to redefine the accomplishment of inclusion in fundamental ways, seem to be occurring within international educational policy-making agencies, as well as within other western countries (Dehli 2004; Krisjansen and Lapins 2001; UNESCO, 2000).

I turn now to an analytics of key policy texts that embody and enact the logic of inclusion and parental involvement within the current special education transformation in Ontario. I work to open up some of complex ways in which these neo-liberal forms of power circulate together in schools in and around the new special education category of student in particular – gifted/autism – inviting, compelling and obliging mothers and families to take up practices of care in ever-restrictive, normalising as well as intensely personalised and privately felt ways. I concentrate on documents from one large urban school board in which my son attended school, and where I have as a result had encounters with the incitement to care in some ways and not others. I am also a teacher in this board. I am therefore in a situated and living relation to these documents. These texts attempt to programmatically enact policies of inclusion and involvement within a local context, practically effecting new identities, populations, knowledges and articulations of autism and care. I begin with policies of early identification as a key strategy of educational inclusion. Following this, I examine the Identification, Placement and Review Committee in more detail, a

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23. Since I: 1) do not identify individuals, 2) did not participate as a mother or teacher with the intention of performing research, 3) anonymize my personal experience within a broader analysis, and 4) conduct my analysis utilizing publicly and readily available (via public websites) educational policy, process and procedures, my work meets the ethical requirements of the *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans*.
provincial regulation made technical within local school board policy. To analyze these sites within the care complex, I work along four “dimensions” as described by Mitchell Dean (1999), and as based on the work of Deleuze. Dean states:

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. (30-32)

In what follows, I allow these related axes of analysis to weave in and through each other in order to reveal what is a deeply embedded normalising logic within Ontario policies of inclusion.

**Ontario Policies of Inclusion**

**Early Identification**

In terms of Asperger’s, children and families are not often subjected to a process of diagnosis or identification before a child enters school. In the context of classroom routines and playground rules, behaviours that previously appeared as ‘troubling’ or ‘quirky’ take on a more threatening tone. They become ‘symptomatic’ of something wrong, something to ‘watch out for.’ Similarly, mothering practices are opened to closer and more formal scrutiny when a child enters school, potentially transforming a mother’s care into failure – her failure to achieve the appearance of normalcy in her child. Importantly, the grid of calculation through which such judgements are made by actors in schools is determined by dominant forms of knowledge production and understandings of child development. For example, developmental norms animate curriculum policy documents, and in later grades, documents such as *Choices into Action: guidance and*
career education program policy (Ontario Ministry of Education 1999, 2003). As soon as a child enters school, curriculum policy directs mothers and teachers to compare an individual child’s development against developmental norms. Indeed, the kindergarten curriculum has an entire section devoted to “personal and social development.” Here, the required achievement of “social competence” is defined in normative terms, as independence, self-regulation, responsibility, empathy (i.e., turn taking and eye contact) and social skills (Ontario Ministry of Education 2003, 30). Within curriculum policy documents, mothers are told that “social competence” is something “children will need in order to play a constructive role as citizens,” and further, that it can only be achieved in establishing an early “partnership with the home” (2003, 30). From the outset, mothers are brought ‘into line’ as key partners in processes of early identification.

Early identification was one of the first educational policy directives following Bill 82 and the establishment of “universal access” to education in 1980 (Ontario Ministry of Education 1982). Bill 82 amended the Ontario Education Act to establish that every child has a legal right to attend a publically funded school (Ontario Ministry of Education 1982, 2006b, 1). Two years later, Policy/Program Memorandum 11 – Early Identification of Children’s Learning Needs – stipulated that school boards must adopt procedures to identify each child’s “level of development” upon entry to school (Ontario Ministry of Education 2000, 6; 1982). Further, the Ontario government now requires that a board’s Special Education Plan include the following statement:

...these procedures are a part of a continuous assessment and program planning process which should be initiated when a child is first enrolled in school...and should continue throughout a child’s school life. (Ontario Ministry of Education 2000, 6)

Thus with the emergence of “universal access” and “inclusive education” as ruling educational mentalities, early identification was incorporated as a key strategy. Policy and supporting
documents on early identification describe key technologies, the IPRC process for example, to be used to flag “exceptional” students and programme early interventions meant to accomplish inclusion. While the explicit rationale of inclusion and early identification is that of welcome, belonging, fairness and equity for “students with exceptionalities,” its intrinsic logic is that of normalisation (Ontario Ministry of Education 2009; Toronto District School Board 2009). It is a strategy that seeks to capture and eradicate “exceptions” to norms of development as early as possible.

The early identification of ‘problem’ children along with programmes of reform involving the ‘expert’ education of mothers is nothing new. Indeed, over the past century so-called absent working class mothers of ‘delinquent’ children or ‘frigid’ autism moms, for example, have variously been subject to close psychological scrutiny and programmes of expert reform (Nadesan 2005, 69-70, 97-99; Rose 1999, 160-181; Walkerdine and Lucy 1989, 29). But by 1982 and the release of Policy/Program Memorandum 11, the language and terms of a mother’s involvement in her child’s development had changed. Under neo-liberal rule, discourses of sensitive mothering and cognitive developmental psychology began to emerge in educational policy as self-evident ‘truths’ as well as in increasingly individualizing terms:

Each school board is required to have approved...procedures to identify each child’s level of development, learning abilities and needs and to ensure that educational programs are designed to accommodate these needs and to facilitate each child’s growth and development...Teachers in consultation with parents must strive to know each child as soon and as thoroughly as possible in order to provide learning opportunities that will help each child. (Ontario Ministry of Education 1982, 1)

It was through a scientifically animated grid of perception and calculation, one that would now include a mother’s sensitivity and attentiveness to individual children’s so-called developmental needs, that exceptional children should be identified and programmes of reform implemented.
On science as a grid of perception, Nikolas Rose says, “The perceptual system of a science, the gaze it constructs for itself, and which makes it possible, is one in which the world impinging upon our senses is normalized in the very act of becoming perceptible” (1999, 150). This is a “gaze” that normalizes, bringing children into view as vulnerable to the dangers of development, and mothers as technicians requiring the expertise of science to govern themselves and intervene in their child’s development effectively. Thus a new way of ‘seeing’ had been embedded in educational policy, and enacted within its multifarious and local incarnations within families and schools. Normality had become an achievement, one “necessitating continual nurturing and surveillance” by mothers and teachers alike (Rose 1999, 203; Walkerdine 1998).

It is important to point out that individualizing the terms of identification and intervention also individualizes a mother’s so-called failure to achieve normalcy in her child, and indeed constitutes disability itself as an individual appearance of failure. Under neo-liberal rule, as the responsibility to normalise children has increasingly been returned to mothers in the context of the ‘private’ family, the capacity to normalise children has been located within maternal practices themselves, and naturalised within a particular kind of scientific and sensitive mothering. This blames mothers, disabled individuals and communities who ‘fail.’ Early identification is a tactic that obscures social relations of class, race and gender, as well as the larger socio-political context of declining resources and centralized control of academic and social standards in schools (Dehli 2004, 57). From its inception, “universal access” to education has meant that inclusion must be achieved and constantly re/achieved on normality’s terms, and in large part through the caring work and self-governance of mothers. The social and interpretive nature of categories such as Asperger’s, the stubbornness of alterity and incomplete reach of
power in the government of interpretive subjects are aspects of disability and care lost within the democratizing vocabularies and normalising technologies of inclusion and care (Butler 2004).

**The Developmental History Form**

An example of a technology that seeks to make early identification practicable is the Toronto District School Board’s (TDSB) *Development History Form* (Toronto District School Board 2009, 146-151). This form acts as a screening mechanism for any signs of ‘abnormal’ development in children entering public schools. Its completion by parents is mandatory for all kindergarten to grade 2 students (Toronto District School Board 2009, 22). The *Developmental History Form* betrays an unquestioned truth in both its title and content: that of a scientifically determined, universal and normed trajectory of physical, social and cognitive development. For example, as primary caregivers and the most likely parent to be filling out the form, mothers are asked to recall their child’s preferred pattern of play. An implied norm of social development animates this question as well as the available answers, which range visually on the page from “alone” to “with others” and finally to “both” (see Figure 3). Children who appear “alone” are both *textually and in practice* (i.e. during playtime) brought into ‘view’ as literally *outside of normal development*. Recall Lorna Wing’s 1981 description of Asperger’s Syndrome as involving core impairments in social interaction and communication (Wing 1981, 1988). Further recall “qualitative impairment in social interaction” as central to the diagnostic criteria for

*Figure 3. Excerpt from Developmental History Form, TDSB Special Education Plan 2009, pg. 150.*

<table>
<thead>
<tr>
<th>21. Does your child prefer to play?</th>
<th>Alone</th>
<th>With others</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Asperger’s Disorder as set out in the Diagnostic and Statistical Manual of Mental Disorders-IV.

Finally, consider the excerpt below (Figure 4) from a gifted checklist for teachers published by the TDSB. This checklist may one of the “next steps” for students who appear “alone” on the Developmental History Form. Not only do ‘symptoms’ such as the preference for solitary play get read back through dominant perceptual grids as abnormal, then, and potentially as

Figure 4. Excerpt from Indicators of an Unusually Advanced Degree of General Intellectual Ability, TDSB Special Education Plan 2009, 152.

<table>
<thead>
<tr>
<th>Need to address emotional issues that relate to giftedness</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Student has no friends with similar interest.</td>
</tr>
<tr>
<td>□ Student is frequently alone doing academic pursuits.</td>
</tr>
<tr>
<td>□ Student does not participate in peer group activities involving sports or other areas in which student does not achieve (reflection of perfectionism).</td>
</tr>
</tbody>
</table>

‘symptoms’ of Asperger’s or even giftedness, but the very act of early identification on forms such as the Developmental History Form checklist fashions and enlives the facticity of autism, giftedness and cognitive psychology as somehow natural and self-obvious ‘truths’ (Walkerdine 1998). As such, the Developmental History Form and checklist are examples of technologies that close off space for alternate sociality in both theory and practice. Further, they endeavour to capture abnormal development in children early as a first measure in the process of educational inclusion, one that increasingly relies on the caring work of mothers within normalising interventions in schools (Ontario Ministry of Education 2007a).

The self-governance of mothers is a pivotal tactic within power relays between dominant knowledges and technologies of rule, relays that seek to define authority and constitute rule. Indeed, given the gap between normality and the child who appears to us daily, mothers are all but invited to worry and wonder about their child’s development as they fill out the Developmental History Form (Rose 1999): “Why are they asking me this?” “Should I be doing something differently?” “Which answer is right?” “Is my child normal?” Certainly, these are all
questions I asked myself as I filled out the form for both my non-Asperger’s and Asperger’s identified son. The very act of filling out the form invites mothers, as primary caregivers, to ‘see’ their child through the perceptual grid of a development discourse and to judge and calculate their past, present and future actions according to these embedded developmental norms. For example, mothers are asked to complete a series of questions about their child’s social, emotional, language and physical development, as well as questions about their child’s involvement in outside activities (or rather, the financial and other access a mother might have to outside activities). For each of these questions, mothers are asked to “provide details,” “explain,” “list,” “comment,” and reveal information about “medical/health information,” formal testing, medication, diagnoses, and involvement in outside autism agencies, for example (Toronto District School Board 2009, 146-151). In other words, a mother must justify and judge her practices of care not only through the perceptual grid of development and scientific expertise, but through the discourse of sensitive mothering.

It is in this way that the Developmental History Form can be understood as a distantiated technology of rule, a textually mediated relay between political “centres of calculation” (Barry, Osborne and Rose 1996, 13) and the ‘private’ hopes, fears, and practices of mothers at home and in schools. On such relays of power, the authors of Foucault and Political Reason state:

These notions of technology, in the sense of complex and heterogeneous relations amongst disparate elements, stabilized in particular ways, enables us to reconnect, in a productive way, studies of the exercise of power at the “molecular” level – in schools, prison cells, hospital wards, psychiatric diagnoses, conjugal relations and so forth – with strategies to programme power at a molar level in such “centres of calculation” as the Cabinet office...or the enactment of legislation. (Barry, Osborne and Rose 1996, 13)
The Developmental History Form is thus one technique that links “strategies to programme power at a molar level,” through policies of early identification and inclusion for example, with a technology of self-governance: the daily practices, concerns and care of educational actors and mothers in families and schools. This is a generative technology, a site of teacher and parent concern, communication and follow-up meetings, a textual and practical enactment of both ‘normal’ and ‘abnormal’ populations and individuals in schools, and a gathering point for both a mother’s worry as well as her involvement in (along with a host of ‘experts’) and even potential resistance to school and home-based normalising interventions of educational inclusion. Through a mother’s desire and ‘will to normalcy,’ then, the intrinsic normalising logic of inclusion is enacted, and the deep mystery of human vulnerability and alterity made both knowable and manageable in schools.

So far, I have considered how linkages between dominant knowledges and technologies and tactics of rule form shifting relays between power centres and local sites of governance within the care complex. These are the sites that mothers find themselves in as they negotiate their “everyday” lives with their autistic child. I would like to shift my emphasis now to consider how the formation of identities, both individual and collective, constitutes an additional axis of power that operates together with knowledges and technologies to establish realms of authority. Identity categories like Asperger’s and giftedness are fashioned in and through regimes of government. They come to appear as truths about individuals and populations, and are integral to the administration of programmes of government and practices of self-conduct in this way. As previously described, Foucault elucidates this mode of power, one which both individualises and totalises, as governmental:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches
him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power that makes individuals subjects. There are two meanings of the word *subject*: subject to someone else by control and dependence, and tied to his own identity by a conscience of self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to. (1982, 212 emphasis in original)

We make ourselves and are made through these categories as certain kinds of individuals and populations, ones that are at times the target of intensive programmes of government and reform (Hacking 1996, 1999; Dean 1999). Asperger’s is a salient example, as the scientific terms of identification and diagnosis increasingly become accepted as ‘truth.’ Technologies such as the *Developmental History Form*, alongside programmes of reform like early identification and educational inclusion, depend on these identity categories for their operation. Without denying the embodied ‘reality’ of autism, it is interesting to point out that western culture seems to have forgotten that Asperger’s is a recently assembled category of individual and population, one which seems to resonate with a number of our other modern fascinations: the mysteries of the human brain, the computer age and the coming of the cyborg, as well as a belief in ‘childhood’ as its own entity, with its own development and thus its peculiar abnormalities (Nadesan 2005; Aries 1962; Tyler 1993).

To return to the *Developmental History Form*, students with ‘autistic symptoms’ or ‘gifted tendencies’ are *already there*, embedded within the questions asked about playing alone and cognitive development, and thus are both textually enacted *and* targeted for improvement by them. The spectre of the ‘normally developing’ child haunts the *Developmental History Form*. This child is the preferred and prefigured citizen of tomorrow that *all* children must strive to become in the name inclusion, as captured in one school board’s mission statement:

The mission of the Toronto District School Board (TDSB) is to enable all students to reach high levels of achievement and to acquire the
knowledge, skills, and values they need to become responsible members of a democratic society...This responsibility extends to our students with exceptionalities, those who have additional social-emotional, physical, developmental, or learning requirements. (2000, 9)

The normally developing child has a capacity for language, a predictable pattern of development and normatively expressed “social competencies” and skills: empathetic eye gaze and turn-taking, autonomy and independence. In this way, students identified early are subjects of and subject to intervention through processes of educational tracking, identification, and heightened ‘parental’ involvement. The active, engaged special education mother is also contained within the questions appearing on the Development History Form. This is special education’s version of the ‘good’ mother – one who acts in alignment with educational objectives. She has the temporal, linguistic, financial and other resources to be integrally involved in her child’s development both before and after her child enters school. This mom reads to her child nightly, attends parenting centres, enrolls her child in nursery school and transports her child not only to and from after school lessons, but also to and from medical appointments and therapies. She is attuned to her child’s development, and is ready to seek the guidance of experts. In other words, the ‘good’ special education mother is one that seeks “extensions” for the becoming person. In this way, the mother who does not practice this kind of conduct is subject to scrutiny through the Developmental History Form, and targeted for improvement along with her autistic child.

Policies of early identification, made technical by diagrams of power and technologies like the Developmental History Form, are a key strategy of inclusion. As articulated above, practical relays between dominant knowledges, new identities and technologies link centres of rule to local sites within the care complex in which mothers and autistic children live out their lives. While policies of early identification explicitly aim to achieve welcome, inclusion and belonging through this complex, the above analysis shows instead an intrinsically normalising logic. This,
ironically, enacts *exclusive* versions of inclusion, autism and care as based on such logic (Graham and Slee 2008). I turn now to more closely examine the Identification, Placement and Review Committee, a second site of provincial and local school board policy that explicitly supports “education for all” while implicitly supporting exclusionary, normalising versions of student, parental involvement, inclusion and care.

**The Identification, Placement and Review Committee**

This section examines Regulation 181/98 of the Ontario Education Act - *Identification and placement of exceptional students* (2005) – as a second key strategy of inclusion. Through the technology of the Identification, Placement and Review Committee (IPRC), Regulation 181/98 provides a means to identify, track, monitor and ultimately subject so-called vulnerable, “exceptional” students and populations to a variety of normalising interventions under the guise of educational equity and inclusion. The IPRC gathers school authorities, community experts and a variety of assessment data together with parents in meetings at the local school level. Thus, when a child (and by implication mothers) fails to achieve the appearance of normalcy through a teacher’s or mother’s care alone, “The IPRC meets and decides if a student should be identified as an exceptional pupil and, if so, the placement that will best meet the student’s needs” (Ontario Ministry of Education 2000, D4). Once a long-term educational option, small self-contained special education classes - intensive support gifted programs, home school programs, autism, learning disability or behaviour classes - are increasingly offered by the committee as short-term interventions only. Indeed, the committee is mandated to consider “regular classroom placement” before any other (Ontario Ministry of Education, 2005). Interventions are increasingly designed to do the work of improvement (i.e., normalisation) so that inclusion in regular (or larger gifted) programmes and Ministry academic and social “targets” can be
achieved “for all” (Ontario Ministry of Education 2006b). There is little room for the mother and child who fail.

In the context of Ontario’s special education “transformation,” families are increasingly offered placements for their gifted/autism child within mainstream gifted programs. These offers are made by school boards purportedly as one of a number of positive educational choices reflective of a commitment as educational service providers. But the gifted programme is a powerfully seductive choice for most mothers and families, inciting an intense desire for their gifted/autism identified child to be and remain included. Compelled by the desire for normalcy or even ‘superior’ cognitive development in their child, mothers and families frequently take up IPRC recommendations to secure their child’s position: changing schools, moving to be within school catchment areas, or engaging expert help outside of the school (i.e., tutors, organizational coaches, social skills programs, psychologists and psychiatrists). Families commit financial and other resources. Mothers take up the work of tracking referrals and progress, attending appointments, and practicing skills to help their child achieve the appearance of normalcy, and appearance on which continued inclusion is based. Mothers are in this way invited to understand and govern themselves and the care of their child in neo-liberal terms, as active, engaged partners and consumers responsible for their child’s success or failure within the new educational marketplace (Dehli 2004). The offer of placement in gifted programmes is governmental in this way, shaping the conduct and identities of mothers and autistic children through notions of educational choice, and resituating expert knowledge within market relations (Dehli 2004).

Below, I examine the IPRC Decision Sheet, a “diagram of power” that technologizes and enacts this neo-liberal version of inclusion, one based on normalising interventions for so-called “exceptional” students and populations. I also consider ways that technologies such as these
depend on a tactic of self-governance. That is, I examine how they recruit mothers into their own desire and will to normalcy – the making of autonomous, responsible and productive future citizens - in their gifted/autism child.

The IPRC Decision Sheet

The *IPRC Decision Sheet* can be understood as a textually mediated encounter with autism as “body out of place” (Ahmed 2000, 55) through which the meaning of giftedness, disability and care is made *do-able*, in part through the participation of mothers. It is completed by school board officials in consultation with parents during IPRC meetings and is relational in this sense. While the format of the decision sheet varies from board to board, Ontario Regulation 181/98 stipulates that the following information be included: a profile of a child’s “strengths and needs,” a statement of decision about whether a child has been identified as “exceptional” by the committee, as well as a statement of decision about whether a child is to be placed in a “regular” or “special education” class (2005, s. 18). Certainly, it is clear that the decision sheet is animated by and animating of the ‘truth’ of normal development (See Figure 5). “Exceptional” students

Figure 5. Excerpt from Ottawa-Catholic *Comprehensive Special Education Plan 2007*, pg. 141.

<table>
<thead>
<tr>
<th>SUMMARY STATEMENT OF STRENGTHS</th>
<th>SUMMARY STATEMENT OF NEEDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RECOMMENDATION</strong></td>
<td></td>
</tr>
<tr>
<td>The Identification, Placement, and Review Committee has/has not identified____________________ as an exceptional student.</td>
<td></td>
</tr>
<tr>
<td>Exceptionality __________________________</td>
<td></td>
</tr>
<tr>
<td>Placement: __________________________ Commencing:</td>
<td></td>
</tr>
<tr>
<td>If Special Class, list reasons for this placement:</td>
<td></td>
</tr>
</tbody>
</table>
become possible only in contrast to “regular” ones who appear to follow so-called natural trajectories of development and meet the requisites of neo-liberal citizenship. Similarly, a “special” education population becomes possible only in contrast to a “regular” one comprised of students who appear to achieve normalcy in the face of the so-called dangers and vulnerabilities of development-gone-wrong. Indeed, Ontario Ministry of Education categories of “exceptionality” depend on previously established norms of development as authorized by cognitive science. According to these truths, students may be identified as “exceptional” by an IPRC in any area of development: behavioural (social/emotional), intellectual, language/communication or physical (see Ontario 2001, A18-A20). Through the technologized process of identification and categorization at the IPRC, then, the ‘truth’ of normal development as well as the boundary between normal and abnormal individuals and populations in schools is relationally and textually enacted by mothers, community experts and educational actors. The implication is that these sites are also ones of potential resistance to limiting educational categories that identify, track and attempt to governmentalize alternate modes of embodiment.

The statement of a student’s “needs” that appears on the IPRC Decision Sheet is particularly interesting because it forms the basis for the provincially mandated Individual Education Plan (Ontario Ministry of Education 2004, 23). This is a document that details how an exceptional student’s needs are to be met in the classroom. There are at least two connotations of the word “need” according to the Webster’s Ninth New Collegiate Dictionary (1991): 1) a duty or obligation, 2) a lack of something required. Thus educational “need” implies that exceptional students are in a state of lack, and secondly that a duty exists to remedy that state of being. To work with an example, a common need identified for Asperger’s identified students is “transitions” (Ontario Ministry of Education 2007, 16). School days demand frequent transitions
between type and length of activity as well as different educational spaces (i.e., the gym, the classroom, the lunchroom, outside recess, assemblies, etc.). Within educational space, Asperger’s identified students not only appear to “lack” the skill to make transitions, but are at the same time required to demonstrate it. Teachers and mothers also have a duty to remedy this state of lack, by practicing interventions that might achieve the appearance of this skill. Common interventions might include playing “transition games” at home, for example, or applying the techniques of applied behaviour analysis. In the name of educational inclusion, an appearance of alter embodiments in educational space become the subject of and subject to programmes of expert intervention. This includes the engagement of mothers in normalising practices, and at times, exposure to tactics of coercion to enforce inclusion (see Chapter 4). Alternate modes of embodiment in educational space – intense concentration for long periods of time, for example – are simply impossible. They are precluded by predetermined norms of sociality, use of space, and partitioning of time. Thus, the IPRC statement of needs is a technology that enacts neo-liberal and normative versions of embodiment and care in schools. It brings disability into ‘view’ as lack, failure, abnormalcy and obligation. These technologies of rule engage students, mothers, families and schools in the making up of “young citizens” through the scientific government of alterity.

The IPRC Decision Sheet is thus a technical means by which realms of authority are established. It acts as a distanciated technology of rule, one that links “centres of calculation” such as Ontario Regulation 181/98 to a mother’s ‘private’ desire for normalcy in her Asperger’s or autism identified child along with her work of care (Barry, Osborne and Rose 1996, 13). For example, as part of the IPRC process mothers and families are implored to consent to the involvement of psychologists and other experts increasingly situated within distanciated
community partnerships. Indeed, section 17 (1) of O. Reg. 181/98 states: “A committee that has received a referral...shall obtain and consider an educational assessment of the pupil” (2005).

Other referrals are made during IPRC meetings themselves. They are notated on the *IPRC Decision Sheet*, a legal document, and become enforceable in this way. Autism teams comprised of community autism experts as well as board professionals (psychologists) are one such common referral. Operating on a consultative market model, these teams are a recent emergence. Through the process of consultation, various diagrams of power – psychological reports and individual and family histories, for example – again bring gifted/autism students and mothers into ‘view’ in terms of lack, failure, and obligation. Mothers receive recommendations that engage them in both the governance of their child as well as their own self-governance, through calculated observation, self-monitoring and practice at home, for example. Students, too, are to be enterprising and autonomous, taking up and improving through recommendations given by these teams. Thus the *IPRC Decision Sheet* acts as a relay, connecting disparate actors and contexts across space and time with a mother’s moral obligation to undertake certain kinds of care. As a distantiated technology of rule, the decision sheet makes the governance of alterity, and therefore human vulnerability, both technical and practicable in schools. By implication, alternate ways of being are precluded, and a mother’s care is implicated in both the enactment, and by implication potential re/enactment, of the very definition of what it means to be human.

The formation of new identities, both individual and collective, is a final axis of power made practicable through diagrams of power like the *IPRC Decision Sheet*. Identity formation is integrally linked to the technical aspect of government and the role of expert knowledge discussed above. In terms of the decision sheet, a student is identified as “exceptional” if the required assessment data gathered for an IPRC meeting aligns with Ministry defined categories.
These categories, along with the psychological assessments used to attach them to students, are both animated by and animating of the ‘truth’ of cognitive developmental psychology and neuroscience. Through this particular scientific ‘gaze,’ they both prefigure and figure certain types of individuals. As introduced earlier in the chapter, categories like gifted/autism are a relatively new emergence in Ontario schools. IPRC committees rely on DSM-IV criteria for Asperger’s Disorder, as well as normed intelligence tests – with accommodation - to make these identifications, ones that are increasing in frequency. Of key importance is the recognition that the process of identifying exceptionalities through these new categories is a productive form of power. It is a process that incites a mother’s worry and care, as made practicable at home and in their involvement with experts in outside agencies, and one that directs teacher programming. It re/organizes individuals and populations in space – from small special education classroom to large gifted ones, quite literally refashioning the boundary between normal and abnormal. Through this process, students and mothers are invited to meet the normative academic and social requirements of neo-liberal citizenship through their own practices of self-government, effectively fashioning new self-understandings through these identity categories: a chance to be more than normal. But these new populations and individuals are closely monitored and tracked for progress. Should they fail, families are ‘offered’ – or made subject to - normalising interventions such as autism teams. Failure becomes an individual problem of governance in this way. Any recognition of social relations or the stubborness of alterity are defiantly absent. Thus identity formation is a critical axis of power, one that utilizes processes of categorization to constitute rule from a distance. Governance is accomplished through a mother’s love and concern, responsibility and moral obligation to care, as well as through her desire for her child to
be normal. Alternate modes of embodiment and self-understandings are made, quite simply, impossible in schools.

To sum up, policies of inclusion like early identification and Ontario Regulation 181/98 purport to provide “new and improved” techniques that achieve inclusion and equity for all. As my analytics has demonstrated, however, they are instead a mode of neo-liberal governmentality, a paradoxical form of inclusion/exclusion that invites and at times enforces compliance with academic and social norms based on the ‘truth claims’ of science. Made technical through diagrams of power like the IPRC Decision Sheet and the Developmental History Form, these new modes of power “make up” new individuals and populations and bring them into ‘view’ as those in need of expert programmes of reform. For those who fail – single, racialized or working class mothers, for example – coercive modes of power and forms of exclusion operate, ones that blame individuals and communities for their failure, the topic of the next chapter. In the face of these exclusionary and at times violent practices, it is imperative to better understand the complex ways that inclusion operates in order to identify and open space for contestation and critically informed practices that work to embrace and learn from alterity.

The ‘Rub’ of Subject and Power

In contrast to inclusion as a mode of power that relies on ‘freedom’ and ‘choice,’ Chapter Four examines how authoritarian power *is integral to neo-liberal rule*. Despite intensive intervention through programmes of inclusion and reform, Asperger’s and indeed, alterity, persists. Mothers and Asperger’s identified individuals perpetually fail to achieve the appearance of normalcy, and are made subject to authoritarian modes of power in this way. Yet even in the face of this direct power, alterity refuses total governmentalization. In this recognition, I return to one of the
philosophical threads that animates my approach – that of the ‘rub’ between power and interpretive subject. Judith Butler says:

Power acts on the subject, an acting that is an enacting: an irresolvable ambiguity arises when one attempts to distinguish between the power that (transitively) enacts the subject, and the power enacted by the subject, that is, between the power that forms the subject and the subject’s own power. (Butler 1997, 15)

Governmentality approaches forget the “subject’s own power.” But if I claim Asperger’s as a way of being-in-the-world then I risk essentialism: we are never outside of language, discourse and governance. I want to suggest along with Butler (2005) and Stiker (1999) that the very discourses and practices that “make” and enact us also always fail to contain us, even as we are made people who perform these meanings given to us. In the act of recognizing that I have been articulated in a particular fashion, I begin to use my being made a particular type – a mother or Asperger’s identified individual – as the very thing that makes it possible to exceed such categories. And these performances are at play with others at play. That is, within a shifting web of power and the ambiguous space between subject and world lies the possibility of resistance and natality (Arendt 1958). This is a space that isn’t fully managed, a space of mystery and desire.  

Chapter Four moves in this direction through an examination of the failure of governance to achieve its utopian goals for all bodies. That is, programmes of government rely on authoritarian modes of power because they have to: alter modes of being embodied in the world persist stubbornly. It is in this tension between body and world that alternative understandings of autism and practices of care might emerge.

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24. I would like to thank Tanya Titchkosky for helping me find the words to articulate this tension.
Chapter 4  Practices of Care: The Enforcement of Inclusion

This chapter examines how government through freedom is integrally linked to government through unfreedom. That is, I seek to reveal how the failure of mothers to achieve normalcy for their child subjects them, along with their child, not only to liberal forms of power, as demonstrated in Chapter Three, but also to more direct forms of power including disciplinary power, sovereign tactics and even violent practices at times (Foucault 1982, 1991a, 2003; Dean 2002; Dehli 2007). These are modes of power and practices that attempt to systematically enforce inclusion and the requisite of normalcy through programmes of ‘improvement’ and coercive means (Dean 2002). The stubborn persistence of alter modes of embodiment in the face of these practices means that, at some level, all mothers and Asperger’s identified children perpetually fail. This chapter explores this paradoxical enforcement of inclusion through an examination of practices of progressive discipline in schools, utilizing both a governmentality and autoethnographical approach. Through this discussion, I attempt to reveal not only the intrinsic logic of liberal/illiberal mechanisms, but the actual lived meaning of neo-liberal and illiberal powers.

In Chapter Five, my final chapter, I explore this inclusion/exclusion problematic through my lived experience of failure and care. Here, I return to my hermeneutic interest in policy, practice and experience, this time placing analytic emphasis on practices. I approach practices as everyday doings, in this case of the lived meaning of Asperger’s and care, that take place relationally between body and world. Practices of care are infused with and animating of governmental as well as direct forms of power, scientific and sensitive mothering discourses, and
often a mother’s desire to achieve normalcy for their child. Practices too, are replete with possibilities for natality in terms of the everyday doing of Asperger’s and care. An emphasis on practices of care then, not only allows me to articulate the complex interconnections between liberal and illiberal forms of power. It also gives me conceptual purchase to ask unsettling questions about Western culture’s interpretive relation to human vulnerability, embodiment and alterity – one that that recruits and subjects mothers and children to government through choice along with coercion. This relationship between liberal and illiberal modes of power is key to opening the possibility for new understandings of disability, inclusion and care.

To do the work of this chapter, I follow my movements within the care complex and include a somewhat broader analytical scope. While I maintain an emphasis on mothering and schooling, I also include the autism service agency as a key site that co-operates in the governance of autism. Through relays between these local sites, I identify practices that attempt to systematically improve identified students and enforce inclusion on normality’s terms. I focus in particular on the new educational practice of progressive discipline as one integrally linked to the accomplishment of inclusion and prominent in the lives of many Asperger’s identified youth and mothers (Ontario Ministry of Education 2008). At first, progressive discipline practices are invitational. They present opportunities to mothers to improve their child through parent meetings or referrals to community autism agencies, for example. When the desired results inevitably fail to materialize, discipline ‘progresses’ to more direct and coercive practices, ones that attempt to enforce requisites of normalcy and new neo-liberal versions of citizenship. To illustrate this complex interplay between liberal and illiberal modes of power in the practical management of embodiment and alterity, I first briefly elaborate a few key theoretical points, utilizing the examples of codes of conduct and functional behaviour analysis as practices that
link inclusion and progressive discipline in schools. Next, I briefly discuss Ontario Ministry of Education parent guides to progressive discipline to elucidate its intrinsic logic of choice and coercion, and its link to the project of inclusion. Finally, I elaborate on an example already briefly introduced in previous chapters, that of applied behaviour analysis (ABA). ABA is a prominent example of direct progressive discipline practices on autistic bodies as accomplished through the care of mothers. Within practices of ABA, a mother’s movements and gestures of care – her time, work, thought and love - are recruited and required as part of the systematic attempt to diminish autistic symptoms and enforce the achievement of inclusion. Throughout, interpretive disability studies returns me to the way in which these interlocking modes of governance articulate the meaning of autism as that of an unliveable life, and human vulnerability as that which must be scientifically known and managed, or more threateningly, forced to comply with new neo-liberalisms today.  

Liberal and Illiberal Rule

This section elaborates a number of theoretical points that are helpful as I work to articulate the logic and effects of the paradoxical enforcement of inclusion described above. First, I return to the work of Foucault whose work was used to understand some of the ways in which identity – Asperger’s in this case - is assembled and lived at a critical nexus, situated where the individual body and population meet, between forces of discipline and regularization (Foucault 1997; Dean 2002; Dehli 2007). This is a complex assertion that I unravel through this section in order to demonstrate some of the crucial ways in which illiberal power is integral to neo-liberal rule.

Foucault tells us that rather than having ‘progressed’ from a sovereign to a disciplinary and finally to a society of government, there is instead a “triangle” of power that operates in and

25. See Lenard Davis Enforcing Normalcy (1995) for further reading on the assembling of ableist norms and their enforcement.
through regimes of practices – in this case the care complex – in complex and circular ways (1991a):

...one has a triangle sovereignty-discipline-government which has as its primary target the population and its essential mechanisms the apparatuses of security. (1991a, 102)

Sovereign and disciplinary forms of power are integral to governmental power, operating through “apparatuses of security” like education, compelling, obliging and enforcing the participation of mothers in ways that align with the objectives of neo-liberal rule. The Ontario Code of Conduct, for example, is an expression of sovereign power in schools, an attempt to directly define and enforce new norms of citizenship and inclusion (Ontario Ministry of Education 2007b). This code, which is circulated by the Ministry, brings State power directly into view (Larner, 2000). It defines rights, responsibilities, and the school’s sovereign right to punish infractions (through the practice of progressive discipline) in neo-liberal terms:

Responsible citizenship involves appropriate participation in the civic life of the school community. Active and engaged citizens are aware of their rights, but more importantly, they accept responsibility for protecting their rights and the rights of others. (Ontario Ministry of Education 2008)

School boards are required to respond to infractions of this code, and in this way, the code of conduct defines what “appropriate participation” means for mothers and children, and targets transgressions that are considered enforceable. Many of the embodied differences of gifted/Asperger’s students – intensity of focus, a nonlinear relationship to time, flapping hands or interruptions to the flow of school time are reframed as infractions and subjected to direct and coercive practices such as ABA, an example taken up later in this chapter. Thus government, through freedom as articulated in policies of inclusion, works integrally with practices of unfreedom like codes and conduct and progressive discipline. The invitation of the alterity of
autism, which holds within it the possibility that inclusion might be thought and practiced otherwise, is effectively disqualified in this way.

It is ironic that inclusion, as a mode of indirect power, sets the stage for more direct measures, drawing and re/drawing spatial and pedagogical boundaries between normal and abnormal, effecting the creation of new populations and individuals to be ‘improved’ and/or disciplined, and eventually returned, or so is the utopian hope, to the project of citizenship in schools. Mitchell Dean (2002) teaches us that such dividing practices and categorisations, which in effect produce dependent populations to be ‘worked on,’ and to ‘work on’ themselves, are integral to neo-liberal rule, effectively re/constituting norms through their very exception to them (also see Davis 1995). In this way, Foucault’s work on bio-power is the method of accomplishment linked integrally to the operation of governmental, disciplinary and sovereign forms of power (1993). Bio-power has two “poles,” demonstrated through the phenomenon of the statistical norm, that together attempt to maximize and extract forces from individuals and populations: the regularization of populations in alignment with norms, and the disciplining of individual bodies to fit these norms (Foucault 1997; see also Dean 1999, 2002). Within education this effects a heightened surveillance of mothers, children and families, as statistics track ever-increasing numbers within new populations like that of gifted/autism, and programmes of reform practically rethink the contours of normalcy and inclusion.

Functional behaviour analysis (FBA), a common ABA practice taught to mothers within relays of the care complex, demonstrates how these two poles of discipline and regularization operate. FBA is a practice used to determine the so-called function of problem behaviour in order to re/shape it in more desired, normative ways (see Figure 6). Knowable and governable functions are attributed to observable behaviours: attention, escape, attaining a desired result or
meeting sensory needs, for example (Ontario Ministry of Education 2007a, 177). To perform an FBA, mothers re/learn perception and care, relating to their child’s behaviour in the home through documented observation and pedagogical/therapeutic intervention. Through scientific observation, target behaviours of concern, ones already predetermined through developmental population norms, are identified and defined (Ontario Ministry of Education 2007a, 53). This is the *doing* of disability, a maternal animation of an Asperger’s child as a problem of individual governance solvable through scientific maternal care. As for the disciplining of bodies, documentation includes not only the detailed recording of empirically observable behaviours, but also their intricate movements: the frequency with which they occur, their duration, as well as observation of antecedents (what occurs before) and reinforcements (what happens after) thought to give impetus to and maintain problem behaviours. Intervention progresses from the external regularization of minute movements – through a mother’s direct touch or verbal prompts, for example – to that of self-regulation. In other words, the disciplining of bodies is tantamount to the achievement of normalcy, first through a mother’s practice of care, but ultimately through

**Figure 6. Excerpt from Ontario Ministry of Education, *Effective Educational Practices for Students with Autism Spectrum Disorders*, 2007, pg. 175.**

**FUNCTIONAL BEHAVIOUR ASSESSMENT: A/B/C/ CHART**

<table>
<thead>
<tr>
<th>DATE/TIME</th>
<th>LOCATION</th>
<th>ANTECENDENT</th>
<th>BEHAVIOUR</th>
<th>CONSEQUENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>What came just before the problem behaviour?</td>
<td>Give a full description of the problem</td>
<td>Describe the exact responses to the problem behaviour</td>
</tr>
</tbody>
</table>

self-governing autistic bodies. Herein lie not only the two poles of biopower - regularisation and discipline – but the integral link of direct power to governmental power.
There is a hint of an evolutionary understanding of normative human development and behaviour that weaves through practices of unfreedom, one that contains a utopian but threatening end. Improvement is required of Asperger’s individuals and populations for entry into the educational project of humanity and citizenship. But this membership comes with a price: the attainment of a docile body. On docility Foucault says, “...[it] joins the analysable body to the manipulable body. A body is docile that may be subjected, used, transformed and improved” (1977, 136). Thus, the complex operation of different modes of direct and indirect power “makes live” the typical movements of life or ways of being embodied - the possible and practicable. But when we fail to appear as typical, this complex of power is also one that “let’s die” the alter movements of life – the impossible, impracticable, forgotten and unreal of atypical ways of being embodied (Foucault 1993, 241). Thus for those mothers, families and children who do not yet – or indeed cannot – ‘fit’ (raced, classed, gendered) scientifically articulated norms, authoritarian modes of power operate to coerce and oblige, or more threateningly, to punish and even push mothers, children and families out of communities and schools (Dehli 2004, 2007; Dean 2002; Erevelles 2000; Watts and Erevelles 2004).

Following Foucault’s triangle of power, mothers and children may be subject to various modes of direct power even as they adopt freedom’s will to normalcy: disciplinary practices such as ABA, coercive measures like expulsions, sovereign measures that enforce citizenship obligations and at their extreme violate human rights through physical acts, the limit of which are forgotten murders within ‘caring’ institutions like schools (Ontario Minister’s Advisory Council on Special Education 2005). Certainly, failure has subjected my son and me to authoritarian and direct measures: suspensions from school, physical restraints, judgements of moral character and the experience of being ‘pushed out’ of community programs and schools.
This complex of power – the care complex - as articulated through dominant discourses and institutional practices and locales, works through neo-liberal and illiberal modes of power, rendering what’s possible, and what’s not, in terms of the everyday doing of disability, Asperger’s and care.

The emphasis on practices of care in this chapter brings deeper questions about vulnerability, power and embodiment to the fore: How can I think of and make claims to the alterity of autistic bodies, claims that might reanimate the way care is practiced, in nonessentializing, transformative ways? If we are never outside of power, then what is natality and how might it be nurtured, again, in critically transformative ways? These are questions generated through the tensions of an eclectic approach that elicits the rub of interpretive subject and power. They return me once again to the animating concern of this thesis - to “take care” of autism differently – and so I attempt not to answer them, but to keep them alive in order to ask disruptive questions. Below, I follow Foucault (1991a, 2003), Dean (2002) and Dehli (2004; 2007), together with interpretive disability studies and feminist methodology in order to bring out the logic and effects of interlocking modes of power, along with these deeper questions of embodiment.

**The Opportunity to Improve: Progressive Discipline**

Through a discussion drawing on Ontario Ministry of Education parent guides to progressive discipline, I demonstrate some of the practical ways in which government through freedom – inclusion - is inextricably linked to government through unfreedom – progressive discipline – in the management of alterity and human vulnerability within the care complex. I understand these guides as textually mediated, practical encounters with power, ones that embed direct forms of power within new vocabularies of improvement, engagement and choice. These massive caring
projects have no use for the disruptiveness of alter, unruly bodies. Yet alter modes of embodiment persist, eluding the requisites of inclusion, productivity and autonomy. Practices of unfreedom - sovereign rule and the disciplining and regularization of bodies - are needed to reform or at an extreme push out unruly bodies under the guise of a mother and child’s failure to engage opportunities to improve.

Practices of progressive discipline were assembled over the past decade in Ontario as public concern and human rights challenges around the issue of safety in schools and the disproportionate impact of safe schools ‘zero-tolerance’ policies on disabled and racialised youth heightened. These challenges culminated in a consultative process in which special education parents were invited by the Ministry of Education to be involved in solving the problem of school safety. This process was publically framed as participatory and democratic, a move toward equity and inclusion (Ontario Ministry of Education 2006a). It resulted in Bill 212 and the Education Amendment Act - Progressive Discipline and School Safety (Legislative Assembly of Ontario 2007). Within the amended act, the mechanism of progressive discipline was practically re/defined, rethinking how and when disciplinary measures were to be used in schools. The explicit logic of progressive discipline is captured within one recent parent guide: “Ontario has shifted away from an approach that is solely punitive toward progressive discipline, a new approach that corrects inappropriate behaviour and offers multiple supports” (Ontario Ministry of Education 2009a; bold in original). This “correction” of behaviour is embedded within vocabularies and mechanisms of involvement and choice: it is to occur through

26. In Ontario, the groundwork for ‘zero-tolerance’ was laid in the Safe Schools Act in 2000 (Legislative Assembly of Ontario 2000). This act established the sovereign right of the Ministry to define a central code of conduct, along with predetermined disciplinary measures made to ‘fit’ the severity of transgressions of the code. In practice, it quickly became clear that zero tolerance relied on and enforced ableist, racialized norms, and that racialized and disabled students were being subject to disciplinary measures more frequently (see School Community Safety Advisory Panel 2008, for example).
“more opportunities” for students to “learn from the choices they make,” “more opportunities to be involved” for parents, as well as “supports” through a proliferation of school-family-community partnerships. In addition, school principals are now directed to consider individual “mitigating factors” before determining “the most appropriate way to respond to each situation” (2009a). In other words, key reforms to the *Education Amendment Act* have included a shift toward mother and student engagement along with the heightened individualization of discipline. On the surface, this appears to be a more equitable and kinder approach to problem behaviour in schools, one that may be more inclusive and forgiving of the alterity of autistic bodies. But what happens when alter modes of embodiment inevitably persist in the face of this individualized and heightened attention to reform? And further, what happens when the reality of social relations in women’s lives disallows involvement and inclusion on public education’s terms?

Indeed, within new practices of progressive discipline as outlined in parent guides, there is little room for failure. Every opportunity for improvement is extended to mothers and Asperger’s identified students, effecting the individualization of failure in moral and neuroscientific terms: failure becomes the fault of mothers who cannot fix lone, defective bodies and brains through their involvement and practices of maternal care. In accordance with the *Education Amendment Act*, parent guides focus on preventative measures and individualized interventions, couching authoritative measures within vocabularies of improvement, engagement and choice:

The principal will consider a range of options to address the behaviour and help students learn from their choices. This could include a meeting with parents, a detention, suggesting the student talk to someone about anger management, or suspension or expulsion...Parents will be more involved in finding solutions to deal with the behaviour. (Ontario Ministry of Education 2009a)
There are many examples of the paradox this involvement entails within parent guides. For example, early intervention is described as integrally linked to progressive discipline practices just as it is for policies of inclusion (Ontario Ministry of Education 2008). But early intervention also effects a heightened surveillance of mothers and autistic students and mothers, defining this population as in need of improvement while seeking to accomplish this improvement at a distance, through community partnerships and the practice of maternal care. Similarly, character and citizen development programs, described as “preventive measures” within parent guides to progressive discipline, not only move to directly teach children the conduct of conduct, but also to involve mothers in this endeavour. Mothers are invited to communicate about citizenship ideals in parent-teacher conferences, to practice citizenship at home, and to become involved on school-based safety committees (Ontario Ministry of Education 2008). Both character and citizen development and early intervention, as just two of numerous examples of the opportunities to improve, are in this sense governmental, as they seek to shape the conduct of mothers and children in particular ways, inviting them to take up new identities and practices of citizenship within distastiated sites. Difficult gifted/autism students are expected to improve and take up the role of enterprising student governable through their freedom, ready for the project of inclusion. Together, practices of progressive discipline, which employ both direct and indirect tactics, devolve the responsibility for the improvement of gifted/autism students onto mothers, Asperger’s identified students and new community partnerships. There is, indeed, no excuse for failing to achieve a docile body within newly reformed progressive discipline practices.

For some gifted/autism students, some of the time, the work of improvement offered through progressive discipline practices is empowering, resulting in new modes of self-understanding, as well as access to new educational programs and privileges, and is generative in
this way (Foucault 1982, 1991a). Despite this, however, and despite invocations of freedom and citizenship, mothers and students who cannot take up this individualized role of self-improvement continue to be subject to authoritarian forms of power. Mothers, gifted/Asperger’s identified students and communities who may lack the temporal, economic or cultural capital, or the desire, to engage with improvement are in this way held responsible for their failure, and may be pushed out of the educational project of citizenship, through, for example, the withholding of educational placement, expulsions or violent practices (Dehli 2004, 2008). Notions of improvement rely on ‘natural’ and ‘normal’ understandings of embodiment and development, along with raced, classed and abled academic and social standards, effectively moving to include the alterity of autism as that which must also always be excluded, even if by direct, coercive or violent means (Titchkosky 2007; also see Dean 2002). Thus through terms of freedom, engagement and choice, progressive discipline practices disqualify alter modes of embodiment in schools. I turn now to examine practices of ABA as the currently preferred intervention for the improvement and disciplining of autistic bodies in Ontario schools. ABA is a prime example of the paradoxical logic through which progressive discipline as a direct mode of power is translated into the everyday practices, hearts and desires of mothers, and directly onto autistic bodies.

**Applied Behaviour Analysis: Practices of Normalization**

In May 2007, the Ontario Ministry of Education released Policy/Program Memorandum (P/PM 140) 140 – *Incorporating Methods of Applied Behaviour Analysis (ABA) into Programs for Students with Autism Spectrum Disorders*. The memorandum states:

> The purpose of this memorandum is to provide direction to school boards to support their use of applied behaviour analysis (ABA) as an effective instructional approach in the education of many students with autism spectrum disorders (ASD). This memorandum establishes a policy
framework to support incorporation of ABA methods into school boards’ practices. (2007c, 1)

The release of Policy/Program Memorandum 140 was the culmination of close to a decade of autism and special education related initiatives within education in Ontario meant to address the ‘problem’ of the rising incidence of autism and safety in schools within an increasingly litigious, consumer oriented and parent savvy special education environment. The memorandum appeals to the authority of a number of government reports that review the efficacy of available autism treatments and conclude that applied behaviour analysis is preferred because it is supported by scientific evidence (Ontario 2007c; Perry and Condillac 2003). Thus ABA is considered to be an effective, evidence-based instructional practice and progressive discipline intervention capable of re-shaping individual behaviour in line with the requisites of inclusion (Ontario Ministry of Education 2007a). During this same time period, a number of government initiated partnerships between schools, autism service agencies and the family established key relays through which the work of maternal care within domestic space became central to the ascendancy of ABA. 27

In contrast to psychoanalytic approaches and more recent cognitive psychological or neuroscientific ones, applied behaviour analysis does not attempt to explain the “core deficits” of autism spectrum disorders nor the inner workings of troubled bodies, minds or souls. Rather, it consists of various practices through which observable behaviours identified as deficits within dominant frames might be directly reshaped or reformed in the context of an embodied relation of care (Rose 1999). Behavioural approaches like ABA draw from Skinnerian psychology, and have been applied within clinical settings to both autistic and non-autistic individuals since the

27. See, for example, the School Support Program, a recent partnership between the Ontario Ministry of Education, the Ministry of Children and Youth Services, Surrey Place (an agency for individuals with developmental disabilities), families and schools. This program supports the incorporation of practices of applied behaviour analysis in schools and families. (http://www.surreyplace.on.ca/Clinical-Programs/Autism/SSP/Pages/Home.aspx, Accessed January 3rd, 2010)
1950s at least. Within the field of autism treatment, ABA as a distinct approach emerged during the 1970s when Dr. Ivar Lovaas attempted to fashion a comprehensive treatment program for autism that drew from both behaviourist and cognitive approaches (Nadesan 2005, 192). A recent Ontario Ministry of Education resource guide summarizes the approach this way:

ABAn uses methods based on scientific principles of learning and behaviour to build useful repertoires and reduce problematic ones. In this approach, the behaviour(s) to be changed are clearly defined and recorded, and the antecedents and reinforcers that might be maintaining an undesirable behaviour, or that could be used to help develop alternative or new behaviours, are analysed. Interventions based on principles of learning and behaviour are then designed and implemented to develop appropriate behaviours... ABA is used according to the individual needs of each student, and may be applied to developing academic skills or behaviours related to social skills, communication, or self-care. (Ontario Ministry of Education 2007a, 52)

ABA, then, is an ideal practice of progressive discipline. It can be easily learned and applied to a variety of problems and within multiple settings by mothers, therapists and individuals alike. Through the practice of ABA, mothers are recruited into the direct governance of their children and their own self-governance. In this way, direct and indirect power interweave as perception is shaped anew in the form of a “reflexive objectifying gaze” (Rose 1999, 241). This new “gaze” recruits mothers in practices of care that attempt to reshape autistic bodies to “succeed in emitting the signs of a skilled performance” (241). ABA is in this way not only a practice of a mother’s will to normalcy, but is a normalising tool that works on the body as a form of disciplinary power, a direct and programmatic attempt to produce docile (non)autistic bodies through a relation of care. Importantly, ABA integrally links a mother’s movements of care, along with her desire, to what is considered “useful” – self-management, autonomy and productivity - within new neo-liberal versions of citizenship and inclusion. Further, ABA programs are individualized, meaning that failure is individualized too, effectively blaming mothers, families and communities who “fail,” subjecting them to coercive and punitive
measures. Utilizing an autoethnographic approach below, I examine the concrete example of “prompting,” a common ABA practice taught to mothers within the relays of the care complex. This last section attempts not only to bring together the threads of this chapter, but also to move the reader toward Chapter 5 in which I examine care as it is lived in everyday life.

**The Shaping of Behaviour: Failure and Alterity’s Excess**

Within various sites of the care complex, I have encountered the demand to practice ABA. Both within school meetings about my son’s problem behaviours and autism service agency workshops, I have been exposed to the various tools of the approach, and have been asked to practice them at home as part of the way I care for my son. If practices are a *doing* of Asperger’s and care as I suggested earlier in this chapter, then they are also a doing of both liberal and illiberal power, one that integrally involves mothers. As a form of liberal power, ABA operates at a distance, through the family and the relation of care between mother and child. As Chapter 3 articulated, this relation embodies the political. It is a relation that is couched within terms of privacy, morality, love, political obligation and responsibility, as it recruits the imaginations, hearts and wills of mothers in the achievement of inclusion and normalcy. At the same time, ABA is a direct and programmatic re/shaping of the movements of autistic bodies. In the name of democracy, equity and inclusion, it is mothers who are made the vehicles of this direct, disciplinary form of power as it entwines and interlocks with their love and freedom. And it is mothers who are blamed when failure prevails. I use this final section as a movement toward my final chapter on lived experiences of care. I suggest here that it is precisely *in failure* that we might find hope. In failure, alterity exceeds the bounds of a scientifically ordered and sometimes coercive version of maternal care. In failure we learn that alter embodiments cannot be fully managed or contained, and in this fact lay the possibility of hope and natality.
To elucidate the way in which practices of care embody liberal and illiberal modes of power – as well as the hope I have named - I work with an example of the practice of ABA in my home from a time of particular difficulty for my son and me.\textsuperscript{28} I work here to “take care” of autism differently by revealing the painful and surprising workings of power and disability in our lives together, along with my ambivalent complicity and resistance. This was a time of constant crisis at school, a time in which the alter movements of my Asperger’s identified son defied rule. In practice, this translated into a ‘progressive’ heightening of school-based discipline, the intensification and close of tracking of my son’s movements within educational space (indeed, he was “shadowed,” his movements, facial expressions, words and gestures recorded in behaviour logs) and the intensification of the demand that my maternal care, as the vehicle of discipline and regularization, become the dis/solution of this dis-ordered body, as if I possessed a secret maternal resource deep within me. Along the way, my involvement with a local autism agency was written into this demand to care in the shape of an IPRC decision, becoming a requisite of my son’s educational placement in this way – I “should” continue my involvement in order to practice strategies in the home that would eventually render my son’s body docile, manipulable within educational space. At the same time, my involvement with this local agency required that I take part in and complete several series of workshops on various aspects of autism spectrum disorder. It was in one of these workshop series that I was introduced to the techniques of ABA and required to practice it at home and in partnership with progressive discipline and ABA in the school. My spot in the autism program and access to behaviour consults would be withdrawn.

\textsuperscript{28} I want to acknowledge that my choice to speak of a difficult time elicits a number of ethical tensions implicit within relations of care. Just as I attempt to honour my son’s privacy and way of being-in-the-world, the demands of normalcy threaten to reduce his uniqueness, just as my words here make the same threat. I attempt to negotiate this tension ethically by honouring alterity. Further, I do not identify or criticize individuals or institutions, but rather write to encourage the asking of critical questions about disability and care within the various pedagogical spaces we find ourselves as those who care.
should I fail to participate; our educational placement uncertain. More than once, the demands of my life interfered and I could not attend nor complete ‘homework.’ I was spoken to about my commitment, my access threatened. As a mother, I was expected to have the ability and will to comply – committing large amounts of time within multiple spaces of the care complex in order to solve the problem of a disordered autistic body through a scientifically ordered and interpretive relation to embodiment that was to occur through my mothering practices and the re-ordering of domestic space.

My first task was to identify “target behaviours” utilizing a functional behaviour analysis in the home. Through this scientific re-ordering of perception, I was to fashion an intervention plan together with my autism consultant based on the tools of ABA that reshaped not only the way in which I practiced care, but also the way in which my son moved through the world. I was to prioritize the most ‘problematic’ behaviours at home and at school. In addition to other target behaviours like compliance or self-regulation, learning to make apologies “appropriately” was identified as a key concern. The situation at school often went from bad to worse when my son attempted an apology, only to ‘grin’ at the person to whom he was sorry. This was particularly dangerous if the other person involved was the principal, teacher or another parent. Indeed, my son’s grins came to be understood as an outward sign of his inner state of a lack of remorse. It was as if in that upward flicker of his cheek – an atypical response to trouble to be sure – he betrayed an un/humanity to be feared, regularized and even forced into compliance through discipline, and physical restraint. Here, a normative display of remorse was linked to the capacity for empathy, a capacity understood as the site at which our humanity dwells (McGuire and Michalko, forthcoming). Indeed, as early as kindergarten, normatively structured demands for displays of empathy based on developmental cognitive psychology are made of children, who are
expected to: “develop empathy for others, and acknowledge and respond to each other’s feelings” (Ontario Ministry of Education 2006c, 31). Clearly, my son’s display of ‘grimaces’ and ‘glee’ in the face of others wronged was a non-response and an unhumanity revealed. To develop the much touted social competence pivotal to the eventual participation in new neoliberalisms of citizenship, both my practices of care and my son’s minute movements needed to be reformed.

My job was to break the task of “apologizing appropriately” into teachable skills, and to use practices of ABA such as prompting and reinforcement (the giving of praise or earning of desired toys) to reshape how these skills – particularly my son’s facial expressions and pattern of eye contact – were performed (Rose 1999, 241-3). Once all of the requisite skills were in place and the performance complete, entry to the educational project of humanity and citizenship might be achieved. I want to briefly consider the practice of prompting as one that embodies and practices direct disciplinary power through a mother’s care onto autistic bodies. In Figure 7 below, four levels of prompts are shown, ones that range from direct intervention, to the self-disciplining of autistic bodies. Prompts are employed as reminders of the “correct” way to

**Figure 7. Adapted from Ontario Ministry of Education. Effective Educational Practices for Students with Autism Spectrum Disorders: A Resource Guide, 2007, pg. 158**

**TASK: Apologizing Correctly/Using Non-verbal Cues Appropriately**

<table>
<thead>
<tr>
<th>PROMPTS:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
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<tbody>
<tr>
<td>1. Verbal prompt</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Physical prompt</td>
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<tr>
<td>3. Gesture</td>
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<tr>
<td>4. Independently</td>
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<tr>
<td>Approaches peer/adult</td>
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<tr>
<td>Gets their attention</td>
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</tr>
<tr>
<td>Looks peer/adult in the eye</td>
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</tr>
<tr>
<td>Says ‘I’m sorry for...’</td>
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perform each skill below. I was to re-order my perception and domestic space as a pedagogical and therapeutic one, catching situations that called for apology in order to practice these skills with my son. Beginning from the point of direct verbal or physical prompts, I was to move to the use of a slight gesture to direct my son’s performance, and finally to the achievement of my son’s self-disciplining, or independent, autistic body. As I ambivalently complied with the teaching of this “skilled performance,” the desire for normalcy in my son a compelling one, a prompt I used was to touch my son’s face gently and reshape his alter expression of a ‘grin’ into the normative appearance of remorse, saying to him “no smile.” Maurice Merleau-Ponty says this about the relation between word and world: “The spoken word is a gesture, and its meaning the world” (1962, 184). Again and again my son and I practiced this performance, my words “no smile” and gesture of care – the gentle touch of his cheek - replete with a world structured through normalcy, science, new neo-liberalisms, direct modes of power and a fear of the unknown of human alterity and vulnerability. Again and again the alterity of my son’s way of being-in-the-world persisted as he told me, “I can’t.” In this particular performance, and despite the press of disciplinary practices and a mother’s will to normalcy, we failed inexcusably, and became subject to heightened surveillance and more coercive forms of discipline and care.

My practice of care was also the practice of integrally entwined modes of liberal and illiberal power and the doing of Asperger’s as impossible, impracticable, unreal and even un-human. Consequences for this failure of maternal care were severe. And yet in this failure is also the reminder that alterity cannot be completely managed. In this ambiguous space between word and world whisper other ways to be in the world and alter ways of knowing. Here, alterity speaks in alter movements and expressions, and the possibility of natality emerges, just as deeper questions about power, embodiment and vulnerability dwell here. As I move now to explore
these questions further in this space of uncertainty and newness in Chapter 5, I remind the reader of Hannah Arendt’s words: “With word and deed we insert ourselves into the human world, and this insertion is like a second birth...” (1958, 176-7). In our ‘failure’ there is hope for something new.
Chapter 5  Living Care: Failure and Suffering

The previous chapters attempted to think through the meaning of autism as a recently assembled identity category, as both an effect and instrument of liberal and illiberal power and the government of bodies, minds and senses under neo-liberal rule. I have asked questions about how new identities and ways to care are assembled and become possible through whole complexes of caring practices, expert knowledges, mentalities of government and institutionalized spaces. I have also interrogated what appears to be an intensifying surveillance of children’s minds, bodies and senses in our time, and the ways that mothers are mobilized and obliged to take part and become invested in projects and practices of early identification, intervention, progressive discipline and normalisation through their own self-governance and governance of their children. This chapter turns now to think through these questions differently. Here, I employ feminist methodology and interpretive disability studies to help me speak of the experience of care – the lived-out-ness of governmental and direct forms of power in everyday, relational and embodied spaces. Regardless of how the government of bodies, minds and senses might operate or not, disability does not exist outside interpretation and social interaction. To return to my theoretical approach, I follow Titchkosky in theorizing disability as it gathers in the nebulous, messy and uncertain space between body and world, a space that is between us (Titchkosky 2003; 2007). It is this more mysterious and embodied space where among other activities we practice and experience care, that I want to dwell in this last chapter.

If, as De Certeau suggests, spatial practices “...secretly structure the determining conditions of social life” (2007, 252) then as I take up the practices of care, I also participate in
creating the world, in the making of the meaning of autism, care and what counts as a life worth living. I reflect on three brief, textually mediated encounters with caring practices that I experienced as the mom of an Asperger’s identified son. My desire is to open care as an analytic space of questions. Returning to where I began and Levinas’ assertion that “To understand is to take care” (1996, 18; see Chapter 2), the work of this thesis might itself considered a practice of care, one in which I struggle with the meaning and language of autism and Asperger’s, the meaning of my own implication in caring practices, and my own struggles to mother a disabled son with and through my experience of chronic illness. My encounters are suggestive that today, practices of care for and about disability are organized as practices of failure. In other words, practices of care turn us away from alterity and instead toward a paradoxical and perpetual search to recover what I suggest is unrecoverable, to work for the ‘yet to be’ of normalcy. I think this problematic is particularly formed through autism today.

**Encounter 1**

When my son was diagnosed with Asperger’s, I attended a *Getting Started* workshop at my local autism organization. As the workshop progressed, I grew troubled and uncomfortable. I was not able to reconcile the ever-changing rhythms of life with my son – surprise, disorientation, beauty, poignancy - with the version of autism and care gathering in the room. Autism was to be understood primarily as a neuro-developmental delay linked to disordered neurology, defective brains and problematic genes. Within the workshops, the ‘truth’ of this scientific version of autism remained unquestioned, “secretly structuring the determining conditions” (De Certeau 2007, 252) of care as parent training workshops, intervention techniques, fee-for-service consults and therapies, extensive readings, GF/CF diets, sensory integration therapy, medication and more. It was suggested that without such care, my son’s ‘delay’ would mean a life of suffering
and exclusion. The ever-present whisper of alterity resonating in our everyday was forgotten by this version of autism and care. Yet by the end of the workshop, I was anxious to ‘get started.’ The struggle my son and I experienced trying to fashion a way to move through the world had been years long and intense. But just what was it I was ‘getting started’ at?

Each version of autism circulating in the Getting Started workshop visually located it in individual bodies, as if it were some ‘thing’ imminently there, separate from time, space and meaning, incorporated as a totalizing way to ‘see.’ As Chapter 1 elucidated, such narratives today profoundly permeate how we understand and ‘live with’ autism. As a totalizing ‘viewpoint,’ these neuroscientific narratives forget the lived and living body that gathers in the space between us. De Certeau describes such a totalizing regime this way:

It transforms the bewitching world by which one was “possessed” into a text that lies before one’s eyes. It allows one to read, to be a solar Eye, looking down like a god…The voyeur-god created by this fiction…knows only cadavers, [and] must disentangle himself from the murky intertwining daily behaviours (2007, 250)

Everyday gestures like finger flapping that I had never thought to ‘see’ before now loomed before me as markers of a defective neurology. Once enjoyable activities, like watching my son’s daily ritual of lining up his cars, now came into ‘view’ as dis-ordered and obsessive, and my caring practices became similarly questionable. In the totalizing viewpoint of neuroscience and cognitive psychology, the autistic body is broken, its most intimate gestures troubling fragments in an overarching fiction of normalcy; autism serving as marker of a dis-ordered neurology in an able-ist world of supposed order and clarity. Maurice Merleau-Ponty teaches us that science forgets perception, mistaking a ‘viewpoint’ for the phenomenon itself (Merleau-Ponty 1962). Perhaps it was this forgetting of the murkiness of the everyday that I was getting started at. With its promises of ‘clear vision,’ this totalizing viewpoint invited me to turn away from living in and
with the alterity of my son’s disability. Rather, I was invited to learn to ‘see’ my son’s
Asperger’s anew, replacing the uncertainty and openness of the meaning of my son’s alter
embodiment with the certainty of scientific knowledge: Asperger’s is a failed and dis-ordered
neurology in deceit of the appearance of normalcy.

If there is an ‘out of order’ of autism, so the logic of normalcy and science goes, then
there must be an original ‘order,’ a desirable place of wholeness we should seek through our
caring practices. Mothers and parents, as if disembodied, are compelled to be active, available
and always ready to educate themselves, try something new, monitor and intervene in their
child’s failure to achieve normalcy. How could we not, when the alternative presented is a life of
exclusion and suffering? Yet I could not reconcile my messy last-minute-single-mom-fibro-girl-
store-bought-cookies life with this ‘vision’ of care. Nor could I reconcile the real-ness of living
in and with my Asperger’s son in the face of the demand to achieve some kind of originary
wholeness through my caring practices. And when I inevitably fail to ‘fix’ autism, then what?
What does the search and work for the ‘yet to be’ of normalcy mean? It means that as I take up
the work of care, I fail over and over again. It means that the practice of care is also today
organized as a practice of failure, and further, that there is a ‘right’ and a ‘wrong’ way to practice
failure today. Above all else, I must not give up. I must succeed through a turning away from and
failing to live in the murky intertwining of the in-between where alterity emerges between us.
After all, there are countless workshops to take and extensive searches to be made. I want to
pause for breath in the midst of the fictions of this regime. Even as the totalizing regime of care
teaches us to ‘see’ clearly and organize our caring practices, the lived and living body of autism
and care exceeds, already rupturing and pulling at the fiction of neuro-normativity. What else
might the perpetual search for the ‘yet to be’ mean?
Encounter 2

I receive an invitation by email from a local autism organization. They are co-sponsoring the screening of a documentary called *Over the Hills and Far Away*. It is to appear at a “cutting edge” international film festival in my hometown. I follow the link to the trailer. It opens onto a scene juxtaposing what appear to be images of native music and healing, with images of a child rocking, focussing inward, arching his back in the throes of what appears to be rage, slipping away from caring arms. The voice of a man says:

In April, 2004, my son Rowan was diagnosed with autism. The feeling was like being hit across the face with a baseball bat. Grief, shame, this weird irrational shame like I’d cursed this child by giving him these faulty genetics. I had to find a way. I had to find a way into his mind. ([http://www.youtube.com/watch?v=klth8prjkAs](http://www.youtube.com/watch?v=klth8prjkAs) Accessed December 28, 2009)

The family’s exhaustive search for answers both literally and figuratively takes them “over the hills and far away,” across Mongolia on horseback. Wanting to know more about the documentary, I find a website about Rowan and his father promoting the book *The Horse Boy: A Father’s Quest to Heal His Son*, on which the documentary was based, I read:

The charming, animated, blue-eyed, brown-haired boy suddenly ceased to say the few words he had accrued...he began to flap his arms and babble, to obsessively line up his toys, to retreat into himself for hours at a time, to avoid eye contact, to scream uncontrollably...as his nervous system erupted...searing him...with pain...traumatizing him, causing him to ‘fly away’ into an otherworld far from the reaches of his distraught, grieving parents. ([http://www.horseboymovie.com/OurStory.php](http://www.horseboymovie.com/OurStory.php) Accessed December 28th, 2009)

I respond with anger and grief. Echoes of life with my son commingle with these disturbing images of care: bewilderment, loss, rages which destroy all sense of direction and meaning, exhaustive searches for answers. I, too, live with the real materiality of autism. I am confronted in this clip by the ways that I have sought out and taken up practices of care, as well as the ways that care has taken me on a perpetual search for the ‘yet to be’: from ‘alternative’ therapies,
autism diets and supplements, to behaviour consultants, medical teams, workshops, skills practice and more. I too, have searched exhaustively. But just what does this perpetual search for the ‘yet to be’ mean with my son living right in front of me? The search for the ‘yet to be’ is a search that turns me away from the whisper of alterity and the space of between-ness. It is a search in which I seek ‘clear vision’ and work to reduce my son’s irreducibility, to ‘fit’ him within a frame of normalcy. It means, as Rod Michalko teaches us, that disability is a difference that ought to make no difference. It is for nothing, at best a “useless difference” that leaves the world unmoved and neuro-normative structures unchallenged (2002, 99-100). This is not to say that I never practice care or move to intervene, I do, but rather that my questions call for a reconsideration of disability as if it is only and always negative, as well as a re-evaluation of the ways in which we today live in and with the alterity of disability as an enactment and practice of maternal care as failure.

Returning to the trailer for Over the Hills and Far Away, we are given Rowan in a world of his own, compelled by an unfathomable internal rhythm, lost to incomprehensible rage, bounded by a dis-ordered neurology. He is shown inhabiting shadows, not social or communicative in any real or meaningful way. The ‘yet to be’ autistic body is imagined as a suffering one, then, inhabiting the world of the unreal, of the almost human. We learn that Rowan’s father has experienced a crushing loss and suffers too, that he felt as if he had been literally “hit across the face with a baseball bat” when he learned of his son’s autism. If my child is taken, is suffering and lost, how can I not perpetually suffer and experience loss too? But might there be a different meaning in this loss and suffering? This question again calls for a reconsideration of disability as if it is only and always negative. I have lived the screams, the “obsession” with lining up toys, and the long inward retreats. Could we also find mystery in the ritual, beauty in the retreats, a
forceful statement in the screams, and care as a mom now mattering differently? But further, my
question calls for a re-evaluation of the meaning of loss and suffering. If I only and always locate
suffering and loss in the boundedness of my child’s failed biology, in his failure to appear as an
instance of normalcy, and my failure to recover and restore him to originary wholeness, then the
world remains unmoved by alterity. Our suffering is - and here I reference Michalko’s critical
discussion of Levinas’ concept of “useless suffering” - for nothing, it is “useless,” perpetual and
meaningless (2002; also see Levinas 1998b). In such a ‘view,’ disability is little more than a “cry
for help” (Michalko 2002, 100) and the concomitant biomedical “ethical requirement to remedy
it” (99). Might our moments of suffering instead or also be a call to the ethical and inter-human,
a possible moment of responsibility in which we might turn toward the irreducible difference of
an other (Levinas 1998a, 2001)? Might this turn move us beyond “useless suffering” and allow
the touch of alterity to move the world between us?

Dwelling in the Space Between

I turn now to go a little deeper into the space of between-ness, in order to think through how we
might practice maternal care by embracing alterity, even in the face of loss and suffering. I work
here to open care as an analytic and existential space of questions. I try to draw near to the
meaning of the alterity of autism and Asperger’s using the rhythm of Judith Butler’s language
from her writings about violence, politics and mourning. From Butler I learn that my body is not
my body, as if it can ever be the autonomous, bounded body-object given to us by the totalizing
regime. My body from the start comes into being through “the crucible of social life” (Butler
2004, 26), through a relationality that ties me to the touch of others in a relation of proximity and
distance, which is also a relation of precarity. I am given over to you, just as you are to me.
Judith Butler says:
Who “am” I without you? ...On one level, I think that I have lost you only to discover that I have gone missing as well...perhaps what I have lost “in” you, that for which I have no ready vocabulary, is a relationality that is composed neither exclusively of myself or you, but is to be conceived as the tie by which those terms are differentiated and related. (2004, 22 emphasis in original)

Is it not also, or instead, ‘we’ - you and me - who are lost, who suffer? I lose ‘you,’ only to lose myself too. I am thrown by the disorientation of this loss, as the way in which I tied myself to you, through the fiction of normalcy, unravels. ‘I’ am called into question: “Who am I without you?” When I turn away and fail to recognize ‘you,’ then you are in a perpetual state of ‘yet to be,’ you are a ‘never be-coming.’ And if you are perpetually lost, then I come into being over and over again as a perpetually searching, working, grieving body of care. The alterity of autism and Asperger’s slips by unrecognized, misrecognized. Yet such alterity pulls and tugs at me in my everyday. It is stubborn even as I do the work of care, of recovery. Butler writes about the relation between those lives that are considered unreal, and violence. If ‘you’ are real but only as symptom, then the violence I do through a totalizing care - overlooking and misrecognizing you as among the shadows of the unreal and knowing you only as a “body out of place” – does not impact you as you “stubbornly live on” (33).

Here, we reach a moment of ethical decision about the way in which we take up and practice maternal care. Can we recognize the irreducibility of Asperger’s and autism as already a way of being in the world? Can we orient to alterity differently? This is a space of questions, of ambiguous and uncertain ties, and of the real, stubborn and disorienting. This is a space that already tugs at us as we fail in our care to recover you. Can my failure to return you to the fiction of originary wholeness instead be a practice of resistance to the reductive impulse of a totalizing regime?
Encounter 3: Care as a Practice of Alterity

I watch my son as he stands at the bathroom sink, enraptured. Water drips slowly from the tap and into a cup. He has been standing and watching for some time now. He is bent over, gazing intently at the level of the rising water. Each drop promises to rupture the tautness of the water’s skin, which finally relents, water gently pouring over the edges of the cup. My son smiles. His fingers flutter softly. “Beautiful,” I think. I watch as he turns the tap on high, a sudden movement as water erupts over the sides of the cup and swirls down the drain. He is excited, walking on toes and fingers fluttering. I call to him, wanting to share his excitement, but he remains with the water, turning the tap back down to a slow drip. I move closer and reach out to him. He stiffens suddenly, arms thrown back, cup released with a bang. His reaction tells me I have caused him pain. I am tempted to say to him, “Stop!” and move to intervene. I struggle to stay in the moment. I have forgotten about the days with water.

As I am moved by the touch of alterity, the ways that ‘I’ am tied to ‘you,’ my son, begin to unravel. In this space of uncertainty between us, where do I turn? Do I turn away and work to achieve normalcy? Do I grieve? Sometimes, yes. But isn’t there a different call in this moment? In the disorientation of the in-between, the stubborn presence of my Asperger’s son calls for recognition: Habituate yourself here, in this space of alterity. Dwell with me in this moment. Take time to become familiar here, too. Orient by disorienting. If I recognize the irreducibility and singularity of my son, and indeed of us all, then ‘we’ emerge in a different relationality in which alterity might disrupt and transform the ‘clear vision’ of our neuro-normative world (Butler 2004, 44; Levinas 1998a, 2001). My body of work asks that we pause in our forgetting and remember perception: scientific versions and practices of care and new neo-liberalisms of citizenship, along with notions of the ‘true’ and the ‘real’ are not somehow ‘natural’ or ‘direct’
expressions of a factual reality. They are an interpretive and constitutive act. There is, too, the real of what has been cast as unreal that we might turn toward, even just for a moment: the persistent tug of alterity. Might we – mothers and caregivers - take a breath here, in this disorienting and confusing space of the in-between? Might the murkiness of the space between us also be the source of a forgotten knowledge about living in and with the alterity and vulnerability of us all, and the openness of the meaning of embodiment? Might our secret be that failure is also a moment of resistance and hope in which we might turn to embrace the alterity of disability as it gathers between us in all of its rapture, anguish, disorientation and surprise?
Conclusion  Taking Care: Toward Further Research and Study

This thesis set out to “take care” of Asperger’s differently. As a mom who struggles and cares, I wanted to create new understandings of Asperger’s that take seriously interpretive disability studies’ claim that disability is something made in the social spaces between us, and not just in isolated, defective bodies or brains (Titchkosky 2000, 38). I used a multivocal approach to unsettle the authority of cognitive psychology and neuroscience and its foreclosure of Asperger’s as a viable way of being-in-the-world with something to teach about embodiment and human vulnerability. To open analytic space for new understandings, I situated my analysis within schools, families and autism agencies, and worked with a paradox that is central to the meaning of embodiment and disability in our time: the existence of a massive complex of ‘care’ alongside coercive power and violent practices that enforce versions of embodiment on normality’s terms.

Within various sites of the care complex, I paid particular attention to how neo-liberal modes of governance prefigure citizens as autonomous, self-regulating subjects of freedom and choice, and to the intensification of ways that maternal care and desire is recruited by and implicated in these forms of governance. I also identified how neo-liberal governance is integrally linked to coercive power and enacts a particular interpretive relation to embodiment, one in which the deep mystery and vulnerability of alterity must be known and managed at all costs. The work of Michel Foucault was integral to this task. Through a hermeneutic shift to an interpretive disability studies frame, I explored failure and suffering, along with amazement and natality, as lived-out meanings of care for mothers, revealing that the very discourses and practices that ‘make’ us also fail to contain us. The ‘rub’ of power and interpretive subject elicited through my multivocal approach is suggestive of a space ‘between’ that cannot be fully
governed, a space of mystery, relationality, tension, openness and possibility in terms of the meaning of embodiment, disability, and indeed, of being human. It is here, in alterity’s excess and my failure/refusal to produce a ‘normal’ son even in the face of the seduction of normalcy and coercive practices, that I have located the possibility of hope.

This thesis is only a beginning. My concept of the care complex calls for further elaboration. It could be employed to understand how other institutional locales, forms of knowledge, identities and technologies shape practices of care and the meaning of disability and embodiment today. The care complex is a way of perceiving care that can reveal its complexity from both a systemic as well as a lived perspective. From this work arises provocative questions about the relation between power and the meaning of alterity. I have asked some of these questions through my discussion of failure as alterity’s excess, and I return the reader to them here: How can I make claims to the alterity of autistic bodies, claims that might transform the way care is practiced, and avoid the dangers of essentialising? What is natality in the context of the fact that we are never outside of power? How might the creative and interpretive act of natality be cultivated? My thesis is one response to these questions among infinite possibilities.

My research has implications for a variety of academic fields where embodiment is a central concern. It is my hope that my work might contribute to emerging work within governmentality, interpretive disability studies, critical race theory and feminist conceptions of care seeking to incorporate alternate understandings of disability and care. My attention to Asperger’s and care through a multivocal approach has particular relevance to the important and emerging conversation between phenomenological and governmentality approaches. Much more remains to be done in terms of exploring how the tensions and resonances between these different frames might generate dialogue not only about deeper philosophical questions of
embodiment, agency and power, but also practical and political questions about how regimes of power get taken up, resisted and lived out at the level of meaning in the everyday. This is particularly important work in the face of intensifying and paradoxical practices of inclusion-exclusion that often involve coercive forms of power and violence.

To end, I return to the animating question with which I began: How might care be re/imagined as a practice of alterity? I would like to suggest that the doing of this thesis has provided one response to this important question. We are never outside of power, but in the effort to articulate our implication in practices of power, including the activity of knowledge production, we struggle with a more creative form of critique that might learn from the difference of alterity and create new meaning (Butler 2004). Titchkosky 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, 237). We act and insert ourselves in the world in creative ways that might even begin to exceed, though always remain articulated within, the categories that have made us (Arendt 1958, 176-7). This thesis has struggled with the tension between power and subjectivity as an alternate way to care about Asperger’s. It is my hope that this struggle has opened analytic space to allow alternate modes of recognizing embodiment and human vulnerability to touch and shift the world in new and more humanizing ways.
Reference List


