THE WAR ON AUTISM: ON NORMATIVE VIOLENCE AND THE CULTURAL PRODUCTION OF AUTISM ADVOCACY

by

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This dissertation brings together a variety of interpretive theoretical perspectives born of the fields of disability studies, critical race theory, cultural studies and queer and feminist studies to analyze the social significance and productive effects of cultural representations of autism. Specifically, this work addresses contemporary enactments of autism advocacy as found in the mass media, education literature and policy as well as in fundraising campaigns. In response to a global/izing economy that privileges the fast, efficient exchange of information and knowledge, I attend to how autism appears in the field of autism advocacy as an abbreviation; its multiple meaning distilled down to a series of ‘red flags’ in awareness campaigns, bulleted ‘facts’ in information pamphlets, statistics in policy reports. I analyze the relationships between these fragmentary enactments of autism and trace their continuities so as to make legible an underlying logic: a powerful and ubiquitous logic that casts autism as a pathological threat to normative life, and advocacy as that which must eliminate this threat, thus, limiting the role of the ‘good’ autism advocate to one positioned ‘against’ autism.

This dissertation shows how dominant, contemporary discourses of autism advocacy that narrate autism as some ‘thing’ to be ‘fought’, ‘combated’, or ‘warred against’ function to shape ‘life’ as conditional and cast autism as (one of) its
condition(s). As autism is discursively and ideologically made separate from the vital category of life itself, and as bodies and minds of living people are relentlessly divided up into vital and non-vital parts, individual and collective life ‘with’ (the condition of) autism becomes life that is conceptualized as ‘almost living’ or ‘mostly dead’. I demonstrate how such an understanding of the conditionality of life is a necessary pre-condition for normative acts of violence – violence enacted in the name of securing the norm and violence that is normalized as necessary.
ACKNOWLEDGMENTS

My dissertation strives to make sense of some of the ways we bump up against one another, how our encounters with others change us. Indeed, this work is tied to and flows from many such encounters, including the provocations of many interlocutors.

I owe a great deal to Drs. Tanya Titchkosky and Rod Michalko; it is the prodigious and wonder-ful debt of a student to her mentors. Tanya has been an electric teacher, an incisive critic, and a good friend. As I write this, Tanya’s book, *Reading and Writing Disability Differently*, is laying on the table next to me. It has not seen the bookshelf in two years. Tanya’s commitment to reading, writing, speaking, imagining and fighting for disability as a socio-cultural phenomenon between bodies – and her desire to continuously return to this phenomenon as a space of and for questions – serves as the foundational orientation of this dissertation. Rod’s respect for and interest in my research and his generous involvement in my education (both in and out of the classroom), has inspired me greatly and has, unequivocally, shaped this dissertation. Over the six years I have known Rod, he has spent countless hours listening to and talking through my work, pushing me with difficult questions and teaching me a great deal about methods of interpretive inquiry. His steadfast support has meant the world. Tanya and Rod – to you both, my deepest respect and gratitude.

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“How we are seen determines in part how we are treated; how we treat others is based on how we see them; such seeing comes from representation”

-Dyer, 1993, p.1
In solidarity with those advocating otherwise.
The ongoing constitution of disability as-a-problem condition is accompanied by writing, reading and otherwise acting as if embodied differences can appear purely – as if they are outside of cultural influence, untouched by political and social organization, as if dominant discourses are not organizing our past, present, and future relations to disability, to impairment, to embodiment.


The truth about stories is that that is all we are...

- Thomas King (2005), The Truth about Stories, p. 2

On the 27th of September 2009, an unnamed 11-year-old autistic boy was murdered by his father in the basement of their family home in Edmonton, Alberta. After killing his son, the father, then, killed himself. I read about the murder-suicide, a few days later, on the CBC’s (Canadian Broadcasting Corporation) newsfeed, though details surrounding the events and those involved were remarkably thin. Those details that were circulated through the popular Canadian news media told the story of a boy’s ‘severe’ autism and his ‘violent’ outbursts, a ‘desperate’ father and ‘costly’ care. The reports told of a child who was living in a group home and who was making progress there. But the
care he had been receiving had become too expensive and his family was told he would be moved to another ‘facility’ (“Man despaired over moving autistic son”, 2009, para. 7). This move, a CBC news report tells us, "pushed [the father] over the edge" (“Man despaired over moving autistic son”, 2009, para. 10).

On September 27th, police discovered the lifeless bodies of the father and son in the basement of the father’s bungalow in northeast Edmonton. News media reported that police made the decision to not release the names of the dead "in order to protect the privacy of the family" ("Dad in murder-suicide had sought help for autistic son", para. 5). While, the situation was labeled a 'murder-suicide', no cause of death was ever released to the public.

~

Three provinces east and less than a month later, another Canadian autistic boy was killed by his parent. On the 25th of October 2009, 15-year-old Tony Khor, was murdered by his mother, Seow Cheng Sim, in a hotel room in Mississauga, Ontario. Strikingly similar stories circulated through the media. The boy was described as "severely autistic", the situation that ended in his murder, as "heartbreaking" and "tragic" (Mitchell & Wilkes, 2009; Tambar, 2009). So close were these stories, that when I first heard mention on Tony Khor's death on the evening news, I, initially, mistook this for updated information on the Edmonton murder.

We heard of a boy – diagnosed as autistic at age 2 – who had grown “progressively worse”, particularly as he entered into his teenage years, and we heard of his “devoted” parents (Mitchell & Wilkes, 2009, para. 11; “Mother charged with autistic son's death”, 2009, para. 6). Tony lived at home with his family, though according to
neighbors, Tony’s parents had been arguing about whether to send the boy to live in a residential care facility. "Their son had become more difficult to handle over the past few years" writes Star reporters Mitchell and Wilkes, "the stress of raising him had become extremely hard for [Sim], who mostly cared for the teen" (Mitchell & Wilkes, 2009, para. 8). Indeed, the couple had been arguing the day of the murder and it was following this argument that Sim took Tony, drove to a local hotel and killed him. While police said that the boy’s body showed “obvious signs of trauma”, they would not officially release the cause of Tony’s death (Tambar, 2009, para. 3).

I begin this dissertation with the telling of the stories of these two cases of violence not because they are particularly unusual or rare. I begin, here, precisely and disturbingly, because they are not. Indeed, in contemporary times and in western/ized spaces, we commonly and even routinely encounter resonant stories of violence against autistic people as these stories circulate through our news sources and through our culture. As the reports of these two murders surfaced and circulated – first the one and then, so soon after, the other – some identified resemblances between them and, importantly, declared these to be related acts of violence.

Following the murder of Tony Khor, the Canadian provincial advocacy organization, Autism Ontario, released a media statement entitled “Ontario Community Grieves Loss of Boy with Autism” (Autism Ontario, 2009)(Fig.1.1). “Yesterday, a mother [Cheng] took the life of her son with autism” the statement begins, “in Canada, this is the second time in a month that a parent has taken the life of their child with autism” (Autism Ontario, 2009, para. 1). Two children were murdered by their parents
Media Release
Ontario Community Grieves Loss of Boy with Autism

October 26, 2009 (Toronto, ON) – Yesterday, a mother took the life of her son with autism. In Canada, this is the second time in a month that a parent has taken the life of their child with autism.

The need for supports and services is keenly felt across Ontario. Families of individuals with Autism Spectrum Disorder know that autism services can be challenging to access. When a crisis occurs, this is often more pronounced.

Studies show that raising a child with autism is more stressful than raising a child with any other disability. Many parents are stretched beyond what they feel they can possibly cope with. In this situation, the outcome was the unthinkable.

“When a child with autism is in crisis, the whole family is in crisis, says Dr. Yona Lunsky, a clinical psychologist and Research Section Head in the Dual Diagnosis Program at the Centre for Addiction and Mental Health.

Dr. Lunsky continues, “Parents need to be able to access crisis supports to help their children but also to help them, the parents. No parent should feel so alone in a struggle that she or he thinks there is only one way out. At the very least, we need responsive crisis services for every child and family. But what are really needed here are appropriate supports prior to the situation developing into an emergency.’’

Autism Ontario offers support and information to families dealing with autism across the province. Executive Director, Margaret Spoelstra acknowledges that crisis intervention services can be a challenge to access for many families, but says, “Taking the life of your child should not be an option. If you are a parent or an individual in crisis, you need to contact your local crisis line.”

1 in 150 children are now being diagnosed with an Autism Spectrum Disorder. Autism is a developmental disability that prevents individuals from properly understanding and responding to what they see, hear, and sense. This may result in severe problems of social relationships, communication and behaviour.

Since 1973, Autism Ontario has been providing information, supports, and advocacy to families, professionals and individuals dealing with Autism Spectrum Disorders.

For more information on autism, and Autism Spectrum Disorder, visit www.autismontario.com.

Figure 1.1: Autism Ontario (2009) media release following the deaths of Tony Khor and the unnamed boy from Edmonton. Reprinted with permission.
in under a month and such violence called for advocacy as a response. In the violent
deaths of 15-year-old Tony Khor and his unnamed 11-year-old peer, advocacy (Autism
Ontario) heard a call to action and such a call, in turn, called advocacy into being. Yet, in
the midst of urgent calls of violence and the immediate necessity of a responsive
advocacy, we seldom ask: what (or whose) call is attended to and what kinds of responses
are, thus, generated? As advocacy is called to action and, so, called into being: what is the
meaning of the being of autism advocacy? This dissertation represents an attempt at
thinking through such multifarious questions.

The Crisis in Crisis

For Autism Ontario, the central call issuing forth from the deaths of the two boys
was the call of desperate parents needing better access to autism services and crisis
supports: “The need for supports and services is keenly felt across Ontario” the media
release states, “families of individuals with Autism Spectrum Disorder know that autism
services can be challenging to access. When a crisis occurs, this is often more
pronounced” (Autism Ontario, 2009, para. 2). Out of the deaths of Tony Khor and his
unnamed peer, Autism Ontario heard the call of many families living with individuals
with autism facing significant social barriers preventing access to much needed autism
services and supports. The problem identified by advocacy is clear: inadequate supports
for parents and families living with autistic people. What is equally clear is the necessary
response of advocacy: the ensuring of more services, better access. As a response to this
problem or call, advocacy, itself, was called into being as that which, of course, works to
secure more and better access to services and supports - a reason for being clearly
Ontario has been providing information, supports and advocacy to families professionals and individuals dealing with Autism Spectrum Disorders” (Autism Ontario, 2009, para. 8).

Yet, a careful examination of the terms and targets of the press release reveals subtle hints that indicate that the call to which advocacy is responding is a multi-sonorous one. The problem-in-need-of-response identified by Autism Ontario is not, simply, inadequate supports and services, but, rather, inadequate supports and services in relation to an underlying “crisis” – “when a crisis occurs” the statement tells us, the lack of access to supports and services is “often more pronounced”. Lying beneath and coming before the call for more access and better services is the call of parents and families in “crisis”. The media release goes on to provide us with informational facts regarding the nature of such “crises”. It tells us, for example, that the crisis at hand is a crisis born of the invariable stress of raising an autistic child: “studies show that raising a child with autism is more stressful than raising a child with any other disability. Many parents are stretched beyond what they feel they can possibly cope with” (Autism Ontario, 2009, para. 3).

In contradistinction to the taken-for-granted (normal) stress of raising (just) a child, raising a child ‘with’ a disability is remarkably stressful, say empirical studies and advocacy organizations in chorus. And, more stressful still is the task of raising a child ‘with’ autism. In addition to the task of raising (just) a child, parents of children ‘with a disability’ and/or children ‘with autism’ must also raise that which (we are told) is not ‘of’ but which comes ‘with’ this child: an individual biological condition of disability or autism. As it is made and kept separate from and extraneous to (just) a child, disability is inscribed by advocacy as the source of parent stress and autism as that which catalyzes
even more stress still. Autism becomes commonsensically understood as some undesirable ‘thing’ that has, simply, as a matter of biology or nature, come to be ‘with’ some people and their families and this ‘with’ of autism is, often times, too much ‘with’ which to cope.

The notion of autism as the originary source of undue stress in family life is secured and supported in the advocacy statement as Autism Ontario provides us with an overview of autism’s biological origin in individuals and a description of its pathologically deviant signs:

1 in 150 children are now being diagnosed with an Autism Spectrum Disorder.

Autism is a developmental disability that prevents individuals from properly understanding and responding to what they see, hear, and sense. This may result in severe problems of social relationships, communication and behaviour.

(Autism Ontario, 2009, para. 7)

The primary call that is attended to by advocacy – the call framed as a “crisis” underlying and exacerbating the need for greater access and better services – is the existence and persistence of an (medically and morally organized) autism that is located in growing numbers of individual bodies, a pathologically ‘disordered’ autism that prevents some individuals from “properly” seeing, hearing and sensing, and that causes “severe problems” in relating, communicating and behaving.

While the statement suggests that the developmental ‘impropriety’ of autism is, clearly and naturally, located and locatable in individual bodies and nowhere else – the ‘1’s in ‘150’s – its characteristic “severe” relationship, behaviour and communication “problems” are framed as the core of a collective “crisis” that begins with the individual
and that, in the absence of autism services and crisis supports, leaks out from this individual, enveloping parents, families and communities. The press release quotes a statement from Dr. Yona Lunsky of the Center for Addiction and Mental Health (CAMH) which speaks to this leaky crisis: “When a child with autism is in crisis” she reminds us, “the whole family is in crisis” (Autism Ontario, 2009, para. 4). Autism, taken for granted as nothing more or less than a biological disorder – some pathological ‘thing’ that prevents ‘good’ responses and incites ‘bad’ behaviours – is naturalized as the originary site of both individual and collective crisis, an identification that, in turn, orients and shapes the necessary response of advocacy. Dr. Lunsky continues by offering us her prescription for advocacy:

Parents need to be able to access crisis supports to help their children but also to help them, the parents. No parent should feel so alone in a struggle that she or he thinks there is only one way out. At the very least, we need responsive crisis services for every child and family. But what are really needed here are appropriate supports prior to the situation developing into an emergency. (Autism Ontario, 2009, para. 5)

In relation to the call of individuals and families in “crisis”, a call that is understood to be, as a matter of nature, born of a pathological autism, advocacy is called into being as that which must mitigate ‘autism crises’ (i.e., through the generation of autism services and crisis supports) before things turn violent (i.e., “[develop] into an emergency”).

I am in full agreement with Autism Ontario that the violence perpetrated against Tony Khor and the unnamed Edmonton boy (and the many other overt and covert acts of violence perpetrated against autistic people in contemporary times) represent a pressing
crisis and that such a crisis requires advocacy as a response. Yet, the crisis I am identifying might be best understood as a crisis of a different order. It resides in the common, taken-for-granted understanding of autism as, simply, a naturally occurring unnatural (pathological) biological disorder – a state of ‘too-slow’ development causing non-normative (transformed, so quickly, to morally ‘improper’) ways of understanding and responding, as well as “problem” relationships, behaviours and means of communicating – and, so, it resides in the question of advocacy, itself.

It is a crisis tied to the ways in which a biological version of autism – a version of autism that is most often secured and supported in and through contemporary performances of autism advocacy – presupposes it to be some ‘thing’ that belongs to some people (i.e., people ‘with’ autism) thereby prohibiting autism from being, in some essential way, a ‘someone’ (i.e., a valid and valuable way of seeing, hearing, sensing, an identity, an autistic person). And so, unlike Autism Ontario, the primary crisis call I hear issuing forth from the violent deaths of these two boys (and the many others like them) is not the call of an individualized biological or biomedical crisis, nor is it the call of a crisis of inadequate supports and services designed to respond to autism as such. The call I hear is the call of a cultural crisis, born of a relentless collective commitment to understanding autism as some ‘thing’ medically pathological and morally undesirable: as some ‘thing’ that some people ‘have’ but cannot ‘be’ and, so, as some ‘thing’ that we all must ‘be against’. Such a conception of autism has important (and, potentially dangerous) consequences for how we understand and perform responsive acts of autism advocacy.
Thinking the ‘Unthinkable’

Attending to the call of this cultural crisis, allows for new ways of critically and reflexively engaging with the risks and possibilities of relating to and across difference, and in so doing, it permits, and perhaps, even, compels us to think carefully about the practices and premises of autism advocacy in contemporary times. Attending to the call of a cultural crisis allows us to attend to how performances of advocating – exemplified in the Autism Ontario media release, but certainly not limited to this – function to produce and sustain crisis, even while making an appeal to quell it. The crisis the Autism Ontario media release fails to attend to or reflect upon is the crisis of the naturalization of the association between autism and stress-induced crisis and the normalization of violence that such crisis is understood to, inevitably, invite.

The press release offers us an explanatory story for the violence that was enacted against Khor and the boy from Edmonton. It provides us with a way of thinking – to borrow the language of the statement – ‘the unthinkable’. It helps us, in other words, to make sense of murder. Vis-à-vis the murders of the two boys, Autism Ontario offers us a neat and easy story of the nature of the problem that led to their deaths and the kind of advocacy response needed to address this problem. As we have seen, Autism Ontario’s advocacy story tells the story of a biological autism that can cause such high degrees of stress in the home that, in the absence of intervening services, “unthinkable outcome[s]” – violence, murder, even – may very well result.

Yet, as acts of advocacy cast the deaths of the two boys as ‘unthinkable outcomes’ of stressed out parents ‘coping with’ disordered children, we are dissuaded from attending to how such acts of violence against autistic people are rendered,
absolutely, thinkable and, even, normal. We – all of us, including those of us engaged in practices and performances of advocacy – are dissuaded from attending to the complex interpretive processes that move us, so quickly, from disability to crisis to violence, and that lead us to the conclusion that parents and families “dealing with autism” are, as a matter of nature and not as a matter of culture, stressed out and strung out to the point where violence is precisely possible, if not, inevitable.

Raising a child with autism is stressful, suggests the media release, and the source of the stress is clear: the ‘bad’ behaviours and ‘improper’ responses of individuals ‘with’ autism. Firmly rooted in biology, the anguish of parents and families is understood by advocacy to be unrelated to a dominant culture – of which acts of advocacy are, invariably, a part – that repeats over and again that autism is nothing more than a problem in need of a solution, some ‘thing’ undesirable, unwelcome and, some ‘thing’ that is sometimes tolerated, questionably accommodated, seldom celebrated: some ‘thing’, simply, to be (at least) rehabilitated and (at best) eliminated. The (dominant and near monolithic) story of autism as a series of ‘improper’ responses of the individual that generate significant stress for families – a story told and retold by dominant enactments of autism advocacy – functions to normalize and naturalize an understanding that violence is a reasonable or ‘proper’ response (albeit an undesirable one) of those “dealing with autism”. Understood in this way, autism is positioned by advocacy as the underlying cause of its own demise. And, such a conclusion, however covert, overtly fails to advocate for autistic people. A close examination of the media release reveals no acknowledgement of the pressing needs of and/or the crisis faced by autistic people as they are made victims of violence. Indeed, let us note how the two victimized autistic
people – the murdered children – were barely mentioned in the Autism Ontario media release, their lives and deaths left unreckoned with, evoked only insofar as they served as an occasion for the contemplation of the crisis of underserviced stressed out parents and families ‘dealing with’ a biological condition of autism.

Attending to the normative and normativizing nature of such stories of autism and advocacy enables us to ask difficult and important questions about the practices and premises of (our) acts of advocacy, and, more broadly, about the culture in which we live. Critically attending to such stories allows us to ask, for example, the following: how do dominant versions of autism that characterize it as a condition of human life instead of a lived human condition – a some ‘thing’ and not a someone – allow for and even catalyze our collective cultural failure to recognize violence against autistic people as a significant, pressing and socio-cultural problem? How are our dominant cultural orientations toward autism as some ‘thing’ pathological and so, as some ‘thing’ to be against – cultural orientations that are supported by dominant acts of autism advocacy – creating the conditions of possibility that render some lives more vulnerable to murder and other forms of (normative) violence? And, how are these same orientations providing for the doubly violent space where the lives and deaths of those violated can be radically forgotten: where it becomes possible for dead children and those who killed them to go unnamed, where the violence delivered to their bodies leaves the kind of mark that, as Judith Butler tells us, “leaves no mark”, a mark, moreover, upon which advocacy seldom remarks (Butler, 2004a, p. 36)? As advocacy is called into being as that which advocates against an undesirable biological condition of autism, how are acts of advocacy failing to advocate for (or even acknowledge) the crisis faced by autistic people...
whose lives are rendered relationally more vulnerable to violence and violation in and by a culture that commonsensically understands autism as some ‘thing’ we, collectively, would rather live without?

The Truth about Stories…

Philosopher Ian Hacking (2009a, 2009b) argues that stories of autism being produced in and that circulated through contemporary western/ized culture, are not so much providing descriptions of an autism that already is. Rather, according to Hacking, such stories are “contributing to the formation of the discourse of autism” (p. 514). Such stories, in other words, are functioning to constitute what autism is and can be. He writes:

I believe that the [autism narrative] genre is helping to bring into being an entire mode of discourse, cementing ways in which we have recently begun to talk, and will talk, about autism. It is developing a language, or, if you will, a new language game, one that is being created before our eyes and ears. This speech is, in turn, creating or extending a way for very unusual people – namely autistic ones – to be, to exist, to live. (Hacking, 2009a, p. 501)

Hacking (2009b) does place limits, however, on what he does and does not count as an autism story or narrative. The genre of autism narrative, for Hacking, does not comprise “expert reports by clinicians or reflections by theorists”, but is, rather, made up of “stories about people with autism, told by the people themselves, or their families, or by novelists, or by writers of stories for children” (p. 1467).
In chorus with Hacking, I begin this dissertation with the assumption that the stories we have – those given to us and those we share – are contributing to the formation of an historically specific autism discourse and that such stories are shaping what autism is and can be in contemporary times. Yet, while what autism is, is, no doubt, being constituted by autobiographical stories written by autistic people, parents’ stories of living with autism and narratives featured in novels about autism, it is also and at the same time being constituted by the – perhaps, more covert – stories told in clinician reports, for example, and in educational policies and practices, in advocacy awareness campaigns, scientific studies and, of course, in the reflections of theorists. As he tells the story of an autism that is undergoing an ongoing “social and cultural evolution” but that is undergirded by “a family of definite biological conditions”, or as he makes sense of autistic people as “very unusual people”, Hacking’s theorizations, too, are involved in the constitution of what autism is and can be (Hacking, 2009b, p. 1467).

What is more, the multiple, diverse and proliferating stories we have of autism are not separate from one another, nor can they be. Hacking (2009b) does acknowledge this. He writes: “different kinds of item influence each other in complex ways. Novelists study autobiographies, whose authors learn from theorists. Parents pick up ideas from novels when they are thinking about their children” (p. 1467). As they circulate in and through culture, stories impress meanings upon one another; indeed, they are enmeshed in an intricate, complex and ever unfolding web of meaning that allows for such hybrid possibilities as, for example, parent biographies that read and function as clinical reports, describing healthy and pathological behaviours, providing checklists of signs and symptoms of biomedical disorder and prescribing therapeutic intervention (for one of

With this in mind, I think that Hacking’s methodological act of delimiting the ‘autism narrative’ to include certain kinds of stories of autism (e.g., autobiographies by autistic people, parent biographies and reflections, fiction novels and storybooks about autism) but not others (e.g., clinician reports, reflections by theorists) not only represents an artificial divide (as all divides, invariably, are), but a divide that makes it too easy for us to forget that what autism is and can be today has everything to do with the ways in which stories appear against a cultural backdrop that privileges the telling of some stories over and against others. This methodological move of drawing the divide, in other words, dissuades us from thinking about power. It moves us away from, for example, acknowledging and questioning the ways in which autobiographies of autistic people are always and differentially left open to the authoritative gaze of autism ‘experts’ – professionals and non-professionals, alike – and, so, are always at risk of being delegitimized and discarded as ‘inauthentic’ or ‘inaccurate’ or non-authoritative. This was evident, for example, in the fallout after autism activist Amanda Baggs’ appearance on CNN where she was interviewed by chief medical correspondent, Dr. Sanjay Gupta, and offered some personal/autobiographical insights of her lived experience as autistic (Gupta, 2007). Following her appearance, Baggs was widely scrutinized by various ‘experts’, some claiming she was ‘not autistic enough’, while others disregarded her autobiographical story altogether by casting it as a ‘hoax’.

If the proliferation of autism narrative is “helping to bring into being an entire mode of discourse”, if it is involved in the constitution of the limits and possibilities for
talking about – and understanding – autism today, then we must address the sheer force of the underlying power structures involved in governing contemporary autism discourses. For, while I am in complete agreement with Hacking that there are autism narratives that are transgressively functioning to create new ways for autistic people “to be, to exist, to live”, as we shall see throughout this dissertation, there are also a great many (dominant and dominating) autism narratives that are repeatedly telling us that autism is not a way of being or existing, and it is no way to live.

If stories are not what we have, but, as both King and Titchkosky suggest, what we are, then we are all – autistic and non-autistic, overtly and covertly, actively and passively – implicated in their telling. Yet, even as we all participate in the telling of the contemporary story of autism, we do not all find ourselves on even ground. Some autism stories are relationally endowed with greater power and (so) more legitimacy – as is quite evident, for example, in the Autism Ontario media release where parents’ stories of autism as crisis were so clearly centered while the stories of autistic people in (sometimes mortal) crisis were not attended to at all. So powerful are some stories, even, that they are widely understood not to be stories at all. For Hacking, for example, an autobiographical account of living with autism is recognized as a story engaged in the constitution of what autism is and can be, while an etiological origin story of autism as a ‘definite’ biological condition remains a taken-for-granted (natural or unstoried) fact.

In response to the dominant, cultural story that tells us that some stories are stories, while others are natural or unstoried facts – ‘just’ observation, information, fact, knowledge – my work understands everything as storied and story-ing. Throughout this dissertation, I read stories of autism in and across a great variety of representational
‘reading materials’, both usual and unusual; I read stories in newspaper articles, scientific studies and historical materials but also in up-to-minute newsflashes, in posters hanging in doctor’s offices and in presidential addresses, in urban billboards and in court decisions, stories printed on paper coffee cups and stories buried in international resolutions.

I draw such ‘reading materials’ from an expansive array of varied and, often, disparate representations of autism – cultural artifacts collected over the course of my six years of graduate study. It began with a clipped newspaper article, here, or an informational pamphlet, there: legible cultural artifacts that, in time, came to fill a great many file folders – both physical and virtual. By the time I concluded the formal ‘data collection’ phase of this dissertation, I had folders brimming with representations produced in and circulating through (contemporary, western/ized) culture: autism information pamphlets, for example, awareness campaign materials, newspaper clippings, images, posters, speeches, public service announcements, statistical reports, webpages, educational materials, government texts, fundraising appeals, policy documents, documentary films, biographies, self-help books, various consumer goods and so on. Some of these sources I actively sought out while others I stumbled upon, quite by accident, as I was going about my day.

Such a fragmentary approach to data collection and analysis allowed me to attend to, account for and begin in the midst of the web of autism stories, stories that are ubiquitously proliferating throughout the west and, so, throughout the world. In a global/izing economy that privileges the fast, efficient exchange of information and knowledge, I attend to how autism appears in everyday life as an abbreviation; its
multiple meanings distilled down to a series of ‘red flags’ behaviours, for example, or
‘terrifying’ statistics or ‘tragic’ outcomes. The theoretical/methodological act of bringing
together seemingly incongruent and fragmented cultural artifacts created what Jasbir Puar
(2007) might call a “non-normative vantage point” from which I, as researcher, could
glean the particularities of their resonances and trace out their continuities so as to,
ultimately, expose an underlying story; a dominant narrative that not only teaches us
something about the values and fears of a (neo)liberal western modernity but that also
works to delimit the multiple, complex and meaningful ways in which autism is put into
discourse in contemporary times (p.xvi).

A Culture at War

As I read across the reams of autism ‘reading materials’, it was difficult to miss
the relentless commitment to and repetition of a dominant, almost monolithic, narrative.
Files collecting and uniting seemingly disorganized representations of autism provided a
surface upon which to glean very organized and very limited cultural scripts. Autism. A
pathology of the mind and body. A grueling cost. A life-draining epidemic. A dangerous
threat. A biological problem needing a biomedical solution, needing to be stopped, cured,
fixed, eliminated. Such limited scripts reveal an even more limited cultural imaginary:
autism is some ‘thing’, the artifacts seemed to repeat, time and again, it is not ‘someone’
– some ‘thing’, they lament, we do not want to have around. I take this story to be
characteristic of a culture ‘against’ autism: a culture that is, as many have (often,
uncritically) said, waging a ‘war’ on autism. A culture that understands itself to be
‘living with’ autism and that wishes to – and works to – live without it.
It is this cultural ‘war on autism’, I argue, that forms the backdrop out of which all contemporary western/ized stories of autism appear and against which these are read. In this way, it provides the power-laden grounds that privilege some ways of storying (thinking, talking, understanding) autism, while marginalizing others.

As I read across the cultural artifacts, I quickly began to notice that the story of autism is very often told and retold by individuals and collectives engaged in, what might, broadly, be described as the work of autism advocacy. Indeed, the contemporary discourse of autism advocacy has become (one of) the most dominant and powerful ways of representing and, so, making sense of autism today.

**Toward a Non-normative Autism Advocacy**

This dissertation explores how, instead of disrupting the dominant cultural orientation against autism by advocating for autism, mainstream forms of autism advocacy, most often, support and sustain it. Indeed, we find ourselves in a contemporary social context where many different kinds of advocates - doctors, celebrities, politicians, journalists, parents, school teachers and shop keepers – are coming together in the ‘fight against autism’; where autism is commonly narrated as a terrifying and terrorizing villain, stalking innocent children and destroying the ‘good’ life. That autism must be ‘combatted’ and ‘defeated’, ‘eliminated’, ‘cured’ is written into US law, institutionalized in public policy and sung throughout popular culture.

While such examples are overt and glaring, there are many other, more covert ways of waging war on autism enacted by contemporary versions of advocacy. Indeed, the work of autism advocacy – as we saw in the opening story of Autism Ontario and as we shall see over and again in the chapters that follow –is most often delimited as the
work of non-autistic people spreading the word about autism as a medically pathological and morally undesirable individual problem of epidemic proportions, the work of securing an abnormal and disorderly autism with the presumed order of normalcy. In chorus with the dominant orientations of our contemporary culture, common, everyday enactments of autism advocacy cast autism as a pathological threat to normative life and call up advocacy as that which must eliminate this threat. Such stories function to shape ‘life’ as conditional and autism as (one of) its condition(s).

This project of examining and analyzing the cultural production of autism and autism advocacy is not an empirical one. As I read across my collection of contemporary cultural artifacts, I do not, for example, attempt to determine which representations of autism are “positive” and which are “negative”, nor am I interested in placing moral judgment or blame on particular individuals or organizations. Indeed, this dissertation rejects individualization of all forms. I begin and end with the assumption that advocacy always and only appears in and of a culture, a culture that, moreover, continually informs us, via entwined processes of medicalization and moralization, that autism is an individual matter – that it is located in and belongs to particular individuals (individuals ‘with’ autism, for example, or families living ‘with’ autism), that life ‘with’ autism is life that is not as it ought to be and that it is, ultimately, the responsibility of individuals to ameliorate any problems or challenges that can and do arise from living life ‘with’ autism. Resisting the persistent, seductive and, I think, dangerous call of this culture’s radical individualism, I claim that the stories we have of autism belong to us all and so are stories that we all must attend to.
In this way, my reading of the cultural production of autism advocacy is always a partial reading, always a reading-with. As I read with and across the collected cultural artifacts, I am reading with, for example, critical interpretive work born of the fields of disability studies, critical race theory, cultural studies and queer and feminist studies. I am also reading with my own experiences as a non-autistic member of a disability community of activists and scholars, as a disability studies student and teacher and as someone who lives an ever-partial relation to disability. I have been raised by and alongside disability. I have been mentored and taught by disability. I have lived disability and I have lived the privilege of moving in and out of it, a privilege that is, in part, accomplished by way of my middleclass whiteness. I also live in and of a world that neither values nor welcomes the ‘difference that disability makes’ (Michalko, 2002), a world that, often, works to eliminate disability altogether. I have and continue to live with, in and amongst disability. And we all do. As I read cultural enactments of advocacy throughout this dissertation, I am always reading with these experiences and the spaces between them that both connect and distinguish them. And so, my reading of contemporary western/ized culture and its production of autism and advocacy is also a writing of these. I write the contours of the contemporary discursive space of autism advocacy, I trace the shape(s) of its privileged/permitted subjectivities and I demonstrate its dangerous logics of exclusion.

In reading and writing the premises and practices of autism advocacy, I am not calling for an abandonment of the project of advocating. Of course, I, too, am engaged in this act. Indeed, my work represents the risk with which all advocates are faced as we find ourselves in the midst of social and political differences: the risk of speaking,
writing, representing, defending, condemning, protesting, championing, fighting and supporting difference from within relational systems of power. To say that advocacy is risky, of course, is not to say that we should stop engaging in acts of advocacy; it is rather to bring into focus the necessity for critical engagement with the historical, geographical and political dimensions and power relations that invariably structure what it means to advocate, and what it is that we are advocating for. If to speak up, speak out, speak-on-behalf-of is one crucial (if not inescapable) function of living with others - and I believe it is - it becomes necessary to trace acts of advocacy along the lines of our (power) relations, to attend to the ways in which acts of advocacy are producing and governing ourselves and others.

The pages to follow represent the belief that the other ‘truth about stories’ is that they could be otherwise; the belief that is in attending to the organization and management of the discursive space of autism advocacy and the constrained production of the subject positions of ‘advocate’ and ‘advocated for’ within these spaces, that we might begin to imagine a non-normative (and non-normativizing) autism advocacy.

Overview

I lay out my thesis in six chapters. I begin, in the next chapter, with a consideration of the symbolic value and the productive effects of the international moniker of autism awareness: the figure of the puzzle. Understanding the puzzle as a kind of “orientation device”, I explore how it is orienting the awarenesses we (can) have of autism in contemporary times and in western/ized spaces (Ahmed, 2006, p.4). The usage of the puzzle by dominant, mainstream enactments of autism advocacy presupposes that the only (desirable) way to orient to a puzzle (of autism) is to try and
solve it. I suggest that there is transgressive value in the theoretical/ methodological act of (re)orienting to the puzzle of autism as a puzzle, and that this act of reorientation can teach us something about the puzzling nature of our relations with and across embodied difference. Such a transgressive re-orientation to puzzles and to people as sites of, inherent, uncertainty demands a theoretical and methodological turn away from the seductive certainty of an empirically knowable autism and moves us, instead, toward the uncertain task of becoming aware of those awarenesses we already have of autism and of advocacy.

I take up this task of ‘puzzling’ taken-for-granted relations in chapter three, “Delivering disorder: Historical perspectives on the emergence of autism and advocacy in the west”, where I look to the emergence of autism as a category of being and to the historical underpinnings that made possible particular and contingent understandings of autism and autistic people. I reveal how historically specific ways of narrating and understanding autism as pathology permitted and even demanded the emergence of very particular versions of advocacy. However, far from being, simply, a response to a disorderly autism, advocacy has become a productive force that has and continues to govern what autism is and can be.

The tangled tie of autism and advocacy is made ever more explicit in chapter four, “Raising the ‘red flags’ of autism: Advocacy awareness campaigns and the development of the human”. Placing autism within the historical context of an enduring biomedical tradition of discrediting and dehumanizing particular bodies – racialized bodies, for example, colonized bodies, queer bodies, classed bodies, women’s bodies and so on – through discourses of developmentalism. I examine how notions of autism as improperly
or not ‘fully’ developed work to create autistic bodies as both deviant and, as always and already in need of development. I show, moreover, how the conceptualization of autism as a ‘not-yet’ developed human inaugurates an advocate who must become literate in reading particular (autistic) behaviours or ways of communicating as “red flag” warning signs of deviancy and who, ultimately, must take up the normativizing role of a (human) developer.

Chapter five, “Act NOW: The s/pace advocacy in a temporality of urgency”, extends this analysis by looking to and ‘getting with’ neoliberal times and its normative and normativizing understanding of developmental time. I examine a multitude of cultural artifacts both mundane and spectacular, as prolific, productive and powerful sites of meaning making that shape collective experiences of the passing of time (i.e., as either too slow or too fast) as well as our understandings of bodies in time (i.e., as being either ‘on time’ or ‘late’). As autism is narrated as a growing threat to the ‘good life’ of neoliberal development, autism advocacy is called into being as that which must generate more and more ways to ‘neutralize’ the non-normative threat of autism by acting now on individual bodies to secure ‘better’ (i.e., more normative) futures for all.

Building on the notion of danger expressed in the ‘red flag’ warning systems analyzed in chapter four and the sense of urgency of the temporal environment depicted in chapter five, chapter six examines the tactics and targets of a culture at war with autism. Born of a culture ruled by normative versions of life, the figure of autism enters our dominant frames of recognition as a kind of cultural ‘outlaw’, always and already guilty of life-threatening crimes of terror. I connect this so-called ‘war on autism’ with another and contemporaneous war – the ‘global’ war on terror – so as to reveal the points
where these war-time discourses converge into a shared (neo/liberal, biopolitical) frame. I suggest that such a frame conditions the possibility for very particular appearances of pathologically terrifying and terrorizing figures in need of militarized ‘ally’/’advocate’ intervention: enemies to be combated and, ultimately eradicated.

The final chapter of this dissertation explores the necessary casualties of a culture at war with autism. Chapter seven, “Collateral Damage: Normalizing violence and the violence of normalcy”, demonstrates how covert and overt discourses of autism advocacy that narrate autism as some ‘thing’ that is ‘in’ and not ‘of’ some people function to shape ‘life’ as conditional and cast autism as (one of) its condition(s). I tease out the danger of this everyday way of conceptualizing autism as a ‘some thing’ and not a ‘someone’ through an examination and analysis of a series of newspaper articles reporting on three recent murders of autistic children. As autism is discursively and ideologically made and kept separate from the vital category of life itself, and as bodies and minds of living people are routinely and relentlessly split into vital and non-vital parts, individual and collective life ‘with’ (the condition of) autism becomes life that can be plotted along a vital spectrum anchored by oppositional poles of ‘life’ and ‘death’. Such a spectrum inaugurates the possibility of new, graded categories of life and death – ‘almost living’ lives as well as ‘mostly dead’ ones. By demonstrating how such an understanding of the conditionality of life is a necessary pre-condition for normative acts of violence – violence enacted in the name of securing the norm and violence that is normalized as necessary – I issue a call for all of us engaged in autism advocacy to attend to the powerful and power-laden stories we have and tell of autism and of advocacy and to tell these stories differently and otherwise.
CHAPTER TWO

Puzzling our Relations: Theory, Method, Ethics

This chapter outlines the theoretical and methodological perspectives crucial to conducting an analysis of representations of autism in contemporary advocacy work and, more broadly, and contemplating the political and social dimensions of ‘living with’ autistic difference. In the pages that follow, I work through theory and method alongside one another as a way to bear witness to the interconnectedness of these two areas in my research. And so, this chapter represents the understanding that theory shapes and guides our orientations and approaches, and method involves much more than mere procedure. As a critical area of scholarship and activism, disability studies exemplifies this comingling of theory and method, both serving as a theoretical approach for my dissertation and shaping its literary and philosophical foundations.

This field of disability studies represents a dynamic, interdisciplinary, theoretical heritage of fiction, art, performance, activism and critical scholarship, to which my work is responding and contributing. Yet, it represents much more than the grounds beneath this work. As disability studies provides a rich theoretical foundation, it, simultaneously, shapes and orients my research project in a particular way. Disability studies shapes the methodological lines that I follow as I conduct an interpretive analysis of cultural representations of autism produced and circulated by individuals and organizations engaged in autism advocacy work. The perspectives I adopt, as a disability studies
A ‘Puzzling’ Approach to Theory/Method

David Mitchell (2002) writes, “nearly every culture views disability as a problem in need of a solution, and this belief establishes one of the major modes of historical address directed toward people with disabilities” (p. 15). As a disability, autism has been theorized – almost exclusively – not only as a problem, but as a biological problem in need of a biomedical solution (Biklen & Attfield, 2005; Douglas, 2010a; McGuire & Michalko, 2011; Nadesan, 2005). And, advocacy has almost always been touted as one such solution (Ne’eman, 2010; McGuire, forthcoming). If we are to theorize autism not as a mere problem in need of a solution, but, rather, as a socially, historically, economically and politically mediated space of questions, then it becomes necessary to stretch and bend current theories and methods. For this reason, this dissertation is interdisciplinary in its scope; it does not subscribe to a single tradition or discipline.

Rather, I bring into proximity multiple and diverse theoretical approaches from across several disciplinary traditions: phenomenological and post-structuralist thought in the fields of disability studies, critical race theory, queer theory, as well as in feminist and post-colonial studies. In doing so, this work pieces together an assemblage of theoretical fragments that might offer transgressive perspectives from which to analyze and critique how the phenomena of autism and advocacy are delivered to us in contemporary times. Put differently, this dissertation will not posit a single, unified approach, but a collection
of approaches, that, taken together, might open up new possibilities for how we can imagine, shape, and respond to autism and advocacy in new ways.

As with all processes of understanding, theories and methods are always and already about our ever-partial awarenesses – what we are and can be aware of – what we can ‘see’ from particular and contingent vantage points, what we ‘feel’ as we come into contact with another. Thus, as a way of introducing theory and method, while also recognizing the inherent partiality and uncertainty of these organizational processes, I reflect on the international symbol of autism awareness, the puzzle piece. In addition to its representational power as a symbol of autism and autism awareness, the puzzle piece represents a methodological and theoretical object that guides – and so limits – perspectives on autism and shapes – and so constrains – responses to autism.

The puzzle is a paradoxical site of limit and possibility. It has been taken up by individuals and organizations engaged in autism advocacy as a metaphor representing the story of the search to find a solution for autism’s purported puzzling mystery. Yet, orienting to the puzzle as in need of a solution is only one, albeit common, way of orienting to puzzles. The puzzle itself – the puzzle as a puzzle – can also tell us something about resisting the persistent, seductive desire for clarity and solution. The puzzle, in other words, can also tell us something about living with partiality and uncertainty.

**Oriented Awarenesses**

This dissertation begins, and ends, with puzzles. In the west (and such a geographical boundary must include those many non-western spaces to which western/izing health discourses are being exported) autism has had a longstanding
association with the figure of the puzzle. In the much the same way that, for example, the pink ribbon has symbolically come to represent breast cancer awareness or the red ribbon, AIDS awareness, the puzzle piece has been adopted as the icon of autism awareness. The puzzle piece brands a great many contemporary advocacy organizations worldwide (Figure 1.1) and it is commonly used to mark ‘autism awareness’ on car bumpers and websites, necklaces and keychains, shopping bags and posters, golf balls, cufflinks and champaign glasses and so many other likely and unlikely places (see Figure 5.4 in Chapter 5). If to tell the story of our awareness of otherness is a necessary (and, even, desirable) function of living with others, it also becomes necessary to understand our awareness stories as functions of power: to attend to the ways in which such stories are producing and governing our selves and others.

In her book, *Queer Phenomenology*, Sara Ahmed (2006) writes: “to be oriented is to be turned toward certain objects, those that help us to find our way” (p. 1). In relation to discourses of autism awareness, the figure of the puzzle is one such object. In the following section, I work through *how* the figure of the puzzle not only marks ‘autism awareness’, but also orients our collective ‘awareness’ of some-thing called ‘autism’ and I attend to the inherent uncertainty of the task of awareness. Of what are we aware, as we become aware of autism? How is the figure of the puzzle orienting us in relation to autism? How is this object, following Ahmed, helping us to “find our way” in relation to autism?

**The ‘Puzzle of Autism’**

I now turn toward this so-called ‘autism puzzle’, trace its jagged contours, and attend to the ways in which it is working to shape our awareneses of and relationships
Figure 2.1: A selection of logos from autism advocacy organizations and initiatives from around the world that draw on the puzzle piece iconography. Organization logos reprinted with permission.
with autism. I ask: how are we in touch with this ubiquitous figure of the autism puzzle? Perhaps we might begin to think through this question by considering how we are in touch with puzzles in general. Consider the example of a traditional jigsaw puzzle.

Jigsaw puzzles are composed of pieces of a whole. They are made up of parts that, if put together in a predetermined way, (re)-create an originary, whole picture. Imagine an unsolved puzzle. In this scene, the puzzle pieces are scattered; they lie, this way and that. In short, the isolated pieces are without any apparent order – a chaotic cacophony of colour, shape. Dominant understandings of puzzles suggest that the reasonable thing to do with this cacophony is to order it. When faced with a puzzle, we solve it or at least try to. In this way, puzzles are connected to a sense of possibility. The puzzle’s possibility – its promise – is that it can be solved by logically uncovering and piecing together the pieces, thus revealing some underlying, sensible and originary order.

With the jigsaw puzzle, possibility is inaugurated by the image on the box. This image recalls the promise that the unpredictable and uncertain disorder of the individual pieces can certainly be brought together and arranged into a sensible, orderly whole. Individual pieces are, then, brought into proximity by the puzzle solver and they are locked into place. The puzzle solving process is governed by a collection of ‘rules’ and, in order to reasonably solve the puzzle, the puzzle solver must abide by these rules. Such ‘rules’ dictate that proximity must be achieved through fitting the pieces together, by orienting the pieces in particular ways and by connecting them in a predetermined order. And, there is a ‘right’ fit and a ‘wrong’ fit. For a jigsaw puzzle to be complete, the pieces must be tessellated, that is to say, the pieces must come together in such a way that there
are neither overlaps, nor gaps. Isolated pieces are transmogrified; the puzzle that is solved is no longer a puzzle at all, but a picture. An old image is made anew. So the story goes.

As I mentioned earlier, autism advocacy often draws on dominant understandings of the jigsaw puzzle as metaphor for the character of ‘autism’. In her essay, “Perspectives on a Puzzle Piece” (1997), Heather Green Allison – a founding member of the UK advocacy organization, the National Autistic Society (NAS) – characterizes the history of the puzzle as symbolic of autism in the following way:

The puzzle piece is so effective because it tells us something about autism: our children are handicapped by a puzzling condition; this isolates them from normal human contact and therefore they do not 'fit in' (para.26).

This same meaning of the metaphor of the puzzle was made particularly explicit when, in honor of World Autism Awareness Day (WAAD) in 2009, celebrity artist Yoko Ono was commissioned by the US-based advocacy organization, Autism Speaks, to create a seven-foot-tall puzzle – entitled PROMISE (Fig. 2.2). Ono’s puzzle – which depicts a scene of a blue sky with white clouds – is comprised of 67 pieces, which, according to Ono, symbolize the 67 million people worldwide affected by autism (Autism Speaks, 2009a). The pieces were broken apart and individually auctioned off to raise funds for autism research, but only with the promise that when the cure for autism is found, all the pieces would be reassembled once again for a day. Said Ono in an interview on the Today Show: “[the puzzle mural] is still imperfect and we’re going to solve the mystery
Figure 2.2: Yoko Ono's 7-foot tall mural, “PROMISE”, unveiled at the United Nations Headquarters in New York on World Autism Awareness Day 2009. “PROMISE” is composed of 67 puzzle pieces which were individually auctioned off to raise money for US autism advocacy organization, Autism Speaks.

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of autism and then we put it back there so that the sky will be complete again” (Autism Speaks, 2009a).

Drawing on the puzzle as metaphor, both Green Allison’s and Ono’s enactments of advocacy suggest that autism is a puzzling ‘condition’ that is locatable in the bodies and minds of certain individuals. Autistic bodies, it is remarked, are “handicapped” by the puzzling condition of autism, and because of this, these bodies are “isolated”, broken apart, and do not “fit in” to everyday “normal” “human contact”. These examples tell us that what is puzzling about autism is that crucial pieces of its presumed whole are missing or unknown. We do not have all of the pieces of the puzzle of autism – the story of what autism is remains an “imperfect” one. And, indeed, without all of the pieces, it is impossible to put together (and thus to have) the whole ‘completeness’ of autism. As Ono’s art piece reminds us, and as per our dominant orientation to puzzles, the reasonable thing to do with a puzzle is to find the missing pieces, to search and re-search, to “solve the mystery” and to find a cure. The solution to autism’s so-called dis-order is conceived of as the revelation of more pieces of (typically, biomedically oriented) information – more accurate brain scans, more precise genetic tests, more case studies – and to connect this information in such a way that gives order to the so-called (‘autism spectrum’) dis-order. The autistic body, itself, is therefore always and already conceived of as inherently dis-ordered, unpredictable, unknown.

Still, even as the autistic body is framed as ‘disordered’ and ‘unknown’, it is simultaneously, framed as order-able, and, essentially, knowable. The puzzle is drawn upon in relation to autism only insofar as the puzzle is interpreted as a problem that requires a solution. Moreover, the figure of the puzzle makes ‘solution’ appear as both
desirable and attainable. The partiality and so the uncertainty of the ‘autism puzzle’ is recognized only with an implicit understanding that knowledge about autism can be made certain with enough sleuthing – the progressive and objective unveiling of the elusive, but nonetheless existent, whole and static ‘truth’ of autism. In this context, what is puzzling about autism is read in a particular way, namely, as a biological problem or puzzle that ought to – and can – be solved, or in familiar biomedical terms, ‘cured’.

Recall that once a jigsaw puzzle is solved, it ceases to be a puzzle; it is instead transformed into a picture. The common sentiments of hope and possibility that have come to be associated with the metaphor of the ‘autism puzzle’ – sentiments symbolized in the image of the open blue sky of possibility from the Ono mural – represent the hope and “PROMISE” that the puzzle might not always remain as such. Put differently, the puzzle metaphor comes to represent the hope that what is puzzling about autism might be solved, what is uncertain may be made certain, what is partial might be made whole; it comes to represent the hopeful possibility that the disorderly body of ‘autism’ might be modified, rehabilitated, and the orderly and expected body of ‘non-autism’ – the metaphorical ‘picture on the box’ – might be recreated, or as is now commonly articulated in autism advocacy discourse, ‘recovered’.

This orientation to puzzles and people implies that autistic difference (that is to say, autism as autism and not as, say, autism on the way to non-autism) is neither valued nor valuable in our collective life and even works to produce and sustain conceptions of autistic difference as non-viable. Yet, as many autistic activists and advocates have articulated, autism is more than merely a puzzle needing to be solved (consider, for example, the autistic self-advocacy pin featured in figure 2.3 with the slogan,
Figure 2.3: Autism advocacy pin from autistics.org, a web project by and for autistic people. Photograph by Eduardo Trejos. Reprinted with the artist's permission.
“I am not a puzzle, I am a person”). Disability studies, too, presents us with another way of conceiving of autism as more than a problem/puzzle in need of a solution. A disability studies perspective – a perspective out of which my work grows and to which I contribute – invites us to contemplate what is puzzling about autism and advocacy and make it matter differently.

Disability Studies

The field of disability studies has given birth to a great variety of critical scholarly and activist work that examines the socio-political dimensions of disability and analyzes socially, geo/politically, historically, and economically inflected processes of excluding and including disabled people in everyday life (see, for example, such disability studies work as Davis, 2002; Erevelles, 1996; Garland Thomson, 1996; Goodley, 2010; Kumari Campbell, 2009; McRuer, 2006; Michalko, 2002; Oliver, 1996; Titchkosky, 2007). Drawing from and beginning in the midst of this rich disability studies inheritance, my dissertation also contributes to the field by thinking through the particularities of contemporary versions of autism and by exploring the unique questions that autism is asking of disability studies in the contemporary moment.

Disability studies is a field which is as varying in its scope as it is cohesive and focused. Titchkosky (2007) writes: “disability studies is an interdisciplinary field inclusive of a great deal of variety since the social significance of disability, its exclusion and inclusion, can be tracked and traced in and by every discipline” (p. 37). The variability of scholarly and activist work being produced in disability studies reflects the diversity and variability of disability itself; the vastness of embodied difference and the meanings attributed to these differences in particular and contingent times and spaces,
and upon uneven and shifting terrain. As Catherine Kudlick (2003) writes: “Disability
takes for its subject matter not simply the variations that exist in human behaviour,
appearance, functioning, sensory acuity and cognitive processing, but more crucially, the
meaning we make of those variations” (p. 763). Disability studies, like (the meaning of)
disability itself, is neither singular, nor static.

Despite the inherent plurality that makes up disability studies, as Lennard Davis
(2006) points out, it does, however, “unite a variety of ongoing work” (p. xvi). Common
threads and orientations tie diverse and sometimes even conflicting perspectives together
to create ‘disability studies’ as an interconnected critical tradition of inquiry. Perhaps
one of the most crucial orientations of disability studies is the notion, here articulated by
Titchkosky and Michalko (2009), that “disability studies does not, strictly speaking,
study disability” (p. 5). A disability studies perspective rejects the dominant and almost
monolithic notion that holds disability as some ‘thing’ – an object – to be observed,
measured and/or studied. As Davis (1995) notes, “disability is not an object – a woman
with a cane – but a social process that intimately involves everyone who has a body and
lives in the world of the senses” (p. 2). In this way, as Dan Goodley (2010) tells us,
disability studies represents a “paradigm shift”; the ‘object’ taken up by disability
studies is a set of social, historical, geo/political, economic and cultural processes that
work to regulate the ways we think about and think through our bodies and the bodies of
others and that produce disability as a socially meaningful category (p. xi).

This notion of disability as a social phenomenon is largely indebted to the
conceptualization of a social model of disability and the foundational work of such
disability studies scholars and activists as Len Barton (2002), Mike Oliver (1990), Colin
Barnes (1998) and Vic Finklestein (1998). Following the 1974 reformulation of
disability by the Union of the Physically Impaired Against Discrimination (UPIAS), the
social model of disability posits a critical distinction between disability and impairment.
Barnes (1998) summarizes this distinction as follows:

Impairment concerns the biological ‘lacking part of or all of a limb, or having a
defective limb or mechanism of the body’ – and disability is about the social: ‘the
disadvantage or restriction of activity caused by a contemporary social
organization which takes no or little account of people who have physical
impairments and thus excludes them from participation in the mainstream of
social activities’. (p. 73 [citing UPIAS, 1976, p.14])

Disability, in the social model, becomes politicized as a state of social oppression and
material disadvantage. Eli Clare (2001) writes of a disability “not defined by our bodies,
but rather by the material and social conditions of ableism; not by the need to use a
wheelchair, but rather by the stairs that have no accompanying ramp or elevator” (p.
360).

The understanding of disability as a politicized social category has other debts
still. Disability Studies is born of and tied to an ongoing history of radical social and
political activisms and to the scholarly writings that have and continue to constitute
feminist movements, for example, as well as queer, class and critical race movements
(Goodley, 2010). The past and present of disability studies and disability activism, has
been and continues to be shaped by the ongoing struggles that confront all oppressed
people in the fight for civil rights and social justice.
Recalling Mitchell’s (2002) observation that disability is, almost always, conceptualized as “a problem in need of a solution” (p. 15), disability studies holds that such a ‘problem’ status – and the resultant social oppressions and material disadvantages faced by disabled people – is neither natural nor inevitable. To the contrary, disability studies holds that disability oppression is related to and perpetuated by dominant cultural ideologies and values (Abberley, 1987). Titchkosky (2007) writes: “a defining feature of disability studies scholarship […] is that it is establishing a tradition of inquiry that problematizes the ways in which disability is figured against an ahistorical, apolitical and even asocial background” (p. 38). The overarching ‘problem’ for disability studies, then, is not the ‘problem’ body. Rather, disability studies problematizes the processes and systems that govern the production of certain bodies as always and already a ‘problem’ and, in this way, distinguishes itself from the more common positivistic studies of the bodies, minds and senses of disabled people that proliferate in many fields of inquiry such as psychology and psychiatry, education, and the medical and rehabilitative sciences.

The foundational move to locate the ‘problem’ of disability in a set of regulatory social processes problematizes, and so disrupts, common and dominant ways of interpreting and responding to disability as an undesirable, individual pathology – a personal tragedy, a private ‘problem’, a biological mistake, a body-gone-wrong, a mind that does not function as it ‘ought to’, some-thing one ‘has’ and must ‘overcome’ and so on (Garland-Thomson, 1996; Linton, 1998; Michalko, 1998; Titchkosky, 2007). In so doing, disability studies offers a space to engage in critical analyses of how social and
physical environments, as well as intersubjective relations, structure and organize material inequities and violences.

**Puzzling our Relations: Theory/Method as a Space of Encounter**

The dominant way of orienting to a puzzle is to seek its solution and this is evident in how the symbol of the puzzle is made meaningful in autism advocacy work. But can it be otherwise? Heeding the call of disability studies, rather than drawing upon the puzzle as a metaphor that objectifies individuals or an individual condition, providing a story of a body-gone-wrong, I am suggesting that we make use of the notion of the autism puzzle as a social act that is directing the ways in which we come into our awareness of autism. As a way to attend to multiple and marginalized conceptions of autistic difference, we might understand autism as a social condition that puzzles, provokes, and questions.

What new possibilities might this re-orientation allow for? If the figure of the puzzle is typically read as marking the possibility of wholeness and certainty, can it not be transgressively re-oriented to as a symbol of partiality and uncertainty? In this act of re-orientation, perhaps we might re-conceive partiality and uncertainty as essential parts of human difference, and therefore as valuable an even as something to desire. For the remainder of this section, I explore how ‘we’ (all of us) might begin to re-orient to the puzzle as a puzzle, not as some-thing that is in need of solving, but as an event that can remind us of the partiality and the uncertainty of our awarenesses and, so, our relatedness; an event that is, and must be, insoluble.

The question remains: in the absence of the possibility for its solution, what is the value of a puzzle? As a way to begin to glean this, I would like to tell a story. This
story is a memory and, as such, I am engaged in an ever-partial process of remembering. And so, this story is, inevitably, about incomplete awarenesses. I was young, maybe six or seven. My younger brother was upset, crying. We were playing together in the sand and then...tears. I remember putting my hand on my brother’s arm, having been taught that that is how ‘we all’ show and express love, that is how we comfort, soothe, make better. I remember him responding to my seemingly ordinary touch by swiftly recoiling his arm, shouting at me, jolting me out of the ordinary.

Only later, many years later, did he articulate that certain kinds of touches, particularly unanticipated ones, are physically uncomfortable, painful even. Only later, many years later, did I re-remember the story of my trying to comfort him, and reshaped the memory with new awareness. When I touched my brother’s arm, I suppose I was expecting him to feel what I would feel – the comforting touch of someone who cared. I acted on the supposition of a cohesive ‘we’. As ‘I’ made contact with ‘you’, I suppose I was expecting our ‘fit’ to be smooth – no gaps, no overlaps. Something, however, failed to get across in our interaction.

In this memory there is an invitation to be puzzled. The story’s gaps and incongruencies, its then-ess and its now-ness, its him-ness and its my-ness, its insoluble puzzles, invite me to begin to address, more broadly, moments and methods of contact on the basis of that which fails to get across. To return to the metaphor of the puzzle, there is no escaping those cracks, those gaps, that hold the pieces in place. And, even while some ‘fits’ might be smooth and comfortable, others might unexpectedly contort us, change our shape, shift our orientation. The interruption caused by disability’s
unexpected and, sometimes even uncomfortable, relation disturbs and, thus, questions the assumed wholeness and completeness of any ‘we’.

Insofar as autism interrupts and thus questions the assumed certainty of how ‘I’ connect with ‘you’, it provides a unique occasion to theorize this ‘we’, to work with and through our awarenesses of others in our research, our writing, our work, our activism, our relationships and, of course, our performances of advocacy. Autism pushes us to trouble our methods as, it would seem, methods are always, somehow, caught up in moments of contact, in acts of touching. How am I, as a researcher, connected to and encountering others? How am I being touched by others? How am I returning this touch? How are we reading, writing, speaking the other – how are we narrating a ‘we’?

Distance and Proximity: Levinas, Ahmed, Butler

As a place to begin a consideration of the impossible and necessary task of telling the stories of our awarenesses, of narrating a ‘we’, I borrow theoretical concepts and analytical techniques – ‘pieces’ – from a variety of fields of inquiry including phenomenology, feminist post-structuralism, queer theory, and post-colonial theory. Each of these ‘pieces’ offers unique and situated perspectives from which we can approach an analysis of our awarenesses of difference and otherness. It is my aim that these theoretical ‘pieces’, shorn together, might create a teetering, fragmentary kind of framework that can open up possibilities for new ways of encountering difference – transgressive ways of imagining the ‘we’ of autism and non-autism that allow space for multiple and, even contradictory, conceptions of this ‘we’.
This dissertation is not a search for answers; and so this theory/method chapter is not, strictly speaking, an attempt to develop a better approach to autism ‘awareness’ of or a more appropriate way of coming to ‘know’ autistic difference. Rather, this chapter is an attempt at laying a foundation for getting and staying in touch with knowledges or awarenesses that are always with us, already mediating our encounters with and across difference.

Thinking along with Emmanuel Levinas (1979), Sara Ahmed (2000) and Judith Butler (2004a), the remainder of this section will explore the puzzling paradox of living in a social world of others, who are – at once – intimately proximal and infinitely distant. Levinas (1986) reminds us that there is always a gap separating me and my other. The face of the other always, already “enters our world from an absolutely alien sphere” (p. 347); it resides entirely outside of me and, therefore, beyond the rational structures of my consciousness. My self-ness appears as autonomous and coherent, contained.

The other’s difference and distance, according to Ahmed, matters insofar as it is marked on and by our skin. Skin is the site of contact, the relational space of encounter between me and others. Skin is the boundary, the borderline marking my separateness from others. My boundedness seems complete. My self-ness appears as autonomous and coherent, contained – a singular and ‘isolated’ piece. However, pieces are only considered ‘pieces’ if they are pieces of something else.

Much like a piece of a puzzle, the ‘I’ is left open and exposed, following Levinas, and vulnerable to the connective touch of the other (Levinas, 1979). Butler suggests that it is precisely this vulnerability, this exposure to the other – to her gaze, to his touch, to violence or respect – that gives every-body an “invariable public
dimension” (Butler, 2004a, p. 26). Like the singular ‘isolated’ puzzle piece, the individual body is composed by the primary sociality of the self-other relation. Butler writes: “given over from the start [my body] bears the imprint, is formed within the crucible of social life” (Butler, 2004a, p. 26). The unevenness of my contours are always shaped and formed – sometimes gently, sometimes violently – by my relations to others, by the ways that I connect to you. I come into my skin – and so, into myself – only and always in proximity to you.

Ahmed warns that we need an analysis of the skin “not as the precondition of exposure or touchability, but as the locus of social differentiation” (Ahmed, 2000, p.155, my emphasis). I am not simply in my skin, and you in yours, and when you appear to me, when I am touched by you, difference is negotiated and organized. Rather, I come into my skin in relation to you – differentiation happens by way of and through our encounter. Ahmed writes: “If we think of the encounter as sociality – that being only emerges through and with others – then we can think about how meetings between particular others do not necessarily presuppose a meeting between two already constituted beings” (Ahmed, 2000, p.143). There is an intimacy in a touch (or touch as speech, touch as text, touch as advocacy, touch as research etc.); there is a closeness. You and I, ‘we’, are caught up in the touch – my being is constituted through our touch and with every touch, with every other, I am touched again and so touched differently: re-constituted, re-formed. It is easy to mistake this intimate and transforming proximity as wholeness and certainty.

Indeed, Butler argues that the relational ties linking the ‘I’ with the other compose us, constitute our very ontology. There are no prior or predetermined ways that
the ‘pieces’ of you and I will fit together. The other perforates or punctures the assumed boundedness of the ‘I’. Drawn in so close, ‘you’ and ‘I’ interlock into a ‘we’. I am in unavoidable proximity with you and, in that proximity, I am pressed into question: If I am partially constituted by you, where do I end and you begin? (Butler, 2004a).

In a world of others, Levinas tells us that the I does not exist alone but rather I exist surrounded by endless others who are always calling to me, connecting to me, making contact, interrupting my illusory solitude. This dispossession of the self by the other is, for Levinas, a movement without return; it is the movement toward the other without possibility of a complete and autonomous return to the self. I am bound to the other for my very constitution and, simultaneously, I can never fully know this other. A paradox. As I am touched by the other, as I touch the other, as I am so close, so proximal to be (re)formed in and through this encounter, something remains distant, inaccessible to me. Ahmed writes that “the overwhelming of the border [between the self and other] involves secrecy; it involves a failure to communicate where what passes between it is not disclosed, is not available to understanding or knowledge” (Ahmed, 2000, p. 154). And, I might add, not available to awareness.

Touch, Ahmed reminds us, is always partial and therefore uncertain. As I touch others (as I read others, write others, face others), I am always “touching other touches that have already affected the sensibility of the skin” (Ahmed, 2000, p.155). Our interactions play out upon uncertain and unpredictable (and politically uneven) terrain, upon layers of touches, and histories of encounters – situated identities that are often not immediately apparent, or are obscured from our awareness. Layers and histories we
cannot ever be fully aware of, but they are there...here...structuring our encounters, organizing our relations, mediating our awarenesses.

And, while, as Ahmed states, “in the encounter, which something might be said or heard, there are always other encounters, other speech acts, scars and traumas, that remain unspoken, unvoiced or not fully spoken or voiced” (Ahmed, 2000, p. 156), we can, she argues, be responsive to the inherent uncertainties embedded in moments of contact, in our interactions and awarenesses. And, while the moment I come into contact with an other is, in some sense, always a moment of non-disclosure, a moment of limit, it is also a moment of possibility. The moment of encounter is where it becomes possible to get in touch with the inevitable partiality of our touches, to become aware of the uncertainties of our awarenesses.

**Excessive Responsibility**

The partiality of being touched by the other claims us as responsible and response-able to and for the other – to be surprised with an other whose appearance or arrival is always unforeseen, unwelcome, but whose touch, nonetheless (re)calls me into being and calls me into an absolute and impossible responsibility. My responsibility to you is, itself, necessarily partial – it can never be wholly fulfilled – precisely because of the other’s infinity, as well as the infinity of others. I am called to attend to this particular other, to offer a response, which is governed by finite and particular circumstances – why this specific other? How have both she and I come to inhabit this particular space at this time? What debts have already been accrued, what violences have already been enacted as I am called to respond? What violences am I sustaining in the response?
In the impossible proximity of the encounter, there is always a remainder. Levinas speaks of this remainder as an ‘excess’:

[This] unassumability’ does not result from the excessive intensity of sensation, from just some quantitative ‘too much’ surpassing the measure of our sensibility and our means of grasping and holding; but an excess, an unwelcome superfluidity… (Levinas, 2006, p. 78).

I encounter the other as an excess, the other’s prior history, their mind, their body, their senses are neither made simply absent nor simply present through our given proximity. Butler, too, unpacks the divisive nature of living and relating in common in terms of a Levinasian excess. She writes:

I cannot muster the 'we' except by finding the ways in which I am tied to 'you', by trying to translate but finding that my own language must break up and yield if I am to know you. You are what I gain through this disorientation and loss. This is how the human comes into being, again and again, as that which we have yet to know (Butler, 2004a, p. 49, my emphasis).

Thus, the sociality of embodied life is mediated by and contingent upon that which is beyond empirical knowledge. Levinas suggests that this sociality (that we exist relationally, that we always make an appearance in the midst of others) rests upon an essential ‘unknowing knowledge’ that is a non-intentional consciousness.

And so, my responsibility to and for the other is a dispossession: “The I loses its sovereign coincidence with itself, its identification in which consciousness returned triumphantly to itself and rested on itself. Before the exigency of the other, the I is
expelled from this rest…” (Levinas, 1986, p. 353). In Butler’s terms, sociality is contingent upon "an unknowingness," that necessarily moves me outside of myself, renders me, in her words, “ec-static” (Butler, 2004a, p. 46).

What is more, there are always other others, always touching me, always demanding response. As I respond to one other, I am foreclosing the possibility of being encountered, or surprised by an other other. Therefore “to say that I am responsible, here and now, is a form of irresponsibility” (Ahmed, 2000, p. 147). *And still, we respond*; if my identity, my very constitution is always and inevitably tied up with the other, I exist only insofar as I am always responding. This puzzling paradox, according to Maurice Blanchot, “leaves nothing intact” (Blanchot, 1995, p. 25).

In the face of the other, the ‘I’ is not ever fully at home with itself (Derrida, 2003; Levinas, 1979). Thinking and writing the other recalls me into responsibility such that I am absolutely altered, dispossessed or displaced from my home, “to be moved by the other such that one ceases to inhabit the same home” (Ahmed, 2000, p.155). In Blanchot’s words, to be touched by the other, to be responsible firstly to and for that other, “withdraws me from my order – perhaps from all orders and from order itself” (Blanchot, 1995, p. 25). To be responsible, to attend to the touch of the other is to be moved from the ordinary, to be put into movement. Ahmed echoes this as she writes that in the encounter “one does not stay in place” (Ahmed, 2000, p. 157). She is, however, quick to remind us that neither does one “stay safely at a distance (there is no space which is not implicated in the encounter). It is through getting closer, rather than remaining at a distance, that the impossibility of pure proximity can be put to work, or made to work” (Ahmed, 2000, p.157). It is within the realm of this paradoxical
‘impossibility’ that we can begin to work through the uncertainty and incompleteness represented by the relationship between autism and advocacy, a responsive relationship that makes its proximity ever distant.

I would like to flesh out this paradox of distance and proximity, this puzzle of how we respond in relation to disability studies. What might autism have to teach disability studies about how to attend and orient to the puzzling task of ‘living with’ others, ‘living with’ difference? In the next section, I work through the question of how autism is puzzling and provoking disability studies and begin to explore what such provocations are teaching disability studies.

**Puzzling Disability Studies**

For participants in the conversation of disability studies, the question of how ‘we’ relate to, and are aware of each other – how we make contact with one another is a critical one; members of disability and disability studies communities are as disparate as we are unified. The question of our relatedness – and of our responses to our relatedness – is a puzzling one. This is all too evident when we consider the vast and variegated array of physical, sensory, cognitive and mental impairments that are put in touch with one another under a rubric of ‘disability’; when we consider disability’s fluidity – how it can appear and disappear, how its meaning can shift and change in different times and spaces, and how anyone can become disabled at anytime; when we consider how systems of ableism come into contact with racialized bodies, queer bodies, classed bodies, gendered bodies, bodies that already have been touched by other (and perhaps multiple) systems of oppression; when we consider the ways in which disability provokes complex and even contradictory embodied feelings of comfort and discomfort,
pride and shame (Chandler, 2009; Chandler 2010) and so on. As Corker and Shakespeare (2002) remind us: “the global experience of disabled people is too complex to be rendered within one unitary model or set of ideas” (p. 15).

Acknowledging the strategic utility of the social model and its emphasis on locating disability and disablement squarely in the realm of the social, some disability studies theorists have moved to re-center the material embodiment of disability (see, for example, Clare, 1999; Corker, 1999; Erevelles, 2002; Goodley, 2010; Michalko, 2002; Titchkosky, 2007). Iris Marion Young (2001) writes:

While the social model of disability destabilizes the assumption that the ‘problem’ with some people has to do with attributes of their bodies and functions, it nevertheless continues to presume a certain fixity to these bodies, and thereby understands many of the experiences and self-conceptions of persons positioned as disabled as grounded in such bodily facts. (Young, 2001, p. xiii)

Attending to the body as a site of meaning making is a transgressive move for it always exceeds. It always slips through the seams of the narrow constraints of unwaveringly certain ‘facts’. As Young gestures toward, the move to re-center the body is not to revisit or reclaim the individual as the site of disability, but rather to acknowledge and attend to the complexities, contradictions and puzzles that are, necessarily, provoked by living bodies and embodied living.

Drawing out some of the complexities of living together as embodied beings, Chris Bell (2006) offers a critical race studies informed critique of disability studies. Scholarly work produced and circulated in the field, Bell argues, is often complicit in both producing and sustaining a normative body of disability studies – as well as a
normal disabled body – as a singular body of whiteness. He writes: “it is disingenuous to keep up the pretense that the field is an inclusive one, when it is not” (Bell, 2006, p. 275). He continues by stating, “disability studies claims to examine the experiences of a vast number of disabled people, yet the form that representation takes is, far too often, a white one” (Bell, 2006, p. 278).

Bell gestures towards the dangerous risks animated by a rigid social model of disability and particular disability rights movements that, as a way to resist oppressive ableist systems of power, subscribe to a monolithic, and indeed, normative (white, middle-class, heterosexual, physically impaired male) disability identity. Such an uncritical commitment to a kind of disability normativity – such a refusal to critically examine the normative grounds upon which conceptions of disability rest – suggests that every disabled person is faced with and fighting against the same kinds of oppressions and striving for the same kinds of dignity, recognition and so on. Bell demonstrates how unreflective and unwavering acts of political solidarity are also acts of essentialism that fail to imagine and address the differential complexities and vulnerabilities faced by disabled bodies who not only transgress dominant versions of normativity but who also transgress a disability normativity – disabled queer and/or trans people, for example, disabled people of color, disabled women, people with psychiatric and/or cognitive disabilities and so on.

In her analysis of ableism within feminist movements, Sherene Razack (1998) describes how hierarchical relations persist within oppressed groups and structure our struggles against oppression. She writes: “identifying as part of a marginalized group allows each of us to avoid addressing our position within dominant groups and to
maintain our innocence or belief in our non-involvement in the subordination of others” (Razack, 1998, p. 132). Razack and Bell point to the invariable ‘cracks’ and ‘gaps’ that appear in any singular normative discourse. Disability, the remind us, is not one; inequities, hierarchies, power and privilege work to separate disability and disability identities and necessarily so.

Still, even as we, importantly, move toward acknowledging the difference made by the differences of our bodies and of our identities, our bodies and our identities relentlessly remind us: we are never one. Marginalities cannot be neatly contained; systems of oppression share “tangled histories”, functioning together to call into existence complex bodies where identities leak and mingle together (Goodley, 2010, p. 36). Embodied identities are often co-terminus, yet are never one.

Vis-à-vis the paradoxical distances and proximities of embodied identities, it becomes important and necessary to theorize disability as an embodied experience and so, a shifting, unstable, transnational and transhistorical category that is, at once, material – life and death, flesh and bone, mind and senses – and ideological – power and oppression, marginality and resistance. Eli Clare (2001) articulates this call for a return to the body. He writes:

Sometimes we who are activists and thinkers forget about our bodies, ignore our bodies, or reframe our bodies to fit our theories and political strategies. For several decades now, activists in a variety of social change movements, ranging from black civil rights to women’s liberation, from disability rights to queer liberation, have said repeatedly that the problems faced by any marginalized group of people lie, not in their bodies, but in the oppression they face. But in
defining the external, collective, material nature of social injustice as separate
from the body, we have sometimes ended up sideling the profound relationships
that connect our bodies with who we are and how we experience oppression.
(Clare, 2001, p. 359)

Acknowledging disability as an embodied entanglement of material and ideological
realities, Clare makes explicit the meaningful, yet leaky boundaries separating relational
identities. He writes:

Let me begin with my body, my disabled queer body. I use the word *queer* in both
of its meanings: in its general sense, as odd, quirky, not belonging; and in its
specific sense, as referring to lesbian, gay, bisexual, and transgender identity. […]
My first experience of queerness centered not on sexuality or gender, but on
disability. Early on, I understood my body to be irrevocably different from those
of my neighbors, playmates, siblings. Shaky; off-balance; speech hard to
understand; a body that moved slow, wrists cocked at odd angles, muscles knotted
with tremors. …This was my first experience of queerness. Only later came gender
and sexuality. (Clare, 2001, p. 359)

Clare writes about coming into embodied contact with queerness by way of disability,
and shaping notions of disability in relation to queerness; how one identity touches the
other, slips into the other, structures and shapes the other and yet, always and somehow
remains distinct.

In this way, Clare is engaged in the non-normative production of disability as an
embodied site of encounter; disability becomes a kind of ‘doing’ that invariably
structures our relationships to our bodies and the bodies of others. Conceived of in this way, disability is a motion and it is putting the body into motion in particular, contingent and mediated ways. Through disability’s disruptive motions – an arm recoiling from a caring touch, a trip on a pavement stone, a white cane sweeping side to side down a crowded street, a stumbling on a word, a sunny afternoon in tears, a body that moves ‘too fast’ or ‘too slow’, a body that is ‘too much’ or ‘not enough’ – disability forbids us to simply ‘going through the motions,’ but instead asks us to live in motion, to stay in motion, to the puzzling spaces between; here and there, you and I (Chandler, 2009; Michalko, 1999; Porter, 1997; Titchkosky, 2007). We live in motion, but we also live with motion – with and amidst the moving bodies of others. And, in the inevitable moments of contact – the moments when I collide into you, or when you brush up against me – we touch. And you and I will, forever, move a little differently. The uncertainty of our touches asks disability studies to attend to its moments of contact with and across difference, and to the ways that we are all moving differently as a result of our encounters with others, for we surely are.

This dissertation grows out of a body of textual work that is ‘disability studies’ while acknowledging that, like all bodies, the body of disability studies appears in relation to and is responsive to a world of other bodies. The bodies of disability and disability studies must be considered in context, always in relation to other bodies, if ‘we’ are to account for such material realities as divergent and even contradictory experiences of impairment and the existence of multiple, intersecting oppressions. And so, this work is, fundamentally, grounded in an understanding that, while particular bodies experience disability in intimate ways, and while certain bodies are made more vulnerable to
material inequities and violences, ‘disability’ is not simply in some bodies and not others – following Titchkosky, Michalko and others, particularly my colleagues at the University of Toronto – disability is always being put into motion in the social spaces between bodies (see, for example, Aubrecht, 2010; Chandler, 2009; Douglas, 2010b; Michalko, 2002; Titchkosky, 2007; Titchkosky & Aubrecht, 2009; Stein, 2010). In this way, when we are talking about ‘autism’, we’re also talking about how autism is related to and is constituted by a relationship to a normative version of non-autism.

Puzzling our relations also requires us to trouble quick oppositions, such as the one I have just set up between ‘autism’ and ‘non-autism’. Oppositional terms make static relationships that are fluid. Autism marks the body in ambiguous ways – it appears and disappears – is noticed and is hidden - as the body moves through different physical, sensory and social spaces, and as it finds itself, as we shall see in the chapters to follow, in different political and historical moments. In this way, autism can and must be theorized as a space - an historically contingent, socially mediated, geo/political and interactional space of questions; a space of power relations, that provides the terrain for encounters across race, gender, class, sexuality, disability and identities, at this moment, I am failing to imagine. And in this space, upon this terrain, we – all of us – are making sense of this thing called ‘autism’ that is many and shifting and endowing it with particular and sometimes conflicting meanings. Autism “awareness”, then, is no simple task. What we are and, indeed, can be aware of becomes contingent upon our moving bodies – yours and mine – as they appear to and encounter one another.
Our awarenesses, then, are always puzzling. And, in this interruption: an invitation. Kari Dehli (2008) writes about noticing dilemmas (which, she writes, “can never be resolved, once and for all”) as a methodological approach (p. 47). She states,

To notice that dilemmas are integral to, or comprise slippages in, practices of government might open up spaces for doing research and being researchers differently. In this sense, dilemmas are surfaces where the instability of researchers’ implications in relations of power can be made visible, and where we can retrieve creative possibilities for new connections and practices... (Dehli, 2008, p. 47)

Thinking through the dilemmas we face as we articulate a ‘we’ - puzzling our relations - can open up new spaces where ‘we’ might critically engage with questions of difference and uneven power relations within disability studies and the disability movement more broadly. Puzzling our relations might open up space for advocacy work to critically engage with questions of power and privilege; to question and resist so-called ‘best practices’ that pathologize autistic difference, to attend to the social significance of militaristic tactics of ‘raising awareness’, in short, to engage in a politics of ‘living with’.

**Endings and Beginnings**

Autism disrupts the way ‘we’ typically make contact and, in doing so, presents us (all of us) with an opportunity to re-imagine the ways we come into contact with the other – to look without necessarily making eye contact, to touch with a tentativeness and an
awareness of the inherent risk in making contact with sensitive surfaces, to research with
an awareness of our partiality and incompleteness. A place to begin.

This work will end and begin with a puzzle. However, unlike the traditional
jigsaw puzzle and unlike the so-called ‘puzzle of autism’, the theoretical/methodological
puzzle I am suggesting in this chapter is neither complete, nor is it on its way to
completion. It is, as Walt Whitman describes, “‘the puzzle of puzzles,’ the puzzle of
being” (Whitman, 2001, p. 25). It is not a recognizable product of myriad pieces
arranged carefully together in particular ways. It is not an elegantly patterned realization
of a prior or expected image. In fact, its pieces come from many different puzzles,
offering fragmentary glimpses of multiple images. The puzzle I imagine will always have
pieces missing and the pieces that are before us are unexpectedly arranged. There are
gaps and spaces of distinctive sizes and shapes. Some pieces are face down. Some pieces
have fallen atop others, obscuring other pieces from view entirely.

The jagged fragments that interlock do not always fit together in the ways we
might typically anticipate. Some of the pieces are upside-down and disoriented, some
come together smoothly and easily. Irrespective of the particularities of their
arrangements, the pieces of this puzzle are always in-touch with one another, though
sometimes the contact that is made cannot be described as a physical nearness. Some
pieces fit so closely that the gap that separates them is almost imperceptible. It is not
unlike the colorful moebius strip puzzle, claimed as a symbol of the neurodiversity
movement.

The pieces of this puzzle often come together in novel and unanticipated ways.
This puzzle’s possibility lies not in being able to re-produce the image on a box, but in
the uncertainty of what new figures might be generated from these surprise encounters, and in what new relations might become apparent. And, to be sure, the puzzle I imagine is not finished...
How does one establish that a person suffers from autism? There is no single physical or behavioural sign which would uniquely secure the diagnosis. The whole history of the patient has to be considered from birth, the nature of the impairments, their severity, and their change over time.


We could write a history of limits – of those obscure gestures, necessarily forgotten as soon as they are accomplished, through which a culture rejects something which for it will be the Exterior; and throughout its history, this hollowed-out void, this white space by means of which it isolates itself, identifies it as clearly as its values. For those values are received, and maintained in the continuity of history; but in the region of which we would speak, it makes its essential choices, operating the division which gives a culture the face of its positivity: this is the originary thickness in which a culture takes shape.

- Michel Foucault (2006 [1961], *History of Madness*, p. xxix

Autism is widely understood, in contemporary times, as a disorder: a diagnostic category particular to the 20th and 21st centuries (Asperger, 1991; Baron-Cohen, 1997; Frith, 1990; Frith, 2003; Kanner, 1943). Vis-à-vis a ‘disorderly’ autism, advocacy is most commonly narrated – and so understood – as that which must ensure autism’s return to order (McGuire, forthcoming). Autism’s purported ‘disorder’, together with the seemingly natural need for advocacy’s orderly response to it is, however, much less often
contemplated as a social phenomenon that can teach us something about how contemporary social relations are ordered\(^1\).

**Presenting Histories and Histories of the Present**

This chapter serves as an overview of the historical underpinnings that provide the conditions of possibility for contemporary Westernizing conceptions of autism and for the emergence of contemporary versions of autism advocacy. By tracing an historical genealogy of autism and autism advocacy in the West, I reveal how the social significance of these related phenomena – the meanings we attribute to them and the understandings they provoke – is connected to and, indeed, achieved against a shifting and contingent cultural backdrop. And so, in this chapter, I not only introduce the historical context of autism and autism advocacy; I also introduce the discursive field that collects autism and autism advocacy as an historically contingent, socially mediated, political and interactional space of power relations that contains and constrains.

As I give an historical account of autism’s emergence as a category of classification – as some ‘thing’ one could be found to ‘have’ – I am necessarily offering one perspective of the history of autism. In contradistinction to the dominant empirical

\(^1\)Contemporary work exploring autism as a social and political phenomenon includes a variety of critical commentary that is posted on the Internet on chat boards and on personal blogs (see, for example, [www.autistics.org](http://www.autistics.org), Kathleen Seidel’s blog [Neurodiversity: A Weblog](http://www.neurodiversity.com), Amanda Baggs’s blog [Ballastexistenz](http://www.ballastexistenz.autistics.org); Michelle Dawson’s historical archive and blog [No Autistics Allowed](http://www.sentex.net/~nexus23/naa_02.html), Steve Graby’s blog [Biodiverse Resistance](http://www.biodiverseresistance.blogspot.com) and Kristina Chew’s now archived [Autism Vox](http://www.blisstree.com) blog that can still be accessed at [www.blisstree.com](http://www.blisstree.com). There is also some sociological research examining the social and political dimensions of disability including Biklen & Attfield, 2005; Broderick and Nc’eman, 2008; Douglas, 2010; Hacking, 2009a; Mallett & Runswick-Cole, (forthcoming); McGuire (forthcoming); McGuire & Michalko, 2011; Murray, 2008; Nadesan, 2005; Timimi, Gardner & McCabe, 2010.
demand for a “whole history of autism”, as is exemplified by Frith’s statement in the opening epigraph, I do not attempt to provide a complete or exhaustive account of the history of autism, nor do I think that this is possible. To write a history – whether it is an individual history or a collective one – is to write an abbreviation. And so, instead of attempting to write an historical totality, this chapter seeks to, in Foucault’s (1997) words, “blow the dust off certain things” (p. 2).

This chapter uses a Foucauldian genealogical approach to write a “history of the present” of autism and autism advocacy, as well as of the subjects (permitted to) dwell within the discursive field that connects and collects these two phenomena (Foucault, 1995, p. 31). I focus on pieces of history and, using a puzzling methodology outlined in Chapter 2, I allow for diverse and often conflicting historical pieces – cultural and historical events, scientific and psychiatric documents, personal observations and narrative, as well as alternative historical readings informed by feminist, race, queer, disability and class studies – to come up against one another in dis-ordered and, so, non-normative ways. I bring these pieces of history into proximity with each other, so as to reveal how they are already rubbing up against contemporary versions of autism and advocacy. Resisting the seductive desire to make causal connections or to search for cogent origins, a genealogy of autism seeks to, following Foucault, make familiar, everyday assumptions about autism and advocacy “strange”, to underscore, in other words, the contingency of our present day “evidences” and our commonsense understandings of how these phenomena operate and interact (Foucault, 2001, p. 77).

To borrow from Foucault’s characterization of the task of writing a genealogy of the history of madness, a critical genealogy of autism does not ask “what in a given
period is regarded as sanity or insanity, mental illness or normal behaviour” but rather asks “how these divisions are operated” (Foucault, 1991, as cited in Mills, 2003, p. 98, *original emphasis*). I will begin, then, by focusing on how shifting and circulating tactics of power – such as processes of ‘pathologization’ and ‘normalization’ – are engaged in constraining embodied categories of ‘deviant’ and ‘normal’, ‘autism’ and ‘non autism’ and are, indeed, shaping what gets counted as self-evident, and necessary responses to autistic difference in contemporary times. In tracing the emergence of ways of knowing autism and autism advocacy and by following the trajectories and tactics of power operating on and within these categories, I provide the foundation for asking a central question of this dissertation: how, in this contemporary moment and in these western/ized spaces, have we come to see ourselves and others as particular kinds of subjects, as subjects who advocate and as subjects who require advocacy?

Contemporary understandings of autism emerged out of and in relation to a psychiatric/biomedical history of identifying and diagnosing its ‘disorder’. In her book, *Constructing Autism: Unravelling the ‘Truth’ and Understanding the Social* (2005), Majia Holmer Nadesan argues that the fact that autism emerges as a diagnostic category in the 20th century is neither happenstance, nor coincidence, but is, rather, a condition of particular historical events and ideologies. She writes:

> The historical matrix of events, knowledge, and professional identities that emerged out of the end of the nineteenth century set the stage for the creation and expansion of twentieth century child psychiatry, and ultimately provided the conditions of possibility for autism to emerge as a diagnostic category (Nadesan, 2005, p. 53).
As a way of examining the conditions of possibility that give rise to the emergence of autism and its advocate, I begin by offering an overview of the historical underpinnings of autism as an articulated and articulatable category.

**Delivering Autism**

The term ‘autism’ or ‘autismus’ (derived from the Greek *autos*, meaning ‘self’) was first articulated in 1911 by Dr. Eugen Bleuler, a Swiss Freudian most noted for his research on schizophrenia (Feinstein, 2010; Kuhn, 2004; Nadesan, 2005; Shorter, 2005). According to Adam Feinstein’s (2010) history of autism:

> Bleuler distinguished two modes of thinking: logical or realistic thinking and autistic thinking. For Bleuler, autistic thinking was not a pathology confined to a group of children […] Bleuler considered autistic thinking a normal mode of thinking in both children and adults. It was evident, he said, in dreams, pretend play and reveries and in the delusions of the schizophrenic. (p. 6)

As is evident in Feinstein’s description, Bleuler’s conceptualization of autism did not understand it as a disorder in and of itself. Autism was, for Bleuler, a mode of thinking. And, while normal subjects may, from time to time, slip into reverie and ‘think autistically’, Bleuler also connected this mode of thinking to psychiatric non-normativity. Autistic thinking was, according to Bleuler, an essential component of a disordered schizophrenia. Feinstein (2010) writes: “[Bleuler] originally included autism as one of what he called the ‘four schizophrenias’. This group was united by ‘four As’ – associated disturbance, affective disturbance, ambivalence and autism” (p. 6).
In the early 1900’s, as well as today, schizophrenia was and continues to be narrated by psychiatry as an undesirable and even dangerous pathological illness of the mind, a narrative that relies on simultaneous medical and moral schemas of classification (Rose, 1989; Szasz, 1995; Szasz, 2010). As it became understood as a sign pointing to schizophrenia’s assumed pathology, autistic ways of thinking, too, became classified, along moral and medical lines, as outside of “logical” and “realistic” ways of thinking.

It was not until the late 1930’s and the early 1940’s that conceptualizations of autism as, itself, a distinct disorder began to be articulated through the contemporaneous work of American child psychiatrist Dr. Leo Kanner and Austrian pediatrician Dr. Hans Asperger (Feinstein, 2010; Grinker, 2008; Nadesan, 2005).

The ‘Fathers’ of Autism: Kanner and Asperger

The term ‘autism’ was first articulated as a disorder (as opposed to as a symptom) by Kanner in his 1943 article, “Autistic disturbances of affective contact” (Kanner, 1943). In this now famous study, Kanner conducted case study analyses of 11 children, who were observed by Kanner to be exhibiting “a rare syndrome,” which he most often articulated as “early infantile autism”, and less often, as “Kanner’s syndrome” (Kanner, 1943, p. 242). In this article, Kanner writes of autism’s “fundamental disorder”, which was “[the autistic child’s] inability to relate themselves in the ordinary way to people and situations from the beginning of life” (Kanner, 1943, p. 242). Kanner documented that the parents of the children in his study referred to their children as:

…having always been “self sufficient”; “like in a shell”; “happiest when left alone”; “acting as if people weren’t there”; “perfectly oblivious to everything
about him”; “giving the impression of silent wisdom”; “failing to develop the usual amount of social awareness”; “acting almost as if hypnotized”. (Kanner, 1943, p. 242)

In contrast to Bleuler’s earlier claim that autism is a symptom of schizophrenia that could be treated as a way of treating schizophrenia, Kanner claimed autism as a distinguishable condition. He writes:

[Autism] is not, as in schizophrenic children and adults, from an initially present relationship. It is not a ‘withdrawal’ from formerly existing participation. There is from the start an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. (Kanner, 1943, p. 242, original emphasis)

Elsewhere Kanner writes:

We must, then, assume that these children have come into the world with innate inability to form the usual biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps. (Kanner, 1943, p. 250)

Unlike Bleuler, who recognized autism as a symptom, Kanner recognized autism as an ‘innate’ condition; a condition which was, itself composed of many symptoms. Autism was, thus, re-conceived by Kanner and his contemporaries as itself the central pathology and threat to (mental) health. Kanner went on to, simultaneously, notice, describe and pathologize many of the movements and/or behaviours that are dominantly considered in
contemporary times\textsuperscript{2} to be ‘classic’ symptoms of autism, including “obsessiveness”, “literalness”, “stereotypy”, “echolalia”, “insistence on sameness”, aversion to eye contact, dislike of loud noises or unexpected/intrusive movements, and an “altogether different” relation to others (Kanner, 1943, p. 250). Indeed, many of Kanner’s initial observations appear as the ‘diagnostic criteria’ for autism in the current iteration of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM –IV) (American Psychiatric Association, 2000).

Asperger, apparently unaware of the work being done by Kanner in the US (Attwood, 2007), was also and at the same time, documenting and articulating autism – what he referred to as “autistic psychopathology” – as a distinct disorder (Asperger, 1991; Grinker, 2007; Nadesan, 2006; Shorter, 2005). Asperger was working at the University Pediatric Clinic in Vienna and published an article in 1944 based on several case studies of children. Like Kanner’s research, Asperger’s work was engaged in the incessant observation and extreme documentation of the ‘abnormal’ signs and symptoms pointing to an innate, interior ‘disorder’. For Asperger, whose studies predominantly focused on so-called ‘high-functioning’ autistic children (children who might now fall under the designation ‘Asperger’s syndrome’), signs of ‘disorder’ revolved around perceived ‘core’ social and communicational deficits.

Asperger identified autism’s impairment as primarily caught up in social relations. He writes: “The nature of these children is revealed most clearly in their behaviour toward other people. Indeed, their behaviour in the social group is the clearest sign of their disorder” (Asperger, 1944, as cited in Attwood, 2008, p. 55). It is, I think,

\textsuperscript{2} See, for example, the contemporary ‘Red Flag’ posters featured in chapter 4 (Fig. 4.1; Fig. 4.2; Fig. 4.3).
crucial to note that Asperger’s work demonstrates the move from merely noticing and documenting signs of difference, to interpreting these as ‘insights’ into the true ‘nature’ of the children under study. Yet, of course, acts of observing and processes of ‘looking’ are highly organized. Dehli writes: “Child psychology's "way of seeing" – its gaze – brings a selection of events, expressions or emotions into view as significant incidents while rendering others as peripheral and unimportant” (Dehli, 1994b, p. 9). These ‘ways of seeing’ are caught up in the production of particular observations and, indeed, work to govern what is and can be ‘seen’ (Dehli, 1994b; Foucault, 1975; Michalko, 1998; Rose, 1989).

As we shall glean more clearly in the chapters to follow, the articulation and documentation of autism ‘signs’ and ‘symptoms’ have political and historical significance insofar as they have been and continue to be employed as bodily markers that work to pathologize, discredit and, even, render vulnerable bodies of difference. This relentless surveillance, of course, paves the way for correction of the ‘signs’ of difference. Indeed, it is significant to note that the birth of a disorder does not (cannot?) happen in the absence of a simultaneous call for order. As Kanner and Asperger recognized autism as a (pathological) disorder, they simultaneously moved to recognizing it as in need of improvement or correction: a disorder in need of order (Kanner, 1943; Nadesan, 2005) and necessarily so.

A history of autism cannot proceed without coming to terms with the particular historical context in which Kanner and Asperger made their discoveries and conducted their research. The time period in which these two men developed their theories of

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3 For a more detailed examination and analysis of processes of ‘looking’ at and studying children’s bodies and how the ways in which our ‘looks’ are governed by biomedical discourse, please refer to Chapter 4.
autism – theories that still very much influence the ways in which autism is dominantly conceived of today – also saw the proliferation and popularization of eugenics movements in Europe, the US and Canada; an historical juncture that saw the promotion of ideologies of racial ‘hygiene’ and, even, the extermination/elimination of those bodies who did not ‘fit’ this racist profile (disabled bodies, for example, racialized bodies and so on) (Gilman, 1985; Gleason, 1999; Snyder & Mitchell, 2006).

Eugenic notions of racial ‘purity,’ ‘fitness’ or ‘hygiene’, and the subsequent measurement and categorization of groups of people into classes of life that were deemed either worthy or – to borrow a phrase coined by Nazi eugenicists Karl Binding and Alfred Hoche – “unworthy of life” (Binding & Hoche, 1920), provided the necessary social conditions that made it possible for increased public and private surveillance of normal and abnormal behaviours. This need for surveillance was framed as particularly necessary in childhood, a stage that was (and continues to be) most commonly narrated as always and already in need of paternalistic intervention (Burman, 1994). The demand for increased awareness of the lines separating ‘normal’ and ‘abnormal’ and the subsequent surveillance and governance of such categorizations, in turn, both produced and sustained morally coded notions that there are ‘right’ or ‘fit’ and ‘wrong’ or ‘unfit’ ways of being in the world.

While such normal/abnormal, fit/unfit distinctions seemed to be rooted in (purported) individual pathologies and/or deviances from the ‘good’ (white, heterosexual, middle-class, non-disabled) race, their significatory meaning stretched well beyond the individual. The ‘fitness’, ‘health’ or ‘hygiene’ of the individual was interpreted as
absolutely inseparable from that of the state as a whole⁴. Indeed, notions of a ‘fit’, ‘healthy’ (i.e., strong, virile, productive and developed) state – the state with militaristic, economic and colonial power – required, and so idealized, particular kinds of ‘healthy’, ‘fit’ citizens (i.e., those bodies who displayed strength, virility, productivity and, of course, good human development) (Payne, 1995; Spackman, 1996). It, therefore, became possible to speak and think of socially/culturally devalued forms of embodied difference in terms of (pathological) ‘threats’ that weakened the health and strength of the state (Spackman, 1996). The notion of an embodied ‘pathological threat’ to the health of the state is sharply exemplified if we think of the violence enacted against particular, pathologized bodies in Europe in the 30’s and 40’s and of how such violence was conceptualized in racist/ableist terms. The millions upon millions of racialized, disabled, queer and politically/religiously persecuted people who were murdered by the Nazi regime were figured first as pathologically deviant bodies threatening the ‘health’ and ‘virility’ of the nation and the race (Snyder & Mitchell, 2006). The Jewish body, for example, was often framed by the Nazi regime as a “cancer on the breast of Germany” (Davis, 2007; Gilman, 1993), an unhealthy malignancy that, of course, required particular kinds of (medicalized and militarized) responses: namely, excision and eradication.

Both Kanner and Asperger, the so-called ‘fathers’ of autism, shared a direct, personal connection with the eugenic/genocidal programs that were being implemented in central and Eastern Europe under Nazi occupation. Kanner was an Austrian Jew, and his mother and three of his siblings were murdered in the Holocaust (Grinker, 2008). Asperger was a pediatrician working at a children’s hospital with disabled children in

⁴ And, as I argue in the later half of this dissertation, the ‘health’ of the individual is still, very commonly, read as a sign of the ‘health’ of the nation state.
Nazi occupied Austria (Attwood, 2008; Grinker, 2008). By noting Kanner’s and Asperger’s (no doubt, different) relationships to Nazi eugenics in Europe in the 30’s and 40’s, I am not attempting to suggest a psychological or even a causal explanation for their interest in surveilling bodies and behaviours, in tracing the line separating ‘normalcy’ from ‘abnormalcy’, order from disorder. However, it is nonetheless important to understand that Kanner and Asperger were living in and touched by a social context where such lines were often the lines separating life and death.

Such divisions were and are extremely instructive; the incessant repetition of—and myriad scientific justifications for—the equation of ‘abnormalcy’ with ‘death’ becomes so ordinary, so commonplace, as to be routinely interpreted as a rational, reasonable or even natural equation. And so, not coincidentally, an historical moment that gave us the possibility for mental/physical ‘purity,’ ‘fitness’ and ‘hygiene’, as well as the belief that the ‘healthy’ body/mind is reflective of a ‘healthy’ society, also saw the proliferation and success of relatively new fields of study aimed at the surveillance of the earliest aspects of human development: ‘child psychiatry’ and ‘child study’. Indeed, the so-called “fathers” of autism were embroiled at the center of these emergent fields.

Kanner himself noted that historically specific cultural attitudes were absolutely central to the birth of child psychiatry. He writes,

When the twentieth century made its appearance, there was not – and there could not be – anything that might in any sense be regarded as child psychiatry. It took a series of definite steps in the development of cultural attitudes to make possible the inclusion of children in the domain of psychiatry. (Kanner, 1935, p. 5)
A close examination of the early institutions of child psychiatry and child study further reveals the entanglements of the study of the mind and behaviours of the child and socio-biological notions of fitness and hygiene.

Consider, for example, the early days of the Yale Child Studies Center, founded by Arnold Gesell, a pioneer in child psychiatry and the director of Child Hygiene for the State of Connecticut (Fagan, 1987). In 1911, Gesell was appointed as faculty of Yale and was given a room at the university to set up a child development clinic where he went on to observe, document and measure ‘normal’ and ‘abnormal’ child behaviours and develop a systematic approach to the study of childhood growth and development (Rose, 1989). Gesell’s work flourished and his clinic grew into a full-fledged center in the years to follow, gaining particular influence during the early decades of the 20th century – the height of the eugenic period – when the need for clear and recognizable means of classifying ‘healthy’ and ‘deviant’ bodies was understood to be of utmost concern and importance for the project of developing and perfecting the human race.

Indeed, Gesell’s own personal commitment to a eugenic ideology was clear. His 1913 article “The village of a thousand souls”, originally published in American Magazine, draws a map of a small, unidentified town populated by growing numbers of “feebleminded” people prone to alcoholism, prostitution, criminality and social and economic failure. He writes,

In many cases, the feeblemindedness is not recognized or understood. The family realize [sic] that the boy is ‘slow’ and wish that people would not tease him so much. ‘But he will get along alright’ the parents say; and this prediction is partially justified. In a village, particularly a rural village, where gardens, barns
and domestic animals are common, the conditions of life are primitive. They may not be too severely complex, for even the feeble-minded boy, who learns how to tend stable, is happy in a simple routine of chores, and masters a simple occupation like sawing wood. [...] The trouble is, someday a ‘harmless’ fellow who has been sawing wood in the village goes into the country, marries and has children...about 80 percent of all cases of feeblemindedness are due to neuropathic heredity...and the feeble-minded have much larger families than normally prudent parents. (Gesell, 1922)

He concludes this scenario by underscoring the need to “supervise” and “segregate” the ‘unfit’ such that they are prevented from reproducing. He writes:

Only the rankest pessimists and believers in noninterference will condone the increase of feeblemindedness and insanity which is occurring in the villages of the land. We need not wait for the perfection of the infant science of eugenics before proceeding upon a course of supervision and segregation, which will prevent the horrible renewal of this defective protoplasm that is contaminating the stream of village life. (Gesell, 1922)

There can be little doubt: Gesell’s commitment to the “supervision” and “segregation” of the “feebleminded” bore considerable influence on and inspiration for his psychiatric research and practice looking at normal and abnormal childhood development⁵ (Gesell, 1922).

⁵ For a closer analysis of the historical and discursive entanglements of the study of human development and the racist/colonial development imperative, see Chapter 4.
Closer to home, the University of Toronto’s Dr. Eric Jackman Institute for Child Study (formerly named the St. George School for Child Study) – a so-called “laboratory school” which holds the “optimistic belief that the human condition could be positively changed through the study of children” – was established by Dr. Edward Bott, the (then) director of research for the Canadian National Committee for Mental Hygiene (CNCMH) (Pols, 2002). Indeed the laboratory school owes its very existence to funding received from the Canadian National Mental Hygiene Commission, as well as by the Laura Spelman Rockefeller Memorial Foundation (Volpe, 2006) – a philanthropic body with its own history of funding eugenic initiatives (Black, 2003; Kay, 1996; Kevles, 1995).

The examples above hint at the ‘tangled history’ of child psychiatry/study and the premises and practices of eugenics. Indeed, they demonstrate how eugenic practices and ideologies were absolutely reliant upon the generation of more and more means of identifying deviance; more and more lines separating normalcy from abnormalcy. Such historical entanglements, in which Kanner and Asperger were, invariably, caught, became the cradle for contemporary conceptions of autism. Born in and of the heyday of child psychiatry and child study in the 30’s and 40’s, contemporary versions of autism, as determined by Kanner and Asperger, were responses to an historically particular demand for clear ways of distinguishing and dividing ‘abnormality’ from ‘normality’, ‘pathology’ from ‘health’ in the name of a scientifically perfectible human race.

With the end of World War II and the subsequent moral shift against a eugenics tainted by the atrocities of the Nazi death camps, a biologically driven approach to autism fell out of favour (at least for a while). The late 40’s, 50’s and 60’s witnessed a rise in the popularity and influence of psychoanalysis, an approach that placed less emphasis on
an individual’s innate ‘nature’ or biology, and instead, favoured tracing the origins of ‘disorder’ to the psycho-social environment. Edward Dolnick observes that, in a post-WWII context, “to be pronature was to be in favour of progress and open-mindedness, while to be pronature was to be backward looking and backward thinking...Nazism stood for ‘nature’, thus psychoanalysis’ identification with ‘nurture’ gave it invaluable moral stature” (Dolnick, 1998, p. 63). The relentless and nuanced documentation of autism ‘symptoms’ by Kanner and Asperger quickly gave way to the search for their origins.

**Bettelheim and the ‘Mothers’ of Autism**

In its most traditional forms, psychoanalytic theory frames ‘normal’ and ‘abnormal’ development of the psyche, or the personality, as a function of early childhood experiences. More particularly, psychoanalytic theory takes up the role of the mother as the crucial arbiter in the psychosocial development of the child (Gleason 1999; Hyvonen, 2004; Nadesan, 2005). In the 50’s and 60’s, various foundational precepts of psychoanalysis became popular – particularly in white, middle-class households – in relation to maternal practices of child-rearing (Hyvonen, 2004). While the mother was understood to be uniquely and, even ‘naturally’, positioned as the rear-er of children and as the prime nurturer of their psycho-social development, she was, nonetheless, always (and differentially, with respect to, say, the mother’s social class, race, disability identification) framed to be at risk of mothering wrong and so, always (and differentially) positioned as at risk of catalyzing ‘poor’ child development outcomes. Dehli writes:

> It was, at one and the same time, "only natural" that women were the obvious rearers and teachers of children, and an apparent fact that some women were less...
able than others to fulfill their "natural" potential. At the same time, it was evident that, even if they were imbued with "natural" potential for maternal virtue, all women, regardless of class or ethnicity, had to be trained in a method largely devised by men in order to rear and teach children correctly. (Dehli, 1994a, p. 202)

Given the “purported fragility” of the psycho-social development of the child, Nadesan (2005) points out, that not only did “mothering [take] on new import”, it “increasingly required the input of experts” (p. 70). “The development of the child” she continues, “could not be pre-supposed; rather it became an accomplishment in itself” (Nadesan, 2005, p. 70). The child was recast as an accomplishment: an accomplishment, no less, of the mother. The looming risk of ‘poor’ mothering and the threat of ‘poor’ child development that flowed as a natural consequence of this, recast the child as a kind of project and the mother as a kind of skilled worker. Motherhood required particular qualifications and skill sets to ensure (most ironically) the ‘natural’ development of the child. One’s mothering skills, it seemed, could (and should) - with the help and guidance of child psychology ‘experts’ – be ‘worked on’, practiced, evaluated, measured and improved so as to make the mother better qualified to engage in the ever-important task of child-rearing.

‘Expert’ knowledge at this time held that ‘good’ parenting must be ‘nurturing’, and good ‘nurturing’ must be administered by the (naturally, though not flawlessly) nurturing mother and in the naturalized sphere of the (typically, white) bourgeois middle-class home (Arnup, 1994; Grinker, 2008). Nadesan argues that a variety of factors shaped a psychoanalytic emphasis on the role of the mother in this particular post-WWII
historical moment, including (but certainly not limited to): “the heightened import afforded childhood in relation to the larger project of social engineering [and] the push to remove women from the work force after World War II” (Nadesan, 2005, p. 83). Indeed, ‘signs’ or ‘symptoms’ of psychological ‘disorder’ – including the ‘disorder’ of autism – were, routinely, traced back to the working mother who had ‘abandoned’ her mothering role and to her ‘disorderly’ home. Gleason writes that, “wage-earning women and ‘family disorganization’ were closely associated […] [and this] put added pressure on women to consider leaving behind the world of work after the war” (Gleason, 1999, p. 57). The educated, white, middle-class mother who worked – the mother who departed from the sphere of the bourgeois middle-class home – was cast as the mother who was neglecting to ‘work on’ her mothering qualifications by refining her skills as a nurturer. Such a system of governance, of course, pre-supposes a particular kind of gendered subject: a mother who can dwell in the sphere of the bourgeois middle-class home. As Dehli suggests in the passage above, mothers marked as working class, racialized – and/or, I might add – disabled, were conceived of as, always and already, ‘un/underqualified’ for the job of ‘good’ nurturating and so, ‘un/underqualified’ for the job of ‘good’ mothering (I address such exclusions shortly).

This particular post-WWII moment saw a wave of popular ‘child development’ literature: advice columns, parent magazines and brochures, childrearing workshops and so on, aimed, specifically, at the white, bourgeois middle-class mother (Arnup, 1994). Consider, for example, Dr. Spock’s immensely popular child-rearing manual, Baby and Child Care (Spock, 1946, as cited by Hyvonen, 2004, p. 10). In relation to an autistic child, the role of the mother was put under constant scrutiny via psychoanalytic analysis
and critique. In this way, the ‘fathers’ of autism were the ‘expert’ surveillers, while the ‘mothers’ of autism became the subject of paternalistic surveillance. And so, even as autism at that time was understood to be a disorder unto itself, it still, in some ways, was being ‘read’ as a symptom, in this case, a sign pointing to a (as we shall see, particular kind of) deviant mother.

With respect to autism, the ties that connected mother and child, also bound them together in pathology. The figuration of a ‘cold’, non-nurturing ‘refrigerator’ mother was inaugurated, at least in part, by Kanner’s earlier observations of autistic children (Kanner, 1949). Indeed, the children observed by Kanner in a 1949 study tended to have parents who were, in his words, “pre-occupied by abstractions of a scientific, literary or artistic nature” (Kanner, 1943, p. 42). From case studies examining 55 autistic children, Kanner observes:

All but five of the mothers […] have attended college. All but one have been active vocationally before, and some also after, marriage as scientists, laboratory technicians, nurses, physicians, librarians, or artists. One mother who was not a college graduate was a busy and well-known theatrical agent in New York City. One, who has a Ph.D. degree, collaborated in the publication of a Middle English dictionary. One stated: “I majored in zoology and could have majored in music. I play the organ, piano, and cello. I wanted to be a doctor but my family didn’t have the stamina. I have often regretted it. I taught school for two years, then worked in an endocrinology laboratory”. (Kanner, 1949, p. 420-1)

Kanner seemed to wonder whether such ‘preoccupations’ from the (bourgeois, middle class) home were not, effectively, evidence of ‘bad’ mothering. He went on to observe
what he called a “genuine lack of maternal warmth” (Kanner, 1949, p. 422). While Kanner did seem to think that these observations were worthy of further inquiry, he did not understand them to be evidence of an originary cause of autism. Recall, autism was, for Kanner, understood to be innate. His image of the cold, unfeeling “refrigerator” mother was, however, famously, re-articulated by Jewish-American psychoanalyst, Dr. Bruno Bettelheim, as an origin of autism’s disorder.

Like Kanner and Asperger, Bettelheim (1972) also described the autistic child as exhibiting an ‘altogether different’ relation to others; as detached, existing in a “private world” and appearing as if locked in a “shell” (pp. 146, 327). However, Bettelheim made a crucial distinction from the conclusions of his predecessors: he rejected Kanner and Asperger’s postulations that autism was ‘innate’ or ‘inborn’. In his words: “My own belief...is that autism has essentially to do with everything that happens from birth on...” (Bettelheim, 1972, p. 393). Bettelheim suggested that autism is not simply a disorder that one is born with, but an acquired condition caused by early childhood experiences. Autism, for Bettelheim, was not simply an innate state of ‘profound aloneness’ (as it was for Kanner and Asperger) but a withdrawal.

Bettelheim described autism as an “empty fortress” (Bettelheim, 1972). Indeed, he went as far as to draw the comparison between the autistic child’s perceived reclusion from humanity with the situation of the Jews imprisoned in concentration camps under Nazi rule. Bettelheim – himself a survivor of Dachau and Buchenwald – writes: “Some victims of the concentration camps had lost their humanity in response to extreme situations. Autistic children withdraw from the world before their humanity ever really develops” (Bettelheim, 1972, p. 7). He continues: “what was external reality for the
prisoners [of Nazi concentration camps] is for the autistic child his inner reality” (p. 65).

As I explore in the later chapters of this dissertation, Bettelheim’s powerful image of autism as a shell or prison (or camp) that incarcerated an otherwise ‘normal’ or non-autistic self continues to this day to have profound, reverberating and dangerous effects on the ways in which autism is conceived of and oriented to.

Like a good psychoanalyst, Bettelheim postulated that the origin of autism’s “self-incarceration” lay with the parents (particularly, the mother). He writes: “I believe the initial cause of withdrawal is rather the child’s correct interpretation of the negative emotions with which the most significant figures in his environment approach him” (Bettelheim, 1972, p. 66). He went on to describe the parents of autistic children as the perpetrators of grievous negligence akin to Nazi prison guards, postulating that only the “extreme of negative feelings in the parents can set the autistic process into motion” (Bettelheim, 1972, p. 127). These ‘extreme’ negative feelings are described by Bettelheim as behaviours and responses exhibited by parents (particularly mothers) who long for their child to have never been born, or to no longer exist (Bettleheim, 1972; Hyvonen, 2004).

Before I move on to explore some of the ways that this notion of ‘refrigerator mother’ was responded to and contested, it is important, first, to examine how discourses of race and class came to mingle with discourses of gender in the psychoanalytic production of autism and its maternal causes. As I have already demonstrated, not just any-body could come to occupy the position of ‘good mother nurturer’: bodies that (who) transgressed the normative contours and the moral constraints of the embodied figure of the non-working, white, middle-class, bourgeois mother – bodies of color, for example,
working class bodies, disabled bodies, women’s bodies that (who) worked too much outside of the home – were cast (albeit differentially) as ‘bad mother nurturers’ in need of (again, typically, white) paternalistic psychiatric supervision.

While there were very limited ways in which one could perform the duties of a ‘good mother nurturer’, there were many ways to be a ‘bad’ mother, and such subjugated positions came with their own productive constraints. As Dehli (2008) notes, a subject position is not always “equally available or can be temporarily or tenuously inhabited” (p. 47). In other words, not just any-body could come to embody the clearly delimited and highly pathologized subject position of the bad/cold mother of the autistic child and (so) neither could just any body occupy the subject position of autistic.

Indeed, these subject positions were, often, only available to those parents who were/those whose parents were perceived as intelligent, educated, successful in the workplace and, so, economically privileged. In this way, the organization of the subject positions of ‘parent of an autistic person’ and by extension, ‘autistic person’, worked to exclude, for example, people of color from participation. The very same social and historical contexts that gave birth to autism as a recognized and recognizable category, also worked to constrain just who was able to be recognized and recognizable as autistic.

As one mother of an autistic person recalls in the documentary film Refrigerator Mothers (2003):

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6 Parents of autistic children are, still to this day, most often represented as eccentric university professors, scientists, researchers, artists, doctors and so on. They are most commonly represented as middle class and white. This dominant narrative of autism as an middle class ‘disorder’ of the (white) west has, no doubt, much to do with the booming ‘autism industrial complex’ – discussed in Chapter 5 – that depends on the incessant consumption of middle-class parents trying to ‘fix’ or ‘develop’ their kids.
According to my doctor, my son could not be autistic. I was not white, it was assumed that I was not educated and therefore he was labeled emotionally disturbed. Here your child has a disability that you recognize and they said, nah, you can’t be that. You can’t even be a refrigerator mother (laughs), the irony of it all.

Classist and racist systems of oppression and domination worked together to deliver the autistic subject as white and middle class, while sexist paternalistic structures organized the role of the mother as the regulator of the ‘normal’ development of the child, and the subsequent ‘healthy’ development of the state as a whole. In this way, the figure of the ‘refrigerator mother’ is a product of co-mingling systems of racism, ableism classism and sexism that function together to pathologize autistic difference and ‘blame’ the (white) mother, while completely excluding bodies of color from even participating in the social phenomenon of autism.

**The Birth of Autism Advocacy**

This political, social and historical terrain provided not only the conditions of possibility for the emergence of autism as a recognized and recognizable ‘disorder’ (a category, as we have seen, with its own particular constraints), it also provided for the emergence of a new (and equally constrained) response to autism: the response of advocacy.

The first formal autism advocacy society was established by a group of parents in the UK in 1962 (Green Allison, 1997). This organization, which, at the time, was called the Autistic Children’s Aid Society of North London, eventually was transformed into what is now known as the National Autistic Society (NAS). In “Perspectives on a Puzzle
“Piece” (1997), founding member Heather Green Allison writes of the birth of the advocacy group:

On 23 January 1962, a group of desperate parents crowded into the living room of 71 Torrington Park, North London and from this meeting The National Autistic Society was born. This was the first group of parents of autistic children to meet with the specific aim of founding a Society to represent the interests of their children (Green Allison, 1997, para. 1).

In her article, Green Allison discusses some of the challenges faced by the burgeoning organization and, in so doing, she gestures toward the very particular social and historical context that surrounded the emergence of autism advocacy. She writes:

In 1962, the need for an independent society for our children was challenged on all sides [...] the founder members of our Society were facing not only the facts of their children's handicap, but also stresses deriving from the views held on it at the time. There was a widely-held view, based on a misinterpretation of Dr Leo Kanner's research, that the handicap was caused by 'cold, intellectual parents', in particular, 'refrigerator mothers'. The handicap was devastating to be accused of causing - it was tantamount to an accusation of child abuse (Green Allison, 1997, para 3).

Green Allison’s reflection bears witness to the relationship between what were commonly held biomedical beliefs of the time about the ‘nature’ and origin of autism (i.e., autism was understood and accepted by biomedicine to be caused by a working and, so, unnurturing mother) and the shape of autism advocacy. The medicalization and
pathologization of autistic difference permitted and even demanded the emergence of very particular versions of advocacy. To go further, what these social and historical processes gave birth to was an advocacy dominated by parents (particularly mothers) that were required to rehabilitate themselves as non-pathological, and so as not blameworthy, for the purported pathologies of their children. Indeed, the solution of autism advocacy has – and continues to have – everything to do with the meaning we ascribe to the problem of autism and vice versa. The shape and meaning of these two phenomena were – and continue to be – intimately bound up in one another.

Vis-à-vis social views of the time that held that being a mother of an autistic child was, in the words of Green Allison, “tantamount to child abuse”, the group formulated an advocacy response that sought to raise awareness about autism as its own ‘disorder’ (Green Allison, 1997). The expressed aim of the National Autistic Society was to engage in fundraising initiatives and to lobby the state for the development of social structures and institutions that would ‘treat’ and ‘educate’ children with autism (Green Allison, 1997). In an effort to achieve this aim, those engaged in advocacy work employed the direct strategy of raising public awareness of autism – i.e., producing and circulating information and knowledge about autism throughout the public sphere (Green Allison, 1997, para. 2). The ‘work’ of autism advocacy, then, took the shape of (1) ‘working on’ or treating autistic people as well as, more generally, (2) ‘raising awareness’ or educating the public about autism as its own disorder (an awareness that, of course, also worked on rehabilitating the images of mothers cast as disorderly). As we shall see throughout the chapters in this dissertation, these twin aims continue to define formal and informal enactments of autism advocacy to this day.
The remainder of the 1960’s and 1970’s saw the proliferation of parent advocates and the establishment of many advocacy organizations. More and more nation-wide autism advocacy organizations were founded during this time, including: the Autism Society (formerly the Autism Society of America) in 1965, the Autism Research Institute (ARI) in 1967 and the Autism Society of Canada (ASC) in 1976. Similar to the establishment of the NAS in the UK, these North American advocacy groups were founded by parents or family members of autistic people and articulate the twin goals of ‘working on’ autistic people and ‘raising awareness’ about autism.

As advocacy organizations continued their mission of ‘working on’ the autistic subject and ‘raising awareness’ about autism, they became, and remain to this day, enmeshed in the contemporary social production of autism itself. Throughout this dissertation, I show how autism advocacy is not simply a response to ‘autism-the-disorder,’ but a productive force that generates and governs what autism is and can be. In ‘working on’ the autistic subject and in ‘raising awareness’ about autism, autism advocacy work is actively involved in the production and legitimization of particular conceptions or ‘awarenesses’ of autism, and particular understandings of which bodies/behaviours must be recognized as always and already in need of advocacy’s labour.

With the growing presence and influence of autism advocacy, and the subsequent growing awareness of autism as a distinct category of classification, the 70’s and 80’s saw more and more people being diagnosed as autistic (Grinker, 2008). And, along with the increase in autism diagnoses came a proliferation of responses to autism. And so emerged new scientific fields of study – behaviourism and the related fields of the
cognitive and neuro psychologies – all ways of making sense of embodied difference that continue to structure the dominant contemporary paradigm.

The work of several researchers such as Marian DeMyer (1981), combined with the increased presence of and pressure from parent-run advocacy organizations, effectively worked to loosen psychoanalysis’ hold on autism, and, ultimately, the psychoanalytic approach was destabilized as the dominant way of orienting to and understanding autistic difference (Grinker, 2008; Nadesan, 2005). Moving away from a psychoanalytic approach that focused on the mother as the origin of autism’s ‘pathology’, new fields of study began to emerge that took the biological body (and mind-as-body) as the primary target of inquiry. New fields in the biomedical psychologies began to turn their lenses of analysis toward individual autistic body – toward behaviours, mental processes and biology. Over the course of the past 30 years, the autistic body was, thus, transformed into both the site and origin of its own disorder.

**Bad’ Bodies and ‘Mis-wired’ Brains**

**Behaviourism**

Perhaps the most notorious behaviourist with respect to discourses of autism is the clinical psychologist, Dr. Ole Ivar Lovaas. In contemporary times, his behaviour modification approach, termed the ‘Lovaas technique’ and widely recognized as Applied Behavioural Analysis (ABA) and Intensive Behavioural Intervention (IBI), is considered ‘best practice’ in the treatment of the ‘disorder’ of autism (Rosenwasser & Axelrod, 2002). As stated by the US Surgeon General in a 1999 mental health report: “Thirty

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7 For example, Dr. Bernard Rimland, advocate, father of an autistic son and founder of the first American autism advocacy organization, the (then) Autism Society of America (ASA), was instrumental in pushing forward a behaviourist research agenda (Hyvonen, 2004; Nadesan, 2005).
years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior” (U.S. Department of Health and Human Services, 1999, para. 23).

In 1987, Lovaas published a landmark study, "Behavioral treatment and normal educational and intellectual functioning in young autistic children", that described autism in terms of outward behavioural manifestations deemed pathological in nature (Lovaas, 1987). Returning to some of the original ‘symptoms’ noted by Kanner, Lovaas described autism in terms of symptomatic behavioural characteristics: “failure to develop relationships”; “problems with language”; “ritualistic and obsessional behaviours” (Lovaas, 1987, p. 3). Most significantly, Lovaas noted the fourth characteristic of autism – “potential for normal intelligence” (Lovaas, 1987, p. 3). Lovaas and his contemporaries gave shape to autism as not only a state of ‘simple’ abnormality (as it was by, say, Kanner and Asperger), but as a set of abnormal (what Lovaas terms “inappropriate”) behaviours understood to be correctable and improvable.

Significantly, the ‘abnormal’ autistic body was infused with the ‘potential’ for normalcy. In this way, Lovaas’ work lay the foundation for a strategy (intensive behavioural intervention) to treat (read: normalize) autism’s perceived abnormality and thus to release its potential for normalcy. Lovaas noted that the goal of his behavioural intervention and modification approach – which consisted of repetition of ‘normal behaviours’, and the use of rewards and aversives, (i.e., the “delivery of a loud ‘no’ or a slap on the thigh contingent upon the presence of the undesirable behavior”) as ways to “suppress pathological behaviour” – was to produce a subject who is “indistinguishable from their normal friends” (Lovaas, 1987, p. 8).
It is perhaps tangential, but nonetheless elucidating, to discuss, briefly, the origins of the Lovaas technique and its early ‘successes’ of suppressing ‘inappropriate’ behaviours deemed ‘pathological’ in order to produce ‘indistinguishable’ subjects. In the 1970s at UCLA, Lovaas (who not only played an influential role in the founding of the Autism Society but is now widely recognized within autism advocacy communities as a kind of ‘hero’ for his research on autism treatments) was a principal investigator on the now-infamous *Feminine Boy Project* (Burke, 1997; Dawson, 2008).

The project – which received at least 1.5 million dollars in federal funding – was aimed at young boys who were observed (by parents or by medical ‘experts’) to be displaying behaviours deemed ‘feminine’ (Burke, 1997). In much the same way as he later observed, documented and described ‘deviant’ autistic behaviours, Lovaas’ earlier research described ‘deviant’ behaviours of the ‘feminine boy’, including those that follow:

(a) Plays with girls,

(b) Plays with female dolls,

(c) Feminine gestures, [including] limp wrist, swishy hand, arm or torso movements, sway of hips, etc., and

(d) Female role play, [including] impersonating or pretending to be a female (like actress, mother, female teacher) when playing games (like house, school, etc.).

(Burke, 1997, p. 39)
The primary goal of this project was to target such “inappropriate” behaviours and ‘treat’ them by using techniques such as repetition of ‘normal’ (i.e., socially determined ‘masculine’) behaviours, and the use of aversives, and rewards (Burke, 1997, p. 39). The funding for the *Feminine Boy Project* was withdrawn in 1976, and, over the course of the next several decades, Lovaas distanced himself from the research that was conducted under the umbrella of this project. However, Lovaas’ behavioural modification work continues to this day at the UCLA Department of Psychology, where the focus is now on the treatment of autistic children through behavioural intervention.

Perhaps in part due to Lovaas’ close ties with the US national advocacy organizations – he played a foundational role in the establishment of the Autism Society – the popularization of behaviourism was and continues to be influential in shaping and shifting advocacy work and autism awareness. The same historical moment that gave rise to a behaviourist ideology that told the story of autism as a disordered but improvable body, also witnessed a shift in advocacy’s awareness of autism. For example, Dr. Bernard Rimland – founder of both the Autism Society and the Autism Research Institute, and close personal associate with Lovaas – began to formally advocate that autism was a “biological disorder that could be treated – or at least ameliorated – with biomedical and behavioural therapies” (Venables, 2006). This embrace of the biomedical perspective as the only viable way to know and respond to autism – an embrace that is reflected in the vast majority of advocacy platforms to this day – gestures toward the contingent social, political and historical dimensions organizing and governing autism advocacy. While behavioural modification is still considered the ‘best practice’ in Western/ized countries when it comes to ‘working on’ autism’s perceived deviance, one
dominant way of knowing, understanding and becoming ‘aware’ of this ‘deviance’ is by way of cognitive psychology and, later, cognitive neuropsychology and neuroscience.

**Cognitive psychology and the neurosciences**

The emergence of cognitive psychology in the 70s and 80s provided still another highly influential response to autism and it (along with its more contemporary incarnations such as cognitive neuropsychology) continues to be utilized and developed as a dominant way of, first, recognizing and, then, knowing autistic difference. For cognitive psychology, the (assumed) pathological nature of autism’s behaviour is not an end in and of itself but is, rather, an *indication* of an underlying biological (structural, chemical) difference in the mind.

Cognitive psychology is distinguishable from its antecedents – psychoanalysis and behaviourism – in a number of critical ways. Unlike behaviourism, which holds observable behaviours as its focal point, cognitive psychology is primarily focused on internal mental states (beliefs, desires, intentions and so on) (Baron-Cohen, 1997; Frith & Frith, 1999). While behavioural observations are one critical component of cognitive psychology, a subject’s behaviour is conceived of not as an end in and of itself, but as a clue or a sign pointing to a subject’s inner mental state or brain function. While the field of cognitive psychology shares with psychoanalysis an interest in so-called ‘inner mental states’, it rejects a psychoanalytic reliance on subjective perceptions and reflection, in favour of a scientific research method – premised on empiricism and objectivity – as a way of studying the cognitive processes of the mind (see, for example, the work of Simon Baron-Cohen, Uta Frith, Michael Tomasello).
A popular field of inquiry in cognitive psychology, particularly with respect to autism, is the study of human Theory of Mind. Theory of Mind is a concept that is used to signal a person’s ability to “attribute mental states (such as beliefs, desires, intentions, etc.) to [oneself] and other people, as a way of making sense of and predicting behaviour” (Tager-Flusberg, Baron-Cohen & Cohen, 1993, p. 3). Theory of Mind hypothesizes that the ability to quickly and effortlessly ‘attribute mental states’ is the ability of the ‘normal’ human and the field of cognitive psychology has developed a barrage of tests (e.g., ‘false belief’ tests) that are drawn upon to empirically determine whether or not an individual possesses Theory of Mind. Based upon test results examining autistic people’s behaviours and responses, cognitive psychologists have concluded: “children and adults with the biological condition of autism suffer, to varying degrees, from “mindblindness” [...] they fail to develop the capacity to mindread in the normal way” (Baron-Cohen, 1995, p. 5). Autistic people, Baron-Cohen (and many others) have suggested, lack empathy. The emergence of cognitive psychology, then, marks a fundamental shift in the understanding of psychiatric ‘disorder’ – what was once a philosophical problem of the mind, now is a knowable, screen-able, biological pathology of flesh and bone.

At the same time that cognitive psychology was emerging as a new and viable way of understanding and classifying the mind with a priori forms and structures, the global/izing west was in the midst of another considerably influential cultural phenomenon – a veritable boom in computers, science and technology (Nadesan, 2005).

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8 And, as noted in McGuire & Michalko (2011), Theory of Mind is sometimes even articulated in cognitivist research as the defining ability of the human; the marker of what is human. As cognitive psychologist Michael Tomasello (et al.) writes in a 2005 article published in Behavioral and Brain Sciences: ‘We propose that human beings, and only human beings, are biologically adapted for participating in collaborative activities involving shared goals and socially coordinated action plans (joint intentions)’ (Tomasello et al., 2005, p. 676).
The 70’s and 80’s saw expeditions to space, the cold war and the race to develop better, ‘smarter’ arms technology, the development of the circuit and a plethora of research focusing on creating various forms of artificial intelligence. Most significantly, however, it was the so-called ‘computer age’ in the West; an historical juncture that introduced the pocket calculator and witnessed the popularization of the personal home computer.

Ironically, as cognitive psychology tended to focus, largely, on ‘natural’ a priori aspects of the mind, it simultaneously adopted technology – specifically the computer – as the principal metaphor for the mind’s organization (Nadesan, 2005; Neisser, 1976). The form and structure of the mind were (and continue to be) articulated as ‘hard-wired’; mental processes were beginning to be thought of in terms of synaptic ‘connections’; cognition started to be described in terms of ‘computational processes’; it became common to understand the mind as working via ‘information processing’ and so on.

Ulric Neisser (1976), who was first to coin the term ‘cognitive psychology’, argued that it was this so-called ‘computer age’ that enabled the cognitive paradigm to emerge as a dominant mode of understanding the mind. The computer age did not simply provide the conditions of possibility for the emergence and mainstreaming of the cognitive psychology paradigm. Nadesan writes that “the cognitive paradigm takes an ‘information processing’ approach to studying the mind” (Nadesan, 2005, p. 104). The computer metaphor, in other words, was not simply a useful way of describing mental processes, rather, understandings of computers and artificial intelligence influenced the way the (embodied) mind was (and continues to be) thought about and understood.

Cognitivism, along with its technologically-inspired way of both knowing and understanding the mind, provided a story about the mind that was and continues to be
immensely appealing to a variety of established fields of thought, and some of its central
tenets were and continue to be adopted by other fields of psychology such as, for
example, behaviourism. It has also spawned new and related (non-psychological)
biomedical fields of study such as, for example, cognitive neuropsychology and cognitive
neuroscience. By conflating cognitive ‘states of mind’ and physiological brain states,
these sibling ‘neuro’ fields make even more explicit the proposition that there are
empirically knowable – biological – origins of ‘normalcy’ and ‘abnormalcy’ (e.g., where
cognitive psychologists might empirically measure one’s possession of Theory of Mind
by a ‘false belief’ test, cognitive neuropsychologists might measure this using brain
imaging techniques). These new ways of thinking of the mind and brain – or, perhaps the
mind-as-brain – have had profound and reverberating effects on the ways autism is
monitored, measured and ‘worked on’.

Consider, for example, the biomedical industry of, what Nadesan (2006) terms,
“autism brain science”, which studies the biological and anatomical ‘anomalies’ of the
‘autistic’ mind/brain (p.148). Commonly employed technologies for studying the autistic
brain range from clinical studies – such as the Autism Tissue Program – that collect and
study ‘pathological’ brain samples of deceased autistic people in order to “advance
autism research and unravel the mysteries of this and related neurological conditions”
(Autism Speaks, 2011a, para. 2) to neuroimaging technologies that (seem to) allow a
glimpse at how the living brain is functioning and malfunctioning (e.g., MRIs, fMRIs,
PET and CAT scans and so on) (Nadesan, 2005). Quite remarkably, contemporary
biomedical practices of measuring and mapping the ‘disordered’ human brain are
detached and divided out from (ongoing) ableist, racist, sexist and heterosexist histories
that draw on comparative anatomy and notions of biological determinism as a means of structuring an empirical hierarchy of embodied life (as I explore in the later chapters of this dissertation, this divide is both artificial and dangerous).

As cognitivism and the related neurosciences have become dominant ways of understanding the mind/brain, cultural understandings of ‘normal’ and ‘abnormal’ have shifted once again. The cognitive paradigm described above provides a model of a human mind/brain that is not only fluid, changing, unfixed, but is even, much like behaviourist conceptions of human behaviour, *improvable*. The neurosciences have introduced, for example, the concept of brain ‘neuroplasticity’, which proposes that the brain (and, so, as these concepts are, utterly, tangled, the mind) is not simply ‘hard-wired’ once and for all but is *plastic* – it can change over time (Nadesan, 2005). In this way, the mind/brain, then, can not only be charted, it can be ‘engineered’, and even – where there is ‘mis-wiring’ – can be ‘rewired’ or ‘repaired’. With this in mind, the crucial distinction that marks the uniqueness of this particular historical moment is that ‘normalcy’ is constructed not as something one has or does not have, but as an embodied *practice*. The ‘normal’ mind/brain is some ‘thing’ that can be ‘worked on’ – whether by the self and/or by medical ‘experts’, observant parents, or by intervening advocates. And so, the ‘normal’ mind/brain is framed as something that can be, eventually, achieved. Achieved, or, perhaps more accurately, approximated.

**The Autism Spectrum and the Improvable Body**

With the release of the latest Diagnostic and Statistical Manual, the DSM-IV in the early 90’s, ‘autism disorder’ was re-articulated as ‘autism spectrum disorder’. Autism is now conceived of, not as a single disorder, with fixed ‘deficits’ but as a
conglomeration of many disorders and syndromes with many ‘deficits’ ranging from ‘mild’ to ‘severe’; from ‘low functioning’ to ‘high functioning’. Despite the seeming openness and fluidity of the spectrum metaphor, this conceptualization of autism instead serves as a way to further classify – and so further pathologize – the minutia of autistic difference. Autism is now comprised of ‘Asperger’s syndrome’, ‘Childhood Disintegrative Disorder’, ‘Rett syndrome’, and the catch-all, ‘Pervasive Developmental Disorder – Not Otherwise Specified’ (PDD-NOS) (Attwood, 2008; Grinker, 2008). The understanding of autism as not merely one treatable disease but as an ‘umbrella’ or ‘spectrum’ of many treatable diseases, whose manifestations range from ‘mild’ to ‘severe’, conceptually gels so easily with neuroscientific notions of ‘plasticity’ and behaviourist notions of ‘improvability’. In this way, the concept of autism as a graded spectrum of possible ways of being is so crucial to dominantly held contemporary understandings of the autistic body that narrate it as some ‘thing’ to be ‘worked on’, modified, improved and to understandings of the role of the advocate as the worker, the improver, the modifier.9

As is evident in the discussions above, ‘disorder’ is no longer conceived of as something that can only be intuited on a psychiatrist’s couch; new developments in technology and ideology have spawned new fields of inquiry such as the ‘cognitive’ and ‘neuro’ sciences explored above and, as seen above, these fields have opened up new ways of ‘seeing’ – and so new ways of ‘knowing’ – autism’s disorder. The dominant contemporary belief that autism dwells, not between people, but in individual bodies has

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9 For further discussion of the phenomenon of the improvable body and the improving work of the ‘good’ advocate, see chapter 4. For an interpretation and analysis of the meaning being made of the concept of ‘spectrum’ in contemporary discourse, see chapter 7.
fueled a prodigious and multi-faceted biomedical (gold\(^{10}\)) rush to find its origin story.
The branches of contemporary biomedical autism research are as numerous as they are
diverse; their objects of study ranging from ‘flawed’ genes to ‘toxic’ childhood vaccines,
from ‘bad’ brain anatomy to acid rain. In the next section, I examine what is widely
considered to be the most accepted way of ‘seeing’ autism’s biological origins: the study
of autism genetics.

‘Flawed’ Genes

The past number of decades has seen the emergence of whole sub-fields of
scientific research focused on the genetics of autism. Such studies seek to reveal
underlying neurobiological pathways connecting genetic mutations (‘bad genes’) to the
behavioural ‘signs’ and ‘symptoms’ that are understood as characteristic of autism. As
Nadesan (2005) writes: “observable ‘autistic’ behaviours and cognitive deficits are thus
believed to be epiphenomena of the underlying organic disorder(s)” (p. 149). It is widely
accepted by geneticists that autism has a 90% heritability rate (Rutter, 2000) and this
truth claim has generated multi-million dollar research initiatives, such as the Autism
Genome Project (AGP) – that attempts to map autism “susceptibility” genes and identify
Resource Exchange (AGRE) – which is the “largest private, open-access repository of
clinical and genetic information dedicated to help autism research” (Autism Speaks,
2011b, para. 1).

While huge amounts of time and money have been invested in coming to know
autism’s genetic origins, the search has generated more complexities and revealed few

\(^{10}\) See Chapter 5 for an examination of the very lucrative ‘business’ of autism.
clear answers. Concluding his overview of contemporary genetic autism research and referencing Hacking’s reflections on autism, Michael Fitzpatrick (2009) writes:

‘So what do we know about autism?’ asks philosopher Ian Hacking, ‘Not much’ is his laconic reply (Hacking, 2006). This, of course, is true: there appear to be a relatively large number of genes, in a wide range of locations, interacting in complex and undetermined ways, and acting through neurophysiological pathways that are little understood. (p. 80)

However uncertain autism’s genetic origins are, it is, nonetheless, important to consider what fuels these particular approaches to knowing autism. The motivating desire – and the presumed need – for more and more genetic discoveries, grows from the desire/need for the development of methods of screening for (and so, screening out) autism. The AGRE, for example, states that its ultimate aim is “more effective treatments, prevention, and possibly a cure for autism” (Autism Speaks, 2011b, para. 1). Such medical/moral desires, of course, take for granted an underlying (and highly contested) truth that a ‘good’ autism research outcome is no autism at all.

With this in mind, I am not so quick to agree with the conclusions drawn by Hacking and Fitzpatrick, above. If we consider the intricate network of underlying assumptions orienting the drive for more genetic research – beginning with the assumption that the sum-total of what autism is, is (and can be) determined by a careful examination of biology and ending with the assumption that autism is not a valuable (viable?) part of collective life – it then would seem, we know quite a bit about autism already. The ‘lack’ of conclusive answers coming out of the field of genetics is almost never taken up as a provocation to think deeply about the inherent uncertainties of fully
knowing the human body, our own and the bodies of others. But “could genetics”, to borrow Rosalyn Diprose’s (1995) question, “make sense in another sense?” (p. 168). Rather than treating this ‘lack’ of certainty as a call for more efficient searching and re-searching, we might, instead, examine how such a call is absolutely tied to a contemporary (neoliberal) historical moment that, as we shall see in chapter 5, is significantly defined by a regime of global capitalism (Rose, 2007). In this – our – historical context, biomedical practices of searching and re-searching represent the investment in and circulation of more and more capital. This is, perhaps, a commitment to the interminable mystification of autism. And so, not unlike the DNA it takes as its object of study, current genetic research divides, mutates and replicates – generating, supporting and/or invigorating multi-million dollar biomedical research industries. Given these somewhat dramatic shifts in the ways in which autism is dominantly imagined in contemporary times, I turn my focus, now, to an examination of how these shifts have shaped parenting, and (thus) advocacy anew.

**Becoming Aware of Autism as Biological Pathology**

Not unlike the ‘child rearing’ campaigns of the 40’s, a renewed drive to ‘educate’ parents (again, particularly white, middle class mothers) re-entered public life in the 1980’s and this drive continues into contemporary times. There are, however, several particularities that distinguish the series of parent campaigns that took hold in the 80’s and 90’s, from earlier ones. Most significantly, the way in which the normal/abnormal child is studied is now motivated by new biomedical paradigms of understanding the body and mind such as the ones described above – cognitivism, neuroscience, genetics and so on.
As psychoanalysis was the primary way of understanding the normal and abnormal development of the child in the 40’s, the parent campaigns, at that time, scrutinized parents (mothers) themselves. As we explored, the 1940’s campaigns saw an increase in the surveillance of the mother and her mothering practices – the disorder of the child was merely a reflection of the disorder of the mother. By contrast, in the 80’s, 90’s and beyond, the disorder of autism itself – as some (pathological) ‘thing’ that happens to some people – has become the target of these campaigns. Surveillance, then, is focused on the individual body of the child, a body that might be harbouring within it – in its genes, its mind or its brain – a biologically pathological autism.

Indeed, as we have seen, autism meets the certainty of contemporary biomedical paradigms with no small amount of uncertainty and this is reflected in the parent campaigns from the 80’s, 90’s and beyond. While autism’s embodied pathology is understood to be certain, as we have seen, its etiological origins remain unknown. Because of this unknown origin, all bodies are understood as potentially disordered. The mother, who was not so long ago under surveillance and scrutiny, must now adopt the paternalistic position of surveiller – she must watch her children and look for bodily manifestations or ‘signs’ of disorder and seek biomedical intervention.

This, of course, does not free the mother completely from being, herself, an object of scrutiny. However, what has changed is what is being scrutinized. In the 1940’s motherhood was governed in terms of a mother’s ability to ‘nurture’ her children, to ‘properly bond’ with her children, and thus help them develop a ‘normal’ character and personality. In the 80’s, 90’s and beyond, the mother now must watch herself as she watches her children’s development; the role of the mother has transformed into that of a
pseudo-biomedical ‘expert’ poised to identify potential signs of ‘pathology’ in her child. Consider, for example, the best-selling pregnancy book of the 80’s and 90’s, *What to Expect when you’re Expecting* (1981), where ‘good’ mothering is synonymous with being aware of the signs of the ‘normal’ child...of, what to expect. It is this particular, contemporary moment that has given us such organizational devices as ‘early warning signs’, and ‘red flags’ – devices that are often promoted and propagated by advocacy organizations as they seek to ‘raise awareness’ about autism (see Chapter 4 for a more in-depth unpacking of this contemporary drive to ‘red flag’ non-normative bodies and behaviours). Motherhood is measured and governed by the mother’s ability to notice these childhood ‘early warning signs’ and stage ‘early interventions’ such as Lovaas’ normalizing Applied Behavioural Analysis.

Shifts in understandings of parenting are, of course, intimately connected to shifts in the shape and scope of advocacy work, as parents and family members of autistic people are often found at the center of formal and informal enactments of advocacy (Klar-Wolfund, 2008). It is ironic and interesting to note that autism advocacy, a phenomenon that was born out of a vehement rejection of the surveillance of the mother, readily embraces, endorses and promotes this new and more covert form of surveillance. Still, the re-introduction of biological – particularly genetic – determinants of autism does tread dangerously close to the ‘mother blaming’ of yore and this proximity has diverted forms of advocacy (and so ways of knowing autism) in new directions. I turn now to an examination of what is often referred to in advocacy discourse as the ‘autism epidemic’ and advocacy’s subsequent ‘war on autism’.
The Era of Autism 'Epidemic’ and Advocacy’s ‘War on Autism’

The past two decades have witnessed a steep rise in the number of people being ‘identified’ and diagnosed as autistic. In a 2004 White paper, the Autism Society of Canada states that, “autism, once considered a ‘rare’ disorder, has increased dramatically from a prevalence of 4–5 in 10,000 (1 in 2,000 to 2,500) 15 years ago to at least 1 in 500 in 2001” (Autism Society of Canada, 2004, p. 4). The Center for Disease control 2010 report on the prevalence of autism states that 1 in 110 (eight-year-old) American children has an autism diagnosis (Center for Disease Control, 2010, p. 27). The Center for Disease Control and Prevention states that it recognizes this purported increase in autism prevalence as “an urgent public health concern” (Center for Disease Control, 2010, p. 22). While, the increase in diagnoses, as Grinker (2008) and Nadesan (2005) have so clearly demonstrated, have, no doubt, much to do with the shifting social, political and historical contexts in which autism appears, the increase in autism diagnoses is often narrated in contemporary times, particularly by those engaged in autism advocacy, as an ‘epidemic’ (Gernsbacher, Dawson & Goldsmith, 2005).

The word ‘epidemic’ has powerful connotations and demands particular kinds of responses. ‘Epidemic’ implies a sudden widespread occurrence of an infectious disease. ‘Epidemic’ evokes fear – something undesirable, often life-threatening, is spreading through a helpless population. Grinker writes that the term ‘epidemic’, “[calls] up associations with plagues that sweep through the streets, something contagious in the air you breath, or in the food you eat, threatening the ones you love” (Grinker, 2008, p. 3).
This notion of ‘epidemic’ has been shaped by and has, in turn, shaped the landscape of science. The past decade has seen innumerable studies examining and evaluating a wide range of environmental causes of autism.

Perusing my collection of newspaper clippings, journal articles and other pieces of ‘data’ collected over the past number of years, autism is, reportedly, caused by such environmental factors as exposure to acid rain, ultrasounds, lead, gluten and/or yeast in the diet, anti-biotics, pollution, electromagnetic radiation, pesticides, excessive hygiene practices and so on and so forth, *ad infinitum*. Surely the most notorious of the environmental causes postulated over the last decade has been the link made between autism and childhood vaccines. While some researchers have argued that autism is caused by the use of thimerosal mercury in vaccines (Geier & Geier, 2003), others have argued that autism is caused by the Measles, Mumps and Rubella vaccination, which, Wakefield (1998) famously – and falsely – claimed, damaged children’s immune systems (see, “Retraction - Ileal-Lymphoid-Nodular Hyperplasia”, 2010 for the Lancet’s retraction of the Wakefield article). In short, the biomedical sciences of today tell us in both covert and overt ways: *the pathology of autism could come from anywhere*. It may be caused by the rain or by poison in our food. It may be in the genes or in the brain. It may even be in the soul. Insipidly, it has infiltrated those measures we take to secure our children from harm or sickness. Hygiene practices. Vaccines. Ultrasounds.

This culturally and historically specific ‘epidemiolization’ of autism and the terror it, invariably, elicits has shaped advocacy once again. The past two decades have seen the

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11 As one autism ‘expert’, Dr. Jerry Kartzinel, states, “autism, as I see it, steals the soul from a child; then, if allowed, relentlessly sucks life’s marrow out of the family members one by one” (McCarthy, 2007).
establishment of hundreds if not thousands of autism advocacy organizations (an ‘advocacy epidemic,’ if you will) around the globe and the vast majority of these are oriented to autism as a biological problem requiring biomedical intervention – a ‘disease’ in need of ‘prevention’ or ‘cure’. Some of the larger North American organizations include: Families for Early Autism Treatment (FEAT), founded in 1993; the National Alliance for Autism Research (NAAR), founded in 1994; Cure Autism Now (CAN), founded in 1995; Safe Minds, founded in 2000; the Autism Canada Foundation, founded in 2002; the National Autism Association founded in 2003; Generation Rescue, founded in 2005. And, in a 2005 corporate-style takeover headed by Bob Wright, the (then) CEO of NBC, vice-chairman of General Electrics and grandfather of a newly diagnosed autistic child, a number of these organizations – NAAR, for example, and CAN amongst several others – were merged to form Autism Speaks. Based originally in the US, Autism Speaks has since gone global, setting up branch offices in Canada, the UK and the Middle East. Autism Speaks is, without a doubt, the largest, the richest and, so, the most influential autism advocacy organization in operation today and it is leading the way in propagating notions of autism as a terrifying epidemic that needs to be stopped by a wide variety of preventative and rehabilitative biomedical interventions.

As is evident in the chapters to follow, contemporary advocacy work performed and supported by organizations, together with informal acts of advocacy performed by independent advocates (parents, teachers, social workers and so on who may not be affiliated with a formal organization but who engage, nonetheless, in performances of advocacy), remains focused on ‘working on’ autistic people and ‘raising awareness’
about autism. Yet, the shape of these twin aims of advocacy has been altered in accordance with the dominant views of our times.

In dominant contemporary discourses of advocacy, to be ‘aware’ of autism, is to be aware of it as a disease of epidemic proportions while the ‘work’ of advocacy gets taken up as ‘working on’ the bodies of autistic people with the desired end of ‘curing’, eliminating or lessening ‘autistic characteristics’. Oriented to autism as a dangerous and spreading epidemic where the afflicted are not immediately apparent, the ‘work’ of contemporary autism advocacy, then, is often narrated as the work of ensuring, securing and/or recovering the ‘normal’ body and mind. Advocates commonly do the work of securing funding for particular (biomedical) forms of research looking to cure autism and/or eliminate autistic ways of being (e.g., the Autism Tissue Project and the Autism Genetic Resource Exchange are both private, Autism Speaks-funded programs and Autism Speaks also significantly funds the Autism Genome Project); of hypothesizing how autism might be avoided (e.g., Generation Rescue’s campaign against MMR vaccination); of raising awareness of autism as a biological problem in need of immediate intervention (e.g., the launching of ‘red flag’ awareness campaigns aimed to help identify ‘signs’ of developmental difference); and of, even, (attempting to) recover the normative body of non-autism (e.g., the implementation of and/or facilitation of access to speech therapies, drug therapies, dietary therapies, behavioural therapies that attempt to diminish or even eliminate the ‘signs’ of autism).

As it represents (and thus, conceives of) autism as a threat to the (social and literal) body of normalcy, contemporary advocacy work issues an effective and powerful ‘call to arms’ against autism. The orientation of contemporary advocacy is clear: to be an
autism advocate is to be positioned against autism, to fight it, combat it, defeat it and so on. Having emerged out of a World War II moment, autism makes an appearance in this moment in the midst of another war – a war with fresh targets and new tactics. It is this contemporary moment in autism and advocacy that I will focus on for the remainder of my dissertation. I do this so as to interrogate how this dominant cultural commitment is systemically producing and sustaining a social environment that is hostile to autistic difference; an environment that, as we shall see, structures and supports possibilities for violence against those noticed as embodying autistic difference. I conclude this chapter by considering how (relational and hierarchical) privileges and power structures organize and legitimize particular discourses surrounding autism in advocacy work today.

**The Politics of Neurodiversity: Ongoing Histories, Changing Meanings**

As Foucault (1980) notes, wherever there is power, there is also resistance. In the face of a widespread pathologization of autism and the dominant cultural desire for its elimination, autistic scholars and/or activists are producing and organizing diverse strategies of resistance. The term ‘neurodiversity’ was first coined in the midst of the ‘advocacy epidemic’ described above, by Judy Singer who states in a recent *New York Magazine* article on the Autism Rights Movement: “I was interested in the liberatory, activist aspects of it—to do for neurologically different people what feminism and gay rights had done for their constituencies” (Solomon, 2008). Indeed, the term is galvanizing for many as it expresses a way of claiming an autistic identity outside of near-monolithic biomedical frames of pathology/cure.

Most crucially, the notion of neurodiversity sits as a cornerstone of several grassroots autism self-advocacy organizations – such as the US-based Autism Self Advocacy
Network (ASAN) – that have emerged in recent years and are founded and maintained by autistic people for autistic people. The power of notions of neurodiversity in claiming a non-medicalized/pathologized autism identity is evident, for example, in the following excerpt from ASAN’s mission statement:

ASAN seeks to advance the idea of neurological diversity, putting forward the concept that the goal of autism advocacy should not be a world without Autistic people. Instead, it should be a world in which Autistic people enjoy the same access, rights and opportunities as all other citizens. Working in fields such as public policy, media representation, research and systems change, ASAN hopes to empower Autistic people across the world to take control of their own lives and the future of our common community. Nothing About Us, Without Us! (Autism Self Advocacy Network, 2011).

Significantly, much of the dissent and resistance coming from the autistic community is proliferating online. In addition to self-advocacy organizations and networks, whole internet communities – blogs, artistic and scholarly e-communities, online forums and so on – have grown around this concept, connecting those who identify as ‘neurotypical’, those who identify as autistic and those who identify as somewhere in the ‘neurodiverse’ middle. The internet is a discursive space of political resistance that is, often, accessible to autistics who communicate via computer, as well as for autistics who find sustained social stimulation stressful and/or impossible. Indeed, the web has provided a forum for a great many bloggers – Michelle Dawson, for example, Kathleen Seidel, Jim Sinclair and Amanda Baggs, to name a small few – to demonstrate how contemporary versions of autism advocacy that advocate ‘against’ autism have
become complicit in the subordination of autistic people. As Michelle Dawson powerfully puts it in one of her blog posts:

“What's the worst thing about being autistic?” I was once asked, as to a child, by an ingratiating health-care professional.

I replied, "Being hated." (Dawson, 2003)

In the face of a call to identify and eliminate autism, Jim Sinclair (1993) writes of autism in terms of an identity. He states that autism is “a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence” (p.2). In this way, Sinclair, and many other members of the neurodiversity movement are suggesting conceptions of autistic personhood and embodiment as ways of reconfiguring how autistic difference is imagined.

By doing this work, I too, am a part of the diversity of an evolving and contradictory history of autism. In providing my reading of the history of autism and advocacy, I, in turn, am writing a history of these. Jasbir Puar (2007) asks: “What does it mean to be examining, absorbing, feeling, reflecting on and writing about the archive as it is being produced, rushing at us – literally, to entertain an unfolding archive?” (p. xix). She addresses this question by continuing: “this question may lend an immediacy to the work, or it may emit a hollow ringing of the past that no longer feels pertinent; even more bizarrely, it may mean that the present is still unrecognizable to us” (Puar, 2007, p.xix). Vis-à-vis the deep uncertainty of the present of autism and autism advocacy, I engage in a project that is, following Puar, one part an historicization of the contemporary moment and one part a compilation – a writing of an alternative archive of autism/advocacy material available for further historicization and interrogation.
CHAPTER FOUR

Raising the ‘Red Flags’ of Autism: Advocacy’s Call to Arms

The old world writhed in convulsions of rage at the sight of the Red Flag

-Karl Marx (1933), *The Civil War in France*, p. 45

...raise the scarlet standard high/within its shade we’ll live and die...

-Jim Connell (2007 [1889]), “Song of the red flag”, para. 2

In this chapter, I will further explore how the phenomenon of autism is being structured by autism advocacy work in a contemporary western/izing moment by performing an analysis of the social significance and productive effects of advocacy campaigns that draw on biomedical knowledges – particularly the disciplinary discourse of human development – as a way to raise ‘awareness’ about autism’s ‘signs’ or ‘red flags’. In so doing, I demonstrate how this version of advocacy – a dominant and almost monolithic one in contemporary times – is giving new meaning to the phenomenon of autism, as well as to the work of autism advocacy, itself. Lastly, I show how discourses of the normally or ‘naturally’ developing human are involved in constraining (and so producing) particular and novel subject positions within the field of contemporary autism advocacy, most notably, the subject positions of the advocate and the advocated for.
To perform the work of advocacy is often to advocate for something (e.g., one might advocate for ‘better healthcare’). Sometimes, the work of advocacy is to advocate for someone (e.g., one might advocate, by contrast, for people’s access to better healthcare). Less often, the work of advocacy is conceptualized as the work of advocating for the self. While such versions of advocacy are diverse and are shaped by differential power relations, they do share a common thread: to advocate is, very often, to advocate for. Yet, contrary to what the term ‘autism advocacy’ might seem to indicate, dominant, contemporary performances of autism advocacy are not generally concerned with advocating for autism (Broderick & Ne’eman, 2008; McGuire, forthcoming). Rather, as I will explore in the pages to follow, the role of the contemporary autism advocate is limited; the ‘good’ advocate must first ‘take a stand against autism’ and, next, actively work in the development of non-autism (normalcy). As subjectivities are always implicated in the relational constitution of other subjectivities, the delimitation of the subject of the autism advocate as one that is ‘against autism’ invariably places strict restrictions on what or who the subject of the ‘advocated for’ can be¹. Within contemporary autism advocacy discourse, the subject of the advocated for – the autistic subject – gets inscribed as a pathologically underdeveloped way of being to be against and, so, as a way of being that is always in need of (normal human) development.

The first move in any advocacy movement is to raise awareness about that which is being advocated for. As I have demonstrated in earlier chapters, our awarenesses of autism are oriented; they are directed, and inseparable from other awarenesses. Our awarenesses of autism are, for example, directed by and inseparable from the prevailing

¹ A process, of course, that works both ways. As I will explore, the delimitation of the subject of the autistic ‘advocated for’ to someone (afflicted) ‘with’ a pathological autism, functions to (re)enforce the limits of the role of the advocate.
awareness of autism as a puzzle in need of a solution as explored in Chapter 2. Or, the awareness of autism as a biomedical (developmental) deviance that can ‘strike’ any-body – an abnormalcy that can appear anywhere, at anytime, and therefore, a problem that, as a matter of commonsense, requires collective attention and heightened vigilance. In contemporary times, autism awareness is, most often, (normalcy’s) awareness of autism’s abnormalcy; its deviance and therefore, its danger. And, awareness becomes awareness of the embodied ‘signs’ that announce this abnormalcy - warning signs, ‘red flags’.

Tanya Titchkosky (2007) writes of the critical importance of attending to the multiple, complex, and often conflicting ways that bodies get constituted in and through textuality, in and through discourse. Bodies, in other words, come into being via multiple, discursive con-texts that give them shape and structure and that allow them to appear as they do. The discourse of normal human development is one such context that works to shape the bodies of (autism) advocates and the bodies who are advocated for and give them meaning. Vis-à-vis a world of text, Titchkosky issues a critical call to “watch our watching, read our readings” so as to “uncover a few of the ways we identify differences” (Titchkosky, 2007, p. 4). It is in this spirit that I will begin to examine how textual discourses of normal human development are being employed by autism advocacy as a way to identify the difference of autism.

Before I move to a phenomenological analysis of particular appearances of the ‘red flag’ metaphor and consider how the perceived need for heightened vigilance is producing and constraining the field of the possible for both the advocate and the advocated for, I will begin by exploring that power-laden discourse so crucial to any
contemporary notion of embodied abnormalcy: the discourse of ‘normal human
development’.

Discourse, Power, Subject

‘Discourse’, following Foucault (1972), is the “general domain of all statements,
sometimes as an individualizable group of statements, and sometimes as a regulated
practice that accounts for a number of statements” (p. 80). Discourse, then, at least in a
Foucauldian sense, is an organized group of statements, practices, utterances, and
knowledges that work to shape how a particular phenomenon appears at a given historical
moment and within precise geographical spaces. Within a network of power relations,
particular phenomena are, thus, produced by way of highly organized sets of rules that
constrain and restrict what is and, indeed, can be said, done and, often, what can even be
imagined. These regulatory sets of rules and structures – that is to say, ‘commonsense,’
shared understandings and assumptions about a particular phenomenon or relations to a
particular phenomenon – are often unwritten, commonly unspoken, and yet, actively
work to produce a given phenomenon by delimiting the field of possible awarenesses of
and responses to it. And so, a given discursive regime works to produce (via a creative
constraint) particular subjectivities – subjects who possess the necessary qualifications to
dwell within the discourse’s frameworks of meaning and within the parameters of its
methods of recognition.

Autism is one such phenomenon that has, as I have outlined in Chapter 3, been
shaped over the course of the last century by a variety of discourses. A dominant
discourse involved in the production of autism, and one that is often drawn on – and
particularly embraced – by contemporary autism advocacy work, is the biomedical
discourse human development.

In *The Order of Things* (1970), Foucault describes his interest in the formation of
cohesive and discrete scientific discourses in the following way. He writes:

I tried to explore scientific discourse not from the point of view of the individuals
who are speaking, nor from the point of view of the formal structures of what they
are saying, but from the point of view of the rules that come into play in the very
existence of such discourse: What conditions did [the so-called ‘father’ of
taxonomy] Linneas (or Petty or Arnauld) have to fulfill not to make his discourse
coherent and true in general, but to give it, at the time when it was written and
accepted, value and practical application as scientific discourse. (p. xiv-xv)

With respect to scientific knowledges, what is of interest to Foucault is not what is said,
whether it is empirically accurate or inaccurate or even who is saying it, but what rules
structure the knowledge, what techniques secure it and what assumptions must already be
in place for scientific knowledge to appear as ‘valuable’ or even as sensical in a particular
historical moment and geo-political space. What is also of interest for Foucault, is the
work accomplished by such knowledge and its generative effects.

Foucault’s work implicitly asks: how are highly organized ‘rules of discourse’
structuring and, indeed, delimiting the field of the possible (the range of possible
articulations, actions, responses, behaviours, questions, choices and so on) and what are
the effects of this? How does discourse actively work to both constrain and enable what
we perceive, how we understand, how we react, what we do, and even who we are and
can be? These productive constraints work to produce particular phenomena as though these phenomena belonged, simply, to the realm of the ‘natural’, the ‘real’ or the ‘true’. Rather, Foucault argues that commonsense understandings of ‘nature,’ ‘reality,’ or what he terms ‘regimes of truth’, are not self-evident, but are inaugurated and sustained by institutions (e.g. governments, universities, practices and institutions of medicine and so on) by way of networks of power relations (Foucault, 1980; Foucault, 2003; Mills, 2003).

Indeed, modern scientific and medical knowledges, or biomedical knowledges, are, perhaps above all other kinds of knowledge or ways of knowing, almost unilaterally, treated in contemporary times as a set of practices derived from and working to first ‘see’ and then relay the (objective) story of ‘natural’, ‘true’ and ‘real’ phenomena (Foucault, 1980; Foucault, 2003). As I demonstrated in the previous chapter, the ‘gaze’ of medicine ‘looks’ at the body and, in the look, it comes to know the body (Foucault, 2003, p. 109). Biomedical knowledges – and the positivistic sets of procedures and practices generated by these knowledges – so often tell us how things are, what things are, and who we are. It is much less often imagined, however, that a reflection on the premises and practices of biomedical knowledges might tell us something about the culture in which we live – about our cultural aspirations and worries, about what we legitimize, recognize, value, and who.

Foucault’s work, and the work of others, demonstrates how biomedical knowledges, far from being simply objective accounts of the nature of phenomena, are powerful and shifting discursive spaces (Canguilhem, 1991; Foucault, 1975; Foucault, 2001; Kuhn, 1962; McClintock, 1995; Rose, 1989; Walkerdine, 1998). For example, Foucault’s work has demonstrated how biomedical discourses have actively shaped
material divisions that work to reify and, indeed, inaugurate discrete categories of ‘madness’ and ‘sanity’ (Foucault, 2001). In Chapter 3, I explored how biomedical discourses have been equally influential in constraining, and thus producing, material categories of ‘abnormalcy’ and ‘normalcy’, ‘autism’ and ‘non-autism’. These examples demonstrate how biomedical knowledges and procedures play a critical role in the production of the very phenomena under scrutiny. As with any discursive formation, biomedicine is revealed as a set of social practices, of highly organized rules, procedures and articulations governed by historically and geo-politically specific relations of power.

It is important to emphasize that power, for Foucault, is not an object or ‘thing’ that can be possessed by a given individual or institution; it cannot be imposed on or wielded over another individual or institution. Rather, power, in Foucault’s terms, “must be analyzed as something which circulates” (Foucault, 1980, p. 98). Foucault conceptualizes power not as a noun, but as a verb – it is not something one has, but rather, it is something one does (Mills, 2003, p. 35). Power, rather than hovering above at the level of suprastructure, is exercised; it is “invested directly in the distribution and play of forces” (Foucault, 2003, p. 52).

It is, thus, crucial to note that the Foucauldian conception of power relations conceives of power not as repressive – but rather, as essentially productive. As Foucault notes, power “needs to be considered as a productive network which runs through the entire social body, much more than a negative instance whose function is oppression” (Foucault, 1980, p. 119). He writes of “a power that is not conservative but inventive, a power that possesses within itself the principles of transformation and innovation” (Foucault, 2003, p. 52). Somewhat paradoxically, then, constraint, for Foucault, is
productive; the tensions and contractions of power relations, in turn, give form and structure to discursive knowledges that are both the effect and condition of power (Foucault, 2003, p. 52). Foucault’s conceptualization of the ‘essential productivity’ of power guides me as I explore the ways developmental discourse (and the subjects of the (autism) ‘advocate’ and the ‘advocated for’ who dwell within its discursive spaces) is inherently limited, or constrained, by particular (permissible) rules of conduct, ways of knowing and frames of recognition.

In *Discipline and Punish*, Foucault writes of the power-laden disciplinary processes inherent in the formation of embodied subjectivities. “Discipline” Foucault states, “makes individuals” (Foucault, 1979, p. 170). What Foucault refers to as ‘discipline’, of course, is not necessarily an overt, external force – an instrument of domination – but is often a subtle discipline, a covert coercion of the (docile) body of the individual. Subjecthood, then, is not, strictly speaking, a pre-given from elsewhere – from the state or the sovereign – but, rather, is revealed to be a process of becoming that begins at the level of the individual.

While, following Butler (1993), “there is no body prior to its marking” (p. 98) – we always and only exist, in other words, in relation to others who shape us and give us meaning – we do engage in the process of making ourselves into subjects (Foucault, 1980). Within discourse, the individual must perform, condition, supervise and know the self according to the (contingent, power-laden, normalizing) rules of the given discursive regime and always in relation to others. Foucault speaks of these confessional ‘technologies of the self’ as central to how we, as individuals, come to occupy the mediated subject positions that are, invariably, tied to a given discursive regime as well
as to other subjectivities that are permitted within a given regime. Within discourse, the individual must adopt those comportments – embodied qualifications – that comply with the ‘rules’ of discourse. The individual must perform her subjecthood in particular ways so as to be permitted to dwell within the discourse’s (limited) parameters of recognition and so as to secure a status of coherency.

The emphasis on the self-making individual should not be confused with a radical ‘free will’. Such radical freedom disappears with the recognition that there are limited subject positions available for habitation in a given discursive regime. Coming to inhabit a set subject position is necessary insofar as it, in Butler’s words, “qualifies a body for life within the domain of cultural intelligibility” (Butler, 1993, p.16). Through confessional technologies of the self, individuals, thus, become tied to the subject positions made available to them in a given discourse, subjectivities that qualify them with the privilege of cultural coherence and intelligibility. In this way, the discursive regime of (human) developmentalism that structures contemporary autism advocacy work gives birth to various historically and geopolitically defined subjectivities: the subject of the autism advocate, as well as the subject in need of advocacy. In an effort to tease apart the particular constraints operating on the subject positions of (autism) ‘advocate’ and ‘advocated for’, it becomes necessary to further examine the historical and geo-political dimensions of the disciplinary discourses of developmentalism.

**Disciplining Development**

The workings of power relations are heavily inscribed in the field of developmental psychology, and in the material practices of intervention that are informed and authorized by it (education and ‘special education’; rehabilitation therapies;
behavioural intervention; social work and so on) (Burman, 2008; Dehli, 1994; Gilman, 1985; Goodley, 2010; Morss, 1990; Rose, 1989; Walkerdine, 1998). Insofar as it is imbued with the dominant (power-laden) empirical authority of biomedicine, the discourse of human development works creatively, following Foucault, via constraint or limitation, to produce particular phenomena. Human development, taken as a ‘truth’ – a natural or given phenomena – is understood to be an empirically derived, descriptive account of ‘developmental norms’ or ‘normal developmental milestones’, naturally-given normative benchmarks that represent, simply, how things are...how bodies ought to be at a given age. The result of what Haraway has termed a ‘god trick,’ the dominant story of human development is so often told as if it is the only possible one (Haraway, 1991, p. 584, Titchkosky, 2007).

Still, we might change our orientation to this thing called human development and ‘look’ at it not as merely a given truth, per se, but, rather, as a ‘regime of truth’ (Foucault, 1980). In other words, we might attend to human development as a discourse that is made in and by culture, as something that exists only insofar as it is always and inevitably organized by discrete, historically/geographically specific techniques and procedures that give it shape and meaning, bestow on it particular value(s) and provide its very conditions of possibility. Orienting to human development not as a truth but as a regime of truth offers us new possibilities for thinking and theorizing the body as it (always) appears amongst and in relation to other bodies (culture). With this orientation, the stages of human development can no longer be conceived of, strictly speaking, as either accurate or inaccurate objective descriptions of how bodies are at a given age. Rather, human development, taken as a regime of truth, can be theorized as one of many
ways of talking about and understanding the body and its comportment; a story that is
tied to and, thus inseparable from, situated and so, contingent, systems of power and
knowledge. I will now turn to the work of Nikolas Rose (1989), Valerie Walkerdine
(1998), Anne McClintock (1995) and others to provide an overview of just some of the
power-knowledge relations at work within the discursive field of human development.

In *Governing the Soul*, Rose (1989), analyzes how relations of power underpin the
emergence of ‘developmental psychology’ as a category of inquiry, and the positivistic
accounts of ‘normal’ and ‘abnormal’ human development that developmental psychology
relies upon. “A developmental norm…” he writes, is,

…a standard based upon the average abilities or performances of children of a
certain age on a particular task or a specified activity. It, thus, not only present[s] a
picture of what [is] normal for children of such an age, but also enable[s] the
normality of any child to be assessed by comparison with this norm. (Rose, 1989,
p. 145)

Developmental standards – paradoxically – both absolutely require and generate the need
for acts of comparison between a given body and the empirically derived ‘normal’ or
‘standard’ body. These acts of comparison, moreover, occur for a given body, not merely
in relation to another ‘standard’ body, but rather the comparison is made between a given
body and a ghostly myth - a conceptual assemblage of isolated aspects of normalcy along
a temporal axis of age. It is only by way of comparison to the mythic average that
individual children can be determined to be either ‘normal’ for their age, or not.

In *Governing the Soul*, Rose lays out a number of illustrations and photographs
that demonstrate and document how the child became the focal centre of psychiatry’s
normalizing gaze in the twentieth century. The scales, charts, photographs, arrays and drawings depicting human development made the human visible and legible in new ways. According to Rose:

Behavioural items that were characteristic and distinctive of different age levels were defined and organized into scales with specifications of the ages at which a given proportion of children could achieve the different levels on each scale. Non-intellectual behaviour was thus rendered into thought, disciplined, normalized, and made legible, inscribable, calculable. Norms of posture and locomotion; of vocabulary, comprehension, and conversation; of personal habits, initiative, independence, and play could now be deployed in evaluation and diagnosis. The discourse of development established a system of perception that was capable of grasping any feature of life that could be construed as changing over time. It grasped life in a form that could be effected through a few simple operations: advanced or retarded? By how many months? In the table, life comes pre-digested, pre-calibrated, pre-normalized. (Rose, 1989, p. 152-3)

In this way, the norm, via simultaneous processes of medicalization and moralization, was inaugurated and celebrated as the ideal. And, more than this, the ‘norm’ was made ‘natural’.

Rose’s work points to the inextricable connection between the emergence of notions of childhood development at the turn of the twentieth century and the contemporaneous emergence of notions of evolution: “Observations of young children could, it appeared, cast light upon the nature of human evolution and the characteristics
distinguishing man from animals” (Rose, 1989, p. 145). The child, it was noted, grew and changed from infancy to adolescence in such a way that seemed to mimic the evolution of humans from a ‘primitive’ state to one of ‘civility’ (Francis Galton’s quasi-evolutionary claim that ‘phylogeny recapitulates ontogeny’) (Burman, 2008). Notions of ‘natural’ evolutionary development (Darwin’s ‘survival of the fittest’), together with notions of linear chronology and progress, combined to produce morally coded understandings of the developing human body, depending on how it measures up to the stages, as ‘fit’ or ‘unfit’, ‘advanced’ or ‘retarded’, ‘savage’ or ‘civilized’, ‘normal’ or abnormal.

In her chapter, “Developmental psychology and the child centered pedagogy,” Valerie Walkerdine (1998) examines how power/knowledge relations have provided the conditions of possibility that have given way to developmental psychology as a legitimized field of inquiry and observation as well as a recognized ‘scientific’ pedagogy. Inherent in developmental psychology’s claim that children develop in a series of coherent, progressive and naturally unfolding stages, which culminate in the attainment of that faculty reflective of ultimate human civilization – reason – is the inauguration of a deviant, un-natural, un-civilized or, more succinctly, ‘degenerate’ subjectivity. The subject position of the social ‘degenerate’ – upon which any conceptualization of ‘normal’ human development inevitably relies and, indeed, is premised – binds particular bodies together as ‘problem’ bodies and underscores the existence and persistence of power within the field of developmental psychology.

Walkerdine traces the history of the emergence of schooling as a kind of intervention, one possible ‘solution’ to particular ‘problem’ bodies, most notably, in the
1800’s, the ‘degenerate’ bodies of the pauper and criminal (Walkerdine, 1998, p. 165).

Critically, Walkerdine points out that both crime and pauperism were understood in terms of deteriorated or underdeveloped moral character; ‘bad habits’ that could be ‘corrected’ by proper instruction/intervention (Dehli, 1994; Walkerdine, 1998). She writes: “It was this understanding of bad habits as the cause of crime and pauperism which led to the possibility of seeing popular education as the answer to the nation’s ills, that is by the inculcation of good habits” (Walkerdine, 1998, p. 165). In this way, the development of a civilized ‘reason’ – a primary mandate of schooling – was put forward as the ‘solution’ to various social problems (problem populations). The intervention of schooling, itself an inherently civilizing project, enabled ‘problem’ students to ‘realize their potential’, to release the possibility of becoming ‘rational’ human beings. As the moralization of ‘social problems’ (bodies with ‘bad habits’, immoral bodies) quickly blended with a medicalization of these same problems populations (‘underdeveloped bodies’ or ‘pathological bodies’), the means of targeting these populations changed. Hence, argues Walkerdine, the psychologization of education (Walkerdine, 1998, p. 169).

Walkerdine traces this ‘marriage’ of developmental psychology and pedagogy (what she refers to as the psychology/pedagogy ‘couple’) back to Darwin and the concept that developmental ‘progress’ requires both the biomedical concern of suitable ‘stock’ (heredity, for example, or contemporarily, genetics) and the moral preoccupation of ‘ideal’ environmental conditions – nature and nurture. She writes:

The movement which produces the individual as an object of science defined in terms of the twin poles of heredity and environment produces simultaneously the need for the development of scientific and empirical apparatuses and techniques
of detection and some form of institutional provision which help produce and normalize such individuals” (Walkerdine, 1998, p. 170).

‘Normal’ human development, informed by the blending of moral and medical understandings of the body and conceived of, ironically, as ‘natural’ development, became something to be facilitated or taught (Dehli, 1994). ‘Humanness’ was made teachable, and necessarily so.

The historical emergence of an understanding of (good) humanness as something that can (and should) be taught, holds great significance when held in tension with contemporary developmentalist discourses, discourses that pervade autism advocacy work and contemporary western/ized culture more generally. I unpack this significance, later in the chapter, as I explore the generative effects of the common stipulation, within discourses of autism advocacy, that requires the (‘good’) advocate subject to engage in the task of working on (developing) the inherently under- (or ‘badly’) developed autistic subject.

The work of Rose (1989), Walkerdine (1998), McClintock (1995), Gilman (1985) and Burman (2008) demonstrates that what (and who) was considered a ‘social problem’ is related to social, political, geographical and historical contexts and thus changes with changing historical tensions and shifting power relations. Consider, for example, how development discourse emerged in the midst of European industrialization and colonialism (Burman, 2008). Walkerdine states that in the 1900s, the “concern with degeneracy finds expression in the necessity of building an ‘imperial race’ and the consequent concern for national efficiency, that is the building of an efficient workforce suitable to the development of the empire” (Walkerdine, 1998, p. 173).
This understanding evokes multiple implications. The emphasis on strength and ‘efficiency’ within the ranks of the ‘imperial race’ require the (white, northern, European) citizenry of the metropole to, quite literally, ‘measure up’ to developmental expectations of the normative ‘natural’ human subject. The so-called ‘degenerate’ white populations of the metropole (those who did not ‘measure up’ – women, criminals, the ‘feebleminded’, the ‘handicapped’, the working classes, prostitutes, gays and lesbians and so on) were framed as necessitating (early) disciplinary intervention (be it psychological, pedagogical and/or judiciary), aimed to facilitate ‘normal’ human development, and produce the ‘respectable’ (and necessarily bourgeois) body. “Degeneracy”, in Walkerdine’s words, “could be nipped in the bud, by regulating the development of children in order to ensure their fitness as adults” (Walkerdine, 1998, p. 170). Or, at least in theory. Of course, this civilizing project was not without its ‘failures’; not all bodies are equally amenable to a pedagogical rehabilitation. In terms of their ability to ‘pass’ as the respectable ‘norm’, bodies were differentially and hierarchically positioned. The body of an able-bodied, white, working class child, for example, might have been better suited for (more compliant to) a normalizing pedagogy of development than the physically impaired body of a white, working class child. And so, some ‘degenerate’ bodies were understood, as, in some essential way, incapable of the norm; this is evident, for example, both in colonial conceptualizations of racialized Europeans and bodies of colour living in the colonies.

Anne McClintock (1995) describes how, in colonial times, racialized bodies were – and insofar as colonization is an ongoing process, particularly here in North America, are – conceptually imagined as ‘anachronistic’, residing in a “permanently anterior time
within the geographic space of the modern empire as anachronistic humans, atavistic, irrational, bereft of human agency – the living embodiment of the archaic ‘primitive’” (McClintock, 1995, p. 30). While giving his inaugural lecture at the University of Jen in 1789, Frederic von Schiller demonstrates this notion of colonized bodies as anachronisms and, further, links this imagined state of anachrony to a state of (pathological) (under)development. He stated:

[The European colonies] show us societies arrayed around us at various levels of development, as an adult might be surrounded by children of different ages, reminded by their example of what he himself once was and whence he started. A wise hand seems to have preserved these savage tribes until such time as we have progressed sufficiently in our own civilization to make useful application of this discovery, and from this mirror to recover the lost beginning of our race. (Schiller, 1789 quoted in Helliwell & Hindess, 2005, p. 414)

But we need not look to the fourteenth century for examples of this kind of colonial logic that delivers the colonized body as a developmental anachrony. Consider, for example, the ubiquity and dominance of contemporary representations of aboriginality that depict the body of the aboriginal as always and already spectral, an antiquated remnant of more primitive times that, somehow, persists in the modern present of a European settler society (Bergland, 2000).

Indeed, the developmental perspective dominated (and continues to dominate) colonial rule, particularly through ideologies spawned by evolutionism (Foucault, 1997, p. 257). Colonial dominance was and is maintained through the surveillance and policing
of bodies, the sharpening of the boundaries separating ‘normal’ from ‘abnormal’
development and the recognition of departures and deviations from ‘normal’ (and always
and already white, male, able-bodied, heterosexual and middle-classed) development as
somatic *pathologies* (Gilman, 1985). In this way, the African, the Jew, the insane, the
feebleminded, the alcoholic, the Native, the sexual deviant are conceptually linked
through discourses of pathological deviance from the esteemed status of ‘fully’
developed human (Gilman, 1985). The biomedical ‘gaze’ that watches for and recognizes
difference as pathology simultaneously inaugurates the necessity for
biomedical/pedagogical interventions that aim to restore not simply ‘health’ and but also
‘civility’.

It is important to note, when considering the interlocking nature of multiple
oppressions that pathologized subjectivities (e.g. as we have seen, racialized bodies,
gendered bodies, classed bodies, disabled bodies and so on) are not equivalent or even
comparable in any straightforward way. However, each process of oppression is
implicated in the other, following Walkerdine, each “mak[es] and re-mak[es] the other
possible, intertwining to produce a discursive and political nexus” (Walkerdine, 1998, p.
173). Understandings of the racialized body as a degenerate body, for example, are
absolutely reliant on and, so, inseparable from, simultaneous understandings of the
(developmentally) disabled body. McClintock gestures toward the entangled nature of
these subjectivities under colonial rule:

In the metropolis the idea of racial deviance was evoked to police the ‘degenerate’
classes – the militant working class, the Irish, Jews, feminists, gays and lesbians,
prostitutes, criminals, alcoholics, and the insane – who were collectively figured
as racial deviants, atavistic throwbacks to a primitive moment in human pre-
history, surviving, ominously in the heart of the imperial metropolis. In the
colonies, black people were figured, among other things, as gender deviants, the
embodiments of prehistoric promiscuity and excess, their evolutionary
belatedness evidenced by their ‘feminine’ lack of history, reason and proper
domestic arrangements. (McClintock, 1995, p. 43-4)

The work of Rose, Walkerdine, Gilman, McClintock and others demonstrates,
historically, how biomedical and psychological formulations of ‘normal’ human
development produce and re-produce colonial (power) relations of, at once, race,
disability, class, gender, and sexuality.

As I explore in the next chapter, these relations continue to be (albeit, differently)
embedded in contemporary biomedical and psychological formulations of ‘development
work’ as is evidenced, for example, in the global(ized) exportation of health and mental
health ‘standards’ (particularly to ‘underdeveloped’ countries) by the World Health
Organization (WHO) as a part of an ongoing ‘development’ process (Titchkosky &
Aubrecht, 2009). As we shall see, the resonances between contemporary ‘development’
work, histories of scientific racism, ableism, sexism and heterosexism and ever-present
and authoritative biomedical notions of progressive and normal human development
cannot be separated, if for no other reason than the shared nomenclature of ‘development’
that can be found at the center of each of these projects and the ghostly myth of the
(white, able-bodied, male, heterosexual, middle-classed) norm that is, inevitably, evoked
and sustained by this nomenclature.
I begin my critical consideration of the use of developmentalism in autism advocacy by situating this discourse within these historical proximities not only to underscore the power-laden terrains that invariably structure any evocation of notions of development but also to begin to attend to the multiple ways that stories we have and tell about bodies (our own and others) are caught up in the very constitution of the category of human. Any enterprise that draws upon and utilizes notions of ‘human development’ – and autism advocacy is one such enterprise – must critically and ethically attend to the field’s historical and present involvement in the production of such oppositional categories as normalcy/abnormalcy, health/pathology and to the conceptual associations that tie these categories to notions of progress/antiquity, reason/irrationality, civility/primitiveness and so on. Moreover, in light of the multiple power relations that circulate through the discourse of developmental psychology, it becomes necessary to reflect on how this discourse is involved in the production of various medicalized/moralized subjectivities. I will now turn to the ‘red flag’ poster - which I am reading as a disciplinary mechanism that draws on the disciplinary categories propagated by developmentalism – and will consider how this genre of advocacy work is implicated in regulatory processes that bear down, simultaneously, on both the individual under observation (the body of the potentially autistic) as well as the individual doing the observation (the body of the potential advocate).2

2 I use the language of potentiality with respect to both the autistic body and the body of the advocate, as disciplinary processes are always invested in the body... becoming.
Raising the ‘Red Flag’

The metaphor of the ‘red flag’ is commonly employed within advocacy discourse as a way of raising (always, as we have seen, oriented) awarenesses about autism. Consider the following two different, and yet distinctly related, autism awareness posters, produced and circulated by two western autism advocacy organizations. Both posters are exemplary of a whole genre of advocacy campaigns, that I am calling ‘red flag’ awareness campaigns.

I have chosen these two examples in particular – a poster from a prominent Canadian advocacy organization, and one from the UK – not only to attend to their common message, but also to demonstrate the pervasive, border-crossing nature of the message. Indeed, the notion that autism is simply a series of ‘bad’ (abnormal, pathological, underdeveloped and so primitive) ways of behaving, acting and interacting that require immediate corrective intervention, and the imperative that ‘good’ advocacy must intervene and correct autism’s perceived abnormalcy are the two cornerstone assumptions of almost every autism advocacy organization operating in and on the western/ized world, today.

The first example is a poster, released in 2007 by the Canadian advocacy organization, Autism Ontario (figure 4.1). At the top of the poster there is a wide band, deep red in colour, that stretches across the width of the poster and provides a background for the bolded header: “Red Flags for Autism”. Just below this band of text, are the words: “Parents should ask their child’s family doctor for referral to a developmental pediatrician if there are concerns with any of the following...” The poster, then, is divided into three sub-sections, three categories of red flags: ‘Communication
Red Flags’, ‘Behavioural Red Flags’ and ‘Social Red Flags’. Each of these subsections, like the title, appears against a deep red background.

Under each of the subheadings are bulleted lists describing the so-called ‘red flags for autism’: means of communicating, behaviours and ways of socially interacting that, we can assume, signal autism’s presence. For example, the bullets read, “no babbling by 11 months of age”; “no simple gestures by 12 months (e.g., waving bye-bye); “no 2-word phrases by 24 months (noun + verb – e.g., ‘baby sleeping’); “Odd or repetitive ways of moving fingers or hands”; “Lack of interest in toys, or plays with them in an unusual way (e.g., lining up, spinning, opening/closing parts rather than playing with the toy as a whole)”; “Does not play peek-a-boo”; “prefers to play alone” and so on. In addition to the bulleted lists of various ‘red flags’, each subsection displays a different graphic depicting smiling children engaged in activities that appear in stark contrast to the ‘red flag’ behaviours – the children depicted are playing together, making gestures to one another, playing with toys in conventional ways. One graphic displays a boy grinning as he holds up a frog to a grimacing girl. Another graphic shows a young smiling boy building a tower with his blocks. A third and final graphic shows two children happily playing together on a seesaw. Below the ‘red flags’ and the graphics that accompany them, appears a bright green band that highlights the statement: “To help your child succeed, help them to communicate”. At the foot of the poster, there is a commercial advertisement for communication software3 and several prescriptive statements, including: “Autism is treatable, early intervention is critical. Know the warning signs of

3 The appearance of a commercial advertisement on an advocacy poster advertising the signs of abnormal developmental is not mere happenstance. In Chapter 5, I explore the entwined relationship between biomedical notions of human development and capitalist notions of economic development.
Red Flags for Autism

Parents should ask their child’s family doctor for referral to a developmental pediatrician if there are concerns with any of the following:

**Communication Red Flags**
- No babbling by 11 months of age
- No simple gestures by 12 months (e.g., waving bye-bye)
- No single words by 16 months
- No 2-word phrases by 24 months (noun + verb – e.g., “baby sleeping”)
- No response when name is called, causing concern about hearing
- Loss of any language or social skills at any age

**Behavioural Red Flags**
- Odd or repetitive ways of moving fingers or hands
- Oversensitive to certain textures, sounds or lights
- Lack of interest in toys, or plays with them in an unusual way (e.g., lining up, spinning, opening/closing parts rather than using the toy as a whole)
- Compulsions or rituals (has to perform activities in a special way or certain sequence; is prone to tantrums if rituals are interrupted)
- Preoccupations with unusual interests, such as light switches, doors, fans, wheels
- Unusual fears

**Social Red Flags**
- Rarely makes eye contact when interacting with people
- Does not play peek-a-boo
- Doesn’t point to show things he/she is interested in
- Rarely smiles socially
- More interested in looking at objects than at people’s faces
- Prefers to play alone
- Doesn’t make attempts to get parent’s attention; doesn’t follow look when someone is pointing at something
- Seems to be “in his/her own world”
- Doesn’t respond to parent’s attempts to play, even if relaxed
- Avoids or ignores other children when they approach

To help your child succeed, help them to communicate.

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*Autism is treatable. Early intervention is critical. Know the warning signs of autism in young children. Act early.*

**FOR MORE INFORMATION:**
AutismOntario - Durham Region
Toll-free Phone/Fax: 1-866-495-4680
Email: durham@autismontario.com
Office: 21980 Highway 12, Sunderland, ON L0C 1H0
Website: www.autismontario.com/durham

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Figure 4.1: Autism Ontario (2007) "Red Flags for Autism" Poster. Reprinted with permission.
autism in young children. Act early.” The poster, then directs you to the *Autism Ontario* website for more information.

Figure 4.2 represents yet another example of a ‘red flag’ advocacy poster produced by the UK’s National Autistic Society (NAS) (2008) (Fig. 4.2). The NAS poster displays the bolded title: ‘Autism is…’. Beneath this title, the text continues:

…a lifelong developmental disability that affects how a person communicates with, and relates to, other people, and how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Over 500,000 people in the UK have autism – that’s one in a hundred (NAS, 2010).

The poster features 14 illustrated vignettes that depict ‘stick figures’ engaged in various activities. Some stick figures appear alone, while others appear in the company of other stick figures, or in the company of inanimate objects. The vignettes illustrating “some” of the possible “ways in which autism is displayed” (NAS, 2010) show, for example:

- A stick person sitting in a chair with a thought bubble and a speech bubble, both containing an image of a train - the text narrates: “Talks incessantly about only one topic”;
- A stick figure, on its knees, building a tower of teacups: “Lack of creative, pretend play”;
- A stick figure flapping its arms: “bizarre behaviour”
- An smaller stick figure turning away from a taller one: “no eye contact”
Autism is...

A lifelong developmental disability that affects how a person communicates with, and relates to, other people, and how they make sense of the world around them. It is a spectrum condition, which means that while all people with autism share certain difficulties, their condition will affect them in different ways. Over 500,000 people in the UK have autism – that’s one in a hundred.

These pin people illustrate some of the ways in which autism is displayed.

- Displays indifference
- Joins in only if adult insists and assists
- One-sided interaction
- Echolalic – copies words like parrot
- Indicated needs by using an adult’s hand
- Does not play with other children
- Talks incessantly about only one topic
- Bizarre behaviour
- Variety is not the spice of life
- Inappropriate laughing or giggling
- Handles or spins objects
- No eye contact
- Lack of creative, pretend play

But some can do some things very well, very quickly but not tasks involving social understanding

Early diagnosis is essential if people with autism are to achieve full potential. It is only when their disability is understood that they can be helped to maximise skills and minimise problems.

For more information contact:
The National Autistic Society, 393 City Road, London EC1V 1NG Telephone 020 7833 2299

Graphic design based on illustrations used by Prof. J. Rende-Short, Australia
and National Society for Autistic Children, USA.

Accept difference, Not indifference.

Figure 4.2: National Autistic Society (2008) poster "Autism is...". Reprinted with permission.
Beneath the vignettes appears the statement: “Early diagnosis is essential if people with autism are to achieve their full potential. It is only when their disability is understood that they can be helped to maximize skills and minimize problems” (NAS, 2010). The small print at the bottom of the poster tells the viewer that it is an adaptation from an original from the University of Queensland in Australia, which further highlights the pervasive, border-crossing nature of the poster’s message (see, also, Figure 4.3 for a selection of examples of near identical posters in Urdu, Hindi, Spanish, French, Malay, Japanese, Czech and Nepali from organizations in Pakistan, India, Dominican Republic, Belgium, Malaysia, Japan, Czech Republic, Argentina and Nepal). Finally, the poster’s viewer can find the organization’s contact information, and their slogan, ‘accept difference, not indifference’.

Peppered with prescriptions, rules of conduct and bullet shaped flags, the posters lay out the field of possibility – the range of possible actions, choices and responses – for both the advocate and the advocated for. The posters direct the eye of the potential advocate – the poster’s imagined audience: i.e., the parent, the teacher, the social worker, anybody who interacts regularly with children. It orients her stance, trains her gaze, educates her in the rule of normalcy (via its deviant double, abnormalcy). And, of course, the posters simultaneously call up a very particular body of ‘the advocated for’, the autistic body, the body to be watched for, the body to which the flags point and of which the flags warn.

I have chosen to group both posters within a genre of advocacy awareness campaigns that I am calling ‘red flag’ campaigns. The Autism Ontario poster (Fig. 4.1) is an example of one of many advocacy campaigns that overtly draws upon the terminology
Figure 4.3: Collage of multilingual international autism awareness posters (top).

Autism awareness posters from (bottom, left to right) India, Dominican Republic, Belgium and Pakistan. Photograph by Eduardo Trejos, reprinted with the artist’s permission. Posters reprinted with permission.
of the ‘red flag’. This ‘red flag’ terminology, however, is not explicitly used in the NAS poster (Fig. 4.2). Still, as we shall see, the latter poster is functionally the same as the former one as it ‘flags’ possible developmental signs of autism, and orients the viewer to recognize these signs as signs of developmental deviance, as signs to beware. The poster that lists ‘signs’ of autism offers the viewer cues that belong to a visual culture where any ‘sign’ of autism is implicitly narrated as a ‘warning sign’. “Images” writes Stuart Hall (2007) “do not carry meaning, or ‘signify’ on their own. They accumulate meanings, against one another, across a variety of texts and medias” (p. 232). The meaning of such autism posters is gained as they are “read in context, against and in connection with one another” (Hall, 2007, p. 232). In this way, the NAS poster need not overtly state that these ‘signs’ are ‘red flags’; the viewer ‘sees’ the ‘signs’ of autism and, inevitably, ‘sees red’.

**Seeing the Signs**

The flag, the potential advocate already knows, is raised by and branded with the immutable authority of the institution of biomedicine. The potential advocate, perhaps not yet immediately familiar with the ‘signs’ of autism being disseminated, nonetheless, immediately recognizes the kind of textual document that is before her. The bulleted lists, the embodied warning ‘signs’, implicitly call up and reference that instrument of measurement so familiar in this historical moment and geo-political space: the human developmental continuum.

While explicit reference of the ‘normal’ developmental continuum does not appear on the Autism Ontario poster – the poster does not say, for example, that the average infant waves ‘bye-bye’ at 12 months, this kind of explicit reference is not
necessary for the poster’s audience. The potential advocate is, inevitably, very familiar with its point of reference: what it is saying and the authority it holds. As Rose (1989) points out, developmental scales have been widely available and extensively disseminated since the 20’s and 30’s (developmental milestones were and are commonly found in psychology textbooks, parent books, teacher resources and so on). In a contemporary digital age, the scales of development have gone ‘viral’. This rapid spread of information is, of course, due, in large part, to the inexhaustible resource of the World Wide Web.

A Google search for “stages of normal childhood development”, for example, yields over a hundred million hits in 0.4 seconds. Parent websites – such as babycenter.com – offer email list-serves that send update messages to parents describing ‘the normal child’s’ week-by-week developmental progress with subject headings like ‘Is your baby walking?’ or ‘Baby poop photos: What’s normal, what’s not?’.

Social networking sites and the popularization of the digital camera has opened up new possibilities for parents to show, tell about and compare their child’s developmental proficiencies. Where, twenty years ago, parents might have compared children’s milestones with a friend or a neighbor, now parents are confronted with the developmental milestones of the kids of 500 of their closest Facebook friends.

Commercial products draw, increasingly, on notions of ‘healthy development’ and developmental fitness as key marketing strategies that target the lucrative niche of anxious middle-class parents seeking to “engineer” their children for “excellence” (Nadesan, 2002). Take, ‘Juicy Juice’, for example, a Nestle variety of fruit juice branded by the slogan ‘growing up healthy at every stage’. Offering a range of juice products,
including ‘Juicy Juice for Brain Development’, the brand claims to help parents raise “healthy” (i.e., well developed) kids (Juicy Juice, 2010). In addition to purchasing brain juice, parents can log on to the company’s website and read up on the normal child development milestones, take a quiz about healthy childhood brain development, access ‘expert’ advice from pediatricians, or print out high contrast flashcards to stimulate their infant’s brain development. Moving from the World Wide Web to the local shopping mall, children’s book sold at the mammoth Canadian bookstore chain, Chapters-Indigo, are arranged and shelved not according to similar themes or genres but according to the age-specific developmental skills that they might cultivate.

Rose underscores that this popularization and wide dissemination of the normal developmental continuum changes how we orient to the bodies of children, how we ‘see’ and ‘read’ them. He writes: “All who dealt with children in their professional or personal life could now have their mind instructed through the education of their gaze” (Rose, 1989, p. 153). Developmental reference points – tables, charts, pictures, illustrations and information – found anywhere from parent magazines to curriculum documents to juice cartons, render the body (and by the body I most certainly mean to include the mind!) visible in particular ways. The viewer of the ‘red flag’ poster (the potential advocate) is directed to ‘see’ the poster’s object-bodies (the potentially autistic) through the lens of biomedicine, the lens of developmental psychology.

The potential advocate, then, must learn to substitute her individual, subjective gaze with the all-seeing objective gaze of medicine - a gaze, as Foucault reminds us, “that [is] not bound by the narrow grid of structure (form, arrangement, number, size), but that could and should grasp colours, variations, tiny anomalies, always receptive to the
deviant” (Foucault, 1975, p. 89). The potential advocate – e.g. the parent, the teacher, the social worker – must learn and take on the role of the medical expert in those spaces out of the reach of the doctor’s gaze, those spaces outside the limits of the clinic; the ‘good’ advocate becomes the ‘doctor’ (i.e., the biomedical expert) of the home, the school, the office.

Developmental psychology, and its central tool of observation and measurement, the continuum of normal human development, produces normative divisions amongst individuals whereby individuals (both the advocate and the advocated for) must either fall within the borders of the ‘normal’ or are excluded from these borders. Divisions sprung from the effects of, what Foucault terms, ‘discipline-normalization’ produce particular bodies not only as either normal or abnormal, but, correspondingly, as ‘right’ or ‘wrong’, ‘good’ or ‘bad’ (Foucault, 2003, p. 52).

“In discipline” writes Foucault, “punishment is only one element of a double system: gratification-punishment” (Foucault, 1979, p. 180). Moreover, these two poles are situated at the nexus of political and moral constraints and, so, take on hierarchical meaning in relation to one another: ‘good’ becomes aligned with dominant normative acts and expectations and ‘bad’, with deviation from this norm. Under disciplinary power, Foucault reminds us, proximity to the norm is invariably rewarded, valorized (and, therefore constructed as permissible, moral, desirable and even natural) while deviation from the norm is punished, marginalized (and constructed as criminal, immoral, undesirable and unnatural). Graham and Slee (2008) remind us, “normalization is a man made grid of intelligibility that attributes value to culturally specific performances, and in doing so, privileges particular ways of being” (p. 86). In the context of the red flag
poster, both the advocate and the advocated for are bound up in the effects of discipline-normalization; the advocate subject who performs or approximates a normalized and normalizing version of advocacy is inscribed/recognized as a ‘good’ advocate, while the advocate subject who moves out of this dominant version of advocacy is inscribed as a ‘bad’ advocate or is not recognized as engaging in advocacy work at all.

At the same time, the autistic subject who performs or approximates a normalized and normalizing version of (full) human development is inscribed/recognized as a ‘good’ or ‘fully’ developed human, meanwhile the autistic subject who does not, cannot or chooses not to approximate this norm, is inscribed as a ‘bad’ or ‘partially’ developed human. Yet, let us note that, within the frames of developmentalism, to be understood as ‘partially’ (human) developed is not to be understood as non-human, per se. Rather, to be understood in this way is to be understood as ‘develop-able’, ‘teachable’ – recalling Walkerdine, it is to be cast as somebody who needs to ‘learn’ humanness (or normative, developmental versions of). As we saw in the historical examples from earlier in this chapter and as I demonstrate in the chapters to come, to be cast as ‘learner’ of humanness, is, nevertheless, to risk not being recognized as a human at all.

Recalling Foucault, disciplinary power is transformative - it alters individuals, it propels us in the making of our selves. Through discipline, the individual’s conduct is made knowable (by both the self and other) in relation to a distribution of possible conducts anchored by oppositional and hierarchical poles of ‘good’ or ‘bad’. As a way to highlight the insidiousness of disciplinary power and its technologies of the self, Foucault draws on Bentham’s panoptic prison - the architectural structure that makes it possible for the observer (the warden, the doctor, the teacher, the supervisor) to observe and
scrutinize inmates (prisoners, patients, school children, workers) at all times, all the while making it impossible for inmates to know whether/when they are actually being monitored. In the panopticon, following Foucault, “visibility is a trap”: In the central tower, the prison guard watches out over a surrounding ring of single-celled inmates: “the panoptic mechanism arranges spatial unities that make it possible to see constantly and to recognize immediately” (Foucault, 1979, p. 196). From his central vantage point, the prison guard is all-seeing, but also unseen. The inmate, unable to see the prison guard, only sees himself through the gaze of his observer. Foucault writes: “the panopticon is a machine for dissociating the see/being seen dyad: in the peripheric ring, one is totally seen, without ever seeing; in the central tower, one sees everything without ever being seen” (Foucault, 1979, p. 196). Foucault proposes that, under presumed scrutiny, the inmates become hyper-aware of their every movement, action, gesture and, eventually, begin to come to know, surveil and, ultimately, police their own behaviours. Observable signs of deviance are, first, monitored and then, gradually, controlled and corrected by the self. Foucault writes: “The perpetual penalty that traverses all points and supervises every instant in the disciplinary institutions compares, differentiates, hierarchizes, homogenizes, excludes. In short, normalizes” (Foucault, 1979, p. 183).

Processes of normalization are enacted via the ‘trap of visibility’ in several different ways in the ‘red flag’ poster. The poster is, indeed, the site where multiple gazes converge. First, consider the gaze of the potential advocate, the imagined viewer of the poster. The ‘red flag’ poster directs and instructs the gaze of the potential advocate to ‘look at’ the behaviours, actions, and interactions of all children, but most importantly, to ‘look for’ a particular set of (abnormal) behaviours, actions, interactions that may require
further intervention, that is to say, more ‘looking’. This ‘more looking’ reveals yet another gaze that is present at the scene of the poster: the gaze of the doctor, the developmental specialist, the medical expert. As the poster says: “parents should ask their child’s family doctor for a referral to a developmental pediatrician if they are concerned with any of the following…” (Fig. 4.1). While the intimacy of the potential advocate’s (i.e., the parent, the teacher, the social worker…) particular vantage point (i.e., the home, the school, those spaces outside of the clinic…) is crucial to the process of ‘seeing’ abnormal development, her gaze is not sufficient.

Expanding on Foucault’s metaphor of the panopticon, the child-object exists in the ultimate peripheric ring: the child’s every behaviour, action and interaction is seen by the advocate, but the child remains unseeing. The panoptic space of the ‘red flag’ poster, however, adds another peripheric ring to its disciplinary mechanism, as the advocate watches the child, she, too, is watched from the central tower of biomedicine: the advocate sees the unseeing child, but she must also see herself, for biomedicine sees all – the advocate watcher, the watched child - and is, always, unseen. The asymmetrical flow of visibility secures the biomedical gaze as a way of seeing that is not required to see itself (Michalko, 1998). For the remainder of this chapter, I focus my analytics sights against this grain of panoptic visibility. I will look not at the bodies being looked at, but rather at the (normative) processes of looking: the gaze of biomedicine and the gaze of advocacy that are always, following Foucault, ‘receptive to the deviant’. Such gazes come into focus at the scene of the ‘red flag’ poster and are caught up, as we shall see, in the very constitution of the human.
Be Aware

There can be little doubt that instruction is a significant intent, function and effect, of the ‘red flag’ poster. The poster, in other words, acts as a pedagogical tool. One thing the poster teaches its viewer is to become visually literate in the understanding that bodies are readable, and thus, knowable, by attentive observation to the signs they emit. The red flag poster teaches the potential advocate to be aware of autism’s flags and, in so doing it teaches the potential advocate how to ‘look’.

In the Autism Ontario poster (fig 4.1), red bands of colour stretch across the top of the poster highlighting, for the potential advocate, where to look. ‘Stop’, the red bands on the Autism Ontario poster tell the advocate. ‘Look here’, direct the iconic stick figures in the NAS poster (fig. 4.2). ‘Look closely’, for, as the First Signs website reminds us, the signs of autism “can be subtle or, to the untrained eye, easy to miss” (First Signs Inc., 2010, para.2). Arrest your gaze on the bodies of children. Will their gaze return yours? When their bare feet make contact with the rough texture of freshly cut grass? See if their toes recoil or relish. Focus on how people move, how they act, how they interact, how they fear. Observe them as they are at play4: Are they interacting enough with other people? Are they interacting too much with objects?

‘Watch’, the posters tell the potential advocate, but only if you embody normalcy. For it is normalcy, the posters point out, that (who) is endowed with the power of the qualification to ‘see’. Abnormalcy is unseeing – deviance can and must only be seen – it does not possess the qualification to dwell within the limits of the space of the see-er; it is

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4 For an insightful examination of the ways in which disabled children’s play has been transformed by the field of developmental psychology as an instrument of surveillance, measurement and evaluation, see Runswick-Cole and Goodley’s (2009) article in Disability and Society, “Emancipating play: Dis/abled children and development and deconstruction”
not qualified to ‘see’ itself. The Autism Ontario poster depicts the faces of normative children conforming to the (already, we can note, gendered, raced, classed, heteronormative, able-bodied) stages of normal childhood development. A grimacing girl makes what the viewer must assume is an ‘appropriate’ gesture of distaste to a grinning boy with a toad: she is, we are to assume, ‘grossed out’ by ‘boy stuff’. A smiling white boy exercises the power that comes with the capacity for coherent and recognized acts of creativity as he builds a tower, in a developmentally ‘suitable’ way, with blocks (and not with teacups). A light-skinned boy and a dark-skinned girl play together on a seesaw, laughing and gesturing to each other, ever maintaining the neatness of a contemporary normative demand for a ‘multicultural diversity’ of representations and the equally normative requirement that diversity can be included only if it affirms and supports the image of normalcy. An image of a girl child, a brown child, (or perhaps even a disabled child), can appear as images of normalcy, so long as these images conform to and sustain the ideal of white, male, heterosexual, middle-class, able bodied normalcy.

The smiling faces of normativity in the Autism Ontario poster provide a striking contrast, when juxtaposed with the absent faces of deviance. The normative children in the Autism Ontario poster face the viewer, while abnormalcy is represented only with faceless bullets, textual descriptions of deviance. In the NAS poster, too, the faces of abnormalcy are missing, obscured, shaded – they do not and cannot face the potential advocate. The faceless bodies depicted in the NAS poster cannot look back at their viewer, as their abnormal bodies are presented only to be seen. Autism does not possess the qualification to see itself for it doesn’t have the qualification of normalcy. In this
way, the ‘red flag’ poster requires that the ‘looker’ – the potential advocate – must embody normalcy. One significant implication, here, is that this field of advocacy, peppered by red flags, leaves little room for autistic self-advocates.

As we have seen, the posters provide a landscape of what the potential advocate must ‘see’ when she looks at children. However, the posters also provide a legend so that the potential advocate may orient herself in this new landscape of autism. The posters not only instruct the advocate where she must look, but how to look, not only how to see, but how to read (Titchkosky, 2007). The posters not only tell the viewer that they must be aware, but also, that they must be wary.

**Be Wary**

While all bodily signs must be watched for potential pathology (a medical imperative), so-called ‘signs’ or ‘red flags’ of autism must be ‘watched out’ for (a moral imperative). And so, in this way, the ‘red flag’ poster gives birth to a very particular (and necessarily watchable) medically/morally deviant subjectivity in need of advocacy: the subject of the autistic.

The Autism Ontario poster, for example, provides the key to de-code the meanings of various ways of communicating, of behaving, of socially interacting. The poster shows potential advocates how to ‘read’ autism - its shape, its landmarks – as nothing more than primitive and pathological deviance (a state of pathological underdevelopment). The fluttering of fingers can no longer be a way of moving, of experiencing space, of interacting, of expressing anxiety, or of showing excitement; preferring to play alone, no longer a viable option. In the presence of the red flag poster, the (excited, angry, upset, or calm) choreography of fingers fluttering is simultaneously
medicalized and moralized; it is re-encoded as “[an] odd or repetitive way of moving fingers”. The quiet play of a lone child in a busy playground is now ‘seen’ as a pathological sign pointing not to personal choice or preference or even to social exclusion, but to (medical/moral) deviance.

Consider yet another example of this process of transforming difference into deviance. In the two posters exemplified in this chapter, the autistic subject is encoded as, simultaneously, excess and lack. James I. Porter (1997) writes:

Viewed in itself…a disabled body seems somehow too much a body, too real, too corporeal, it is a body that, so to speak, stands in its own way. From another angle which is no less reductive, a disabled body appears to lack something essential, something that would make it identifiable and something to identify with; it seems too little a body: a body that is deficiently itself, not quite a body in the full sense of the word, not real enough (p. xiii).

The ‘red flags’ point to autism, following Porter, as both ‘too much’ and ‘not enough’. Autism is ‘seen’ as either empty presences (a body that is, somehow, more than a normal body - a body abnormal in its excess: ‘inappropriate giggling’; ‘oversensitive to certain textures’; ‘talks incessantly’), or excess absences (‘no babble’, ‘no gestures’, ‘no eye contact’, ‘no response’; ‘lack of creative play’ and so on). Of course, the absent (and yet, in its absence, very present) referent inherent in these observational moral qualifications of too much/not enough is the body of normalcy that is, we must presume “just right”. In this way, the ‘red flag’ poster overtly points to (‘bad’) deviations from the developmental norm (‘too much’/‘not enough’), and, thus, invariably re-enforces the (‘good’).
requirements for normalcy (‘just right’).

Let us note how the poster is also, perhaps more covertly, engaged in enforcing the boundaries of what can be recognized as a ‘good’ advocate. The normal or ‘good’ viewer of the red flag poster - the ‘good’ parent or teacher, the ‘respectable’ autism advocate – must, as we have seen, direct her gaze in chorus with the demands of the poster, and so the demands of the biomedical institution of developmental psychology. Under the powerful guidance of biomedicine, the ‘good’ autism advocate must watch and worry about her watching, as she watches and worries about her children.

In the midst of watching (being aware) and worrying about (being wary) normal/abnormal development, the potential advocate is, finally, positioned by the ‘red flag’ poster to ‘see’ autism as something that inherently signals danger, something to be feared, something against which we must be warned – some ‘thing’ to beware.

**Beware**

The red flag metaphor is a well-established one in the contemporary west; the symbolic meaning of the red flag is widely accessible as a matter of common sense. We are, most often, very literate as to the cultural significance of the red flag, we are aware of its demands. Its evocation references a variety of meaningful scenarios and, in so doing, weaves together several different, yet related, meanings. Faced with the metaphor of the red flag, we might be put in mind of the red cloth waved by a matador inciting the bull to charge, or the red banner raised by the revolutionary as a call to revolt, insurrection. The red flag metaphor evokes the image of the socialist, raising the flag, rallying the working class, or the sailor, hoisting the red pennant, as a warning of rough waters ahead. We are
reminded of the crimson standard raised by the soldier in a cry of battle. At once, the evocation of the red flag incites, provokes, defies, decrees and warns. And, in the midst of all of these demands...autism.

Although the NAS poster makes no explicit use of the ‘red flag’ metaphor to orient and instruct the viewer in the ways of looking, it succeeds in accomplishing the same effect through its use of the icon of the stick figure. The stick figures that appear on this poster are quite familiar; these figures are ubiquitous in everyday life. We often see the stick figure standing at attention outside washrooms, crossing the street, slipping on wet floors, falling off ladders, minding the gap, and, if the figure appears using a wheelchair, perpetually pointing to a more accessible space (Titchkosky, forthcoming). Indeed, the stick figure used in this poster is, perhaps, most famous for his appearances on directional/instructional signage, traffic signs, and caution/warnings signs.

The stick figure represents the universal figure. It is gender-less, race-less, class-less, age-less (although, admittedly, the figure does sometimes appear wearing a particular accessory - a skirt, a hardhat, a wheelchair - depending on the regulatory function of the sign). Due to this absence of identificatory features, the default figure serves to ‘stand’ for the ‘any-body’. Any-body can cross this street. Any-body must mind the gap. Any-body can use this washroom. Any-body can do any of these things, that is, so long as the any-bodies conform to the regulatory stipulations of the spaces that the sign marks and designates (i.e., we intuitively know that not just any-body can use the women’s washroom and not just any-body has access to the subway station so as to be in a position to ‘mind the gap’).
And so, we know a few things about the appearance of an any-body. We know, for example, that its appearance is almost always an instance of regulation. Typically, the any-body appears on caution signs (e.g., the icon of the figure slipping on ‘wet floor’ signs) or directional signs (e.g., the skirted washroom icon indicating where to access the woman’s washroom). In both situations, however, when this figure makes its appearance it is in order to issue a warning to its viewer, a red flag. The any-body slipping on the wet floor issues an overt warning: ‘Attention! Be careful! Proceed with caution! You may be in danger!’ The skirted washroom icon that signifies ‘woman’ issues the, perhaps, more subtle warning that it is only particular ‘types’ who are welcome, or more correctly, permitted within. To be permitted entrance into those spaces marked by the regulatory any-body of the skirted washroom icon, we know, we must possess certain qualifications.

Let us return, now, to the any-bodies marking the NAS poster. Recall, for example, the any-body, looking away from another any-body: ‘no eye contact’. Or, the any-body flapping its arms: ‘bizarre behaviour’. As these figures appear in a context of a whole genre of stick figures whose task is to warn, the poster’s viewer is already – upon first ‘look’ - oriented to see the stick figures and the (autistic) behaviours they underscore, as ‘red flag’ warnings. Far from embarking on a project of “accept[ing] difference”, as per the NAS slogan, the organization’s poster issues a warning against certain (unwelcome or unqualified) ‘types’ of behaviours, actions and interactions, and, in so doing, reinforces which ‘types’ of people are welcome (are qualified to exist) within the collective (normative) space of the social.
As graphic designer Eric Lewallen points out in “A history of the stick figure”:

“That little, iconic, round-headed fellow on signs [...] makes us think twice before taking the wrong door, or helps us so we don’t really need to think at all” (Lewallen, 2008, para. 2). The stick figure helps us think twice, or not at all. Indeed, the same can be said of any warning sign. Or, insofar as the function of the warning sign is to issue an alert that can be quickly and universally understood and acted upon, the warning sign makes us think twice until we don’t have to think at all. Forms of knowledge and ways of knowing merge with the object of knowledge (Rose, 1989, p. 150). The ‘red flag’ poster, the poster that functions to raise awareness, asks its viewer to notice – to think twice about – behaviours, actions, interactions. However, once the potential advocate’s awareness is raised, once – to borrow from Paul Gilroy – her “sensorium” has been “educated”, the mere appearance of the ‘red flag’ behaviour is enough to ‘naturally’ change the behaviours, actions and interactions of the advocate: the ‘good’ advocate sees the ‘signs’ of autism and, seemingly instinctively, she is poised to act against it (Gilroy, 2000, p. 42).

As we learn to beware of certain bodies, certain actions, certain gestures, we also learn something about what these bodies, actions, gestures represent and it is here where we might glean just how the ‘red flag’ advocacy poster is engaged in producing and constraining the limits of the compulsory human. Warnings are never issued for something we value, a condition that we would like to have in our collective life. Weather warnings are not issued for pleasant, sunny days with gentle breezes. Warnings, we know, warn against something undesirable: flood warnings, terror warnings, pandemic warnings, and so on. It is in this intertextual space of danger and warning that ‘autism’ is made to appear. In the discursive field of the red flag poster, autistic
development is not conceived of as (a) ‘good’ development, and, therefore, is framed up as ‘not full’ (human) development at all.

'Seeing Red'

As Marx reminds us in the opening epigraph, comportment is altered at the sight of the ‘red flag’. The ‘old world writhed in convulsions of rage,’ he says, at the mere glimpse of a waving piece of crimson clothe. We see the flag and our comportment changes. As vigilance is performed and as the signs of developmental deviance are noticed, the ‘potential advocate’ slides into the position of ‘good’ advocate. The subject of the ‘good’ advocate, then, made in the moment of ‘seeing’ difference/deviance, is poised to act in a particular and constrained way: See flags, see autism. See autism, see danger. See autism, see red. In the shadow of the ‘flags’ that point to autism as pathological underdevelopment, the advocate is positioned to ‘see red’ and, in ‘seeing red’, to stand on guard, as if a sailor warned of rough waters ahead; to charge forward as if a bull barreling toward the matador’s flag; and to fight as if a soldier being called to battle. We see the flag and our comportment changes.

Vis-à-vis an autism that is conceived of as a state of being ‘not fully’ (humanly) developed, the ‘good’ advocate’s only reasonable reaction is to attempt to restore normalcy to autism’s abnormalcy, to facilitate autism’s ‘full’ human development, to teach humanness. Within the discursive space of red flag advocacy, the advocate subject’s only intelligible choice is to swiftly and surely strike out against autism, to seek out medical doctors to treat its signs, to seek out interventions to diminish or eliminate all traces of autism’s embodied difference, to ensure normalcy.
And so, it is no surprise that ‘red flag’ posters overtly or implicitly effect a call to action that narrates as target the very object under scrutiny – autistic ways of being. See a developmental pediatrician, the poster tells the potential advocate, arrange ‘intervention’, eliminate conspicuous, flag(rant) behaviours. The red band of color in the Autism Ontario poster tells the potential advocate that danger is ahead, while below, a green band of colour, underscores the need for swift and immediate action: ‘Autism is treatable. Early intervention is critical.’ Similarly, the stick figures in the NAS poster function to flag danger, while the text at the bottom of the poster directs action. “Early diagnosis is essential”, says the NAS poster “if people with autism are to achieve their full potential. It is only when their disability is understood that they can be helped to maximize skills and minimize problems” (NAS, 2010, *my emphasis*). Face to face with an imminent danger gestured toward by the appearance of the stick figure, the potential advocate is directed to seek an “early diagnosis” of autism in their child so as to ensure equally early interventions are attained to help ‘maximize’, (presumably, developmentally ‘appropriate’ or neurotypical) “skills” and “minimize” (red flag) “problems” so as to, ultimately, allow the child to reach his or her “full potential”.

Read alongside the developmental warnings issued by the stick figures and the rhetoric of the progressive, sequential stages of human development, human development is, so quickly and so easily, conflated with human potential. In this way, the poster suggests that the autistic body – in and of itself – cannot be understood as ‘fully developed’ and, so, nor can it be understood as, inherently, replete with potential. Still, while the poster presents autism as a naturally and inevitably unsuccessful human embodiment, it simultaneously promises that success and fullness *is possible*. While the
red flags cry out: ‘here goes the not-yet (developed) human’, notions of diagnosis and, subsequent, intervention do the work of saying: ‘maybe one day’.

Not unlike the civilizing project of schooling from the nineteenth century (and beyond), contemporary notions of ‘early intervention’ are replete with the hope that, respectability can be achieved, developed. Normacy’s prerequisite standards can be learned. Contemporary advocacy discourses promise that with the proper (biomedical) intervention (ranging, for example from doctor approved food products to bio-medically endorsed therapies\(^5\)) any body’s potential for (‘full’) human development can be released. Modern medicine and its therapeutic offshoots tell us that any body can meet (or even, exceed) the norm. Indeed, the notion of the changing and changeable, improvable, developing body as something to be watched, measured and, should the body fail to measure up, corrected, enhanced – or in Nadesan’s (2002) words, ‘engineered for excellence’ – seems to open up possibility. Indeed, this discourse of improvement promises that any body can be a ‘good’ and respectable human – any-body can (and must) conform to, or at least approximate, the (white, male, middle-class, non-disabled, heterosexual) normative ideals – any-body can achieve their ‘full human potential’ with the ‘right’ and timely (i.e., early) intervention.

A qualification like all others, normalcy, it seems, can be earned. “Full potential” is something to be achieved, says the NAS poster, but only if early diagnosis and disciplinary interventions are secured. It is assumed that early intervention, the attainment of ‘right’ or ‘good’ (and so, normalizing biomedical) services can intervene on the body of the autistic person, can discipline its undisciplined behaviours, actions and interactions, diminish the autism and reform (or, perhaps, release) the possibility of

\(^5\) See chapter 5
normal human development. And, so the autistic life is endowed with possibility only if this life is understood as moving/being moved toward non-autism, only if autistic ways of being – flags – are eliminated by biomedical intervention. Eliminated or, at the very least, lessened. In this way, the autistic subject is configured within autism advocacy discourse and via notions of normal or natural human development, as the not-yet (developed) human.

**The Developing Human and the Human Developer**

Judith Butler writes critically about how certain lives are – through mediated frames of recognition and interpretation – made to fall outside of the limitations of a normative notion of what the human must be...lives that, by way of various discursive strategies and within multiple systems of oppression – are not regarded as human life, or are fashioned, even, as ‘non-human’ life (Butler, 2004a; Butler, 2009). Of course, to be recognized as a life that is ‘not-quite-a-life’ is to be placed in a perilous position indeed and I will explore this further in the chapters to follow (Butler, 2004a, p. 34).

While the red flag poster is clearly engaged in narrating the autistic life as ‘not-quite-a-life’ – as an unwelcomed, undesirable and even threatening way of being in the world – the posters, and developmental discourses more broadly, are doing something other than setting up a straightforward distinction between human life and non-human life. The body to which the flags point and of which the flags warn is not seen as a body

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6 Of course, any understanding of ‘nipping’ autism ‘in the bud,’ absolutely requires autism and personhood to be separate entities – autism must be an appendage, some ‘thing’ some people ‘have’ and, likewise some ‘thing’ that can be removed. There is no room in this conceptualization for autism to be conceived of as an identity – an intrinsic aspect of one’s personhood. I will explore this theme in much greater detail in Chapter 7.
that has fallen outside of human development and therefore outside of that space in which human life is and can be recognized. Rather, as we have seen, amidst red flags, the autistic body is seen as failing to develop fully. It is narrated as an underdeveloped body, unsuccessful at following the progressive, rigid stages of human development. The not-quite-a life of autism is delivered by the red flag campaign, then, not so much as a non-human life, but as the life of a ‘not-yet’ (developed) human. And, so, an intermediary subjectivity emerges, a subject that is not developed but is, nonetheless, develop-able. Via simultaneous processes of medicalization and moralization, the poster implicitly teaches us that (normal or ‘good’) humanness, while not implicit, can be helped along, developed.

Here we have the birth of a subject that must never be left alone until it becomes “indistinguishable from [its] normal friends”...to quote Dr. Ole Lovaas, whose Applied Behavioural Therapy, as we saw in chapter 2, is widely considered ‘best practice’ for treating autism. With the possibility of a develop-able human life, the subject position of the (good) advocate is framed as both the vigilant surveiller of human deviance (‘look for warning signs’) and a human developer whose vital aim is to ‘act early’ and facilitate ‘normal’ human development...and, by extension, to produce the ‘respectable’ (and necessarily non-autistic) human.

It quickly becomes evident that one’s potentiality - one’s potency, power, respectability, indeed, one’s bare possibility become contingent on conformity to the ever-loaded scales of normal human development. Possibility, it appears, is not as possible as it seems at first blush. With respect to the subject positions of both advocate and advocated for, normative life is the law and, as such it is absolutely compulsory.
Indeed, under what Lennard Davis calls a ‘hegemony of normalcy’, the only possible way to secure possibility itself is to exist within the limits of the normal (Davis, 1995, p. 48). In this way, while the law of normative life is compulsory, the enactment of normalcy becomes necessary. In each of the examples in this chapter, the ‘good’ (developing) human is extracted from the pulsing and contracting (political, historical, geographical) realms of power and is reintroduced as a ‘natural’ category of being, or, if nature should fail (as it sometimes does) as an individually controllable state that can be secured via the moral/medical demands of ‘good’ advocacy and the ‘right’ (biomedical) kinds of intervention.

In this chapter, we have seen that in order to secure the status of ‘good’/recognizable advocate – and, therefore, in order for it to be possible to do advocacy and be an advocate – the advocate must subscribe to and enact a normal and normalizing version of advocacy. Already possessing (and, always, always performing) the prerequisite qualification of normalcy, the ‘good’/recognizable advocate must learn to ‘see’ abnormalcy, to worry about it, to read it as danger. The contemporary autism advocate is always and already poised to act as a defender of normalcy, and so, she is always and already poised to fight that which threatens normalcy: difference. And so, autism’s possibility is tangled up in the possibility of autism advocacy. Under the law of normalcy, the only possible way for the autistic subject to be read as a ‘good’ or ‘full’ human life is to learn, approximate, perform normalcy.

A body – whether it be the body of the advocate or the body of the advocated for – that does not, cannot or chooses not to perform normalcy is a body that finds itself a kind of ‘outlaw’, cast outside the limits of possibility and potentiality. While related, of
course, the material consequences of ‘casting out’ (Razack, 2008) differ as we move from advocate subjectivity to autistic subjectivity. While, the advocate who moves outside advocacy’s normative frames of recognition is at risk of being excluded from participation in advocacy, the autistic body that (who) does not, cannot or chooses not to perform or approximate normal human development, risks being cast out from the (ever exclusionary) space of the human. Such an exclusion, as I will explore in the chapters to come, is also and necessarily a matter of life and death.
CHAPTER FIVE

Act NOW: The S/pace of Advocacy in a Temporality of Urgency

Getting a picture of the autism epidemic is a little like filming a war that engulfs the whole world.


The voluntary creation of a permanent state of emergency has become one of the essential practices of the contemporary state.

- Giorgio Agamben (2005), *State of Exception*, p.2

There’s no time to think…

- Bob Dylan (1978)

In the summer of 2007, one of the many places where one could learn about autism’s ominous and growing presence and the necessity for its swift elimination was on the sides of a special series of paper Starbucks cups. The over 5 million cups that were put into circulation across the US displayed a quote from Autism Speaks’ co-founder, Bob Wright (Fig. 5.1). It read as follows:

Every 20 minutes – less time than it will take you to drink your coffee – another child is diagnosed with autism. It’s much more common than people think, with
one out of every 150 children diagnosed. Learn the early warning signs of autism, and if you’re concerned about your child’s development, talk to your doctor. Early intervention could make a big difference in your child’s future (Autism Speaks, 2007, para. 3).

This chapter looks to a multitude of cultural artifacts both mundane and spectacular – to paper coffee cups, international resolutions and billion dollar presidential investments – as prolific, productive and powerful sites of meaning making. I ask: What meaning might we make of knowledge expressed on the sides of cardboard coffee cups? “Every 20 minutes”. “Early intervention”. “1 in 150”. A venti latte, no foam, two warnings and a prescription. How do these words, these numbers, come to matter? How do they make matter the bodies they grasp as well as the bodies that, quite literally, grasp them? While these particular Starbucks cups tell us a great many things, one thing is certain: they tell us that a clear relationship exists between autism, advocacy, time and consumption.

Both autism and autism advocacy appear in the discursive space of the Starbucks cup as functions of time. Wright, for example, characterizes autism in terms of “warning signs” and “concerning” development – it is a state of being off-tempo with the normative meter of human development. Late development. Missed milestones. And, just as autism is narrated as a state of being stuck in the developmental past, its meaning, simultaneously, becomes enmeshed in notions of futurity: autism’s developmental anachrony, Wright informs us, is “concerning” precisely because it threatens all the possibilities the future holds. What is more, autism’s ‘too slow’ development, the quote tells us, is happening too fast. “Every 20 minutes”, Wright reminds us, “another child is diagnosed” (my emphasis). The speed at which autism is happening is underscored by
Figure 5.1: Starbucks cup with quote from Autism Speaks co-founder Bob Wright. “Autism Speaks” (2008), photograph by Nate Peterson. Reprinted with the artist’s permission.
numerical measurements of its prevalence: “it’s much more common than people think,”
the coffee cup reminds us, “with one out of every 150 children diagnosed”.

The ticking time clock that counts up appearances of autism delivers autism
advocacy, too, as a function of time. Wright’s statement addresses the potential autism
advocate in the imperative. It says: “Learn the early warning signs of autism, and if
you’re concerned about your child’s development, talk to your doctor”. Now is the time
for immediate action, the coffee cup suggests. Act now for the earlier autism’s warning
signs are noticed and identified, the faster (biomedical) help can be enlisted to speed up
autism’s developmental slowness: “early intervention could make a big difference in your
child’s future”. Evoking understandings of lingering pasts and eclipsed futures, too fast
appearances of too slow bodies, late milestones and early interventions, Wright’s
Starbucks cup quote demonstrates how the meaning of autism and advocacy get tied
together by the ticking of the second hand. I turn now to an unpacking of this meaning.

Getting with 'our Times'

This chapter attempts to look to – or ‘get with’ – our times. I attend to historically
specific texts and contexts with the belief that these can tell us something about the
cultural meanings we ascribe to particular embodied subjectivities, particularly the
subjects of the advocate and the advocated for within contemporary western/izing
discourses of autism. I ask: how do the particularities of ‘our times’ – our particular
historical and political time and contemporary understandings of the normative meter of
time itself – provide the conditions of possibility for the appearance of dominant versions
of autism and autism advocacy? And, how do everyday cultural representations of autism
and autism advocacy shape our experience of the passing of time (i.e., as either too slow
or too fast) and our understandings of bodies in time (i.e., as being either ‘on time’ or ‘late’, ‘timely’ or ‘untimely’)? Lastly, I ask, how is the urgent space and pace of advocacy working to constitute the relational subjectivities of both the advocate and the advocated for?

As the Starbucks cup reminds us, we no doubt live in fast and furious times. The ‘fast food’ orientation of Starbucks, the disposable ‘to go’ character of the paper coffee cup, together with its “every 20 minutes” factual refrain, certainly attest to this. Indeed in a contemporary neoliberal context where ‘timing is everything’, there is, as we often say, ‘never enough time’ and we are, it seems, perpetually ‘running late’.

In contemporary the neoliberal milieu, time is often treated as a desired and desirable commodity – some ‘thing’ we, collectively, want more of and of which we never have enough. It is common, for example, to hear talk of the desire or need to ‘keep’ or ‘buy’ time. We are regularly and routinely informed by magazines, television talk shows, friends and family, that we just need to ‘make’ or ‘take’ ‘more time for ourselves’ and, to this end, we are offered a barrage of ‘time saving tips’ and a variety of products that will help us to better ‘manage’ and ‘budget’ our time. And, if time is a commodity – if it is a thing that can be and is bought, sold and circulated – it is, perhaps, the quintessential commodity insofar as without it no other commodity is within reach. And so, time becomes a kind of capital. Indeed, ways of ‘spending’ our time capital are deeply morally coded and, thus, are associated with a spectrum of rewards and punishments. We encourage and privilege some ways of spending time as “time efficient”, while we discourage and even stigmatize other ways of spending time as a
‘waste of time’. Time, today, is implicitly understood as something useful (and therefore, by extension, something that can be misused).

Commonsense understandings of the importance of grasping and keeping hold of time, the collective awareness that time is always running out as well as the moral organization of how we use our time (i.e., oppositional understandings such as ‘time efficiency’/‘wasting time’; ‘time well spent’/’time squandered’) deliver us into the heart of a very particular culture; a culture, as many theorists have noted, that is in the grip of a near constant and seemingly limitless state of acceleration (Castells, 2009; Hassan, 2009; Virillio, 1986). It seems that in speeding up (our actions, our desires, our responses, or tasks, our pace of living) – in other words, in using or spending our time ‘wisely’ – we might, somehow, secure more time. Or, so the logic goes. Move quicker, our culture demands, think faster, understand immediately, develop earlier, learn younger, look farther, work more, produce more, consume more. And do it now.

In his book, *Empires of speed: Time and the acceleration of politics and society*, Robert Hassan (2009) describes this process of speeding up as a compulsion mediated by the cultural signs and symbols of our time:

This is a life where one’s whole subjectivity blends into a flow of blurring and accelerated tasks. Obligations, incursions, commitments and projects are constantly juggled and foreshadowed toward a short-term horizon. In the 24/7 chronoscopic world that surrounds us, its signs and symbols, signifiers and referents restlessly flicker and buzz to impress their urgency on our daily existence, compelling us to synchronize our lives to the increasing tempo of the overarching economy of speed (p. 23-24).
Hassan provides us with a snapshot of an (our) ‘economy of speed’, which is, in his words, “borne of the interactions of globalization, neoliberalism and information technologies” (p. 23). And, indeed, as a great many theorists have noted, so much of western modernity’s ‘cultural acceleration’ – this so-called ‘economy of speed’ – has precisely to do with the infiltration of market rationalities into the social order of the everyday; as Hassan remarks: “the ‘need for speed’ is tied to the basic need for the capitalist to derive profit” (Hassan, 2009, p. 56). Time is money and more time is, by extension, more money. The fast-paced ‘produce more, consume more, live more’ ideology of the market seeps into our lives and propels us along at great speed thus orienting our consciousness of time as well as governing our actions and reactions in time.

Hassan suggests that contemporary subjectivities get swept up – are shaped by and, in his words, ‘blended’ with – the restless buzzing and flickering of mediated ‘signs of the time’, “cultural orientation devices”, perhaps – puzzle pieces, red flags, Starbucks coffee cup statistics – that, recalling Sara Ahmed (2006) “help us to find our way” (p. 1) by, as Hassan states, “impress[ing] their urgency on our daily existence”, altering the rhythms of our bodies as well as our understandings of ourselves and others. While paper coffee cups are surely mundane cultural artifacts of the first order, following Puar (2007), “the trivial must be attended to precisely because marking it as such may mask or obfuscate its deeper cultural relevance” (p. 67). Such artifacts, no doubt, orient us to life as a question of time; they help us to find this way of life sensible and even necessary.
Coffee Time

The disposable Starbucks coffee cup – a ‘sign of the times’ to be sure – orients, explicitly, to time. In the west, there are, for example, a great many normative understandings of ‘coffee time’. ‘Don’t talk to me before I have my morning coffee’, ‘I need to have my caffeine fix before I get to work’, are common refrains of daily life. Indeed, coffee is often understood in everyday life as that which eases the transition between the stasis, and so, the non-productivity, of sleep and the movement and productivity of the work or school day. Coffee – a stimulant – wakes us up, speeds us up, helps us to ‘get going’ and the disposable character of the ‘to go’ coffee cup anticipates and even encourages this. The disposable cup allows and even promotes the consumer to consume the beverage on the go. ‘Move on’, the cup hints, ‘be on your way’. Now is the time for hurried movements down crowded streets with paper coffee cups in hand. Drink ‘on the go’ to ensure that you are ‘on time’ for the neoliberal demands of more production and more consumption. Buying a coffee ‘to go’ might even ‘buy you some time’ for other things. Multitask, the paper cup directs. In these times of so little time, don’t waste time only drinking coffee. Consume while you move, while you work, while you socialize, while you read. And, as the Starbucks cup in our example not-so-subtly hints, it shouldn’t take you too long to drink your coffee. Less than 20 minutes, to be sure.

And so, as we consume our coffee on the go and consume it fast, we become available to consume other things. As we sip our morning coffee on our way to work, for example, we might also consume a fact or two about autism. In this way, the disposable coffee cup not only orients us to drink on the go, ‘the medium of the Starbucks cup is the
message’, to take liberties with Marshall McLuhan’s (2001) famous phrase, as it also orients us to learn about autism while we drink and so, to learn about it ‘on the go’. This fast-paced temporality is not conducive to ‘high maintenance’ reusable coffee cups or leisurely coffee breaks. And, neither is it conducive to the significant time necessary for thinking through the complex ways we imagine ourselves and others or how we relate to and across difference. Now is not the time for slow encounters with autism’s meaning or for deep consideration of the difference autism makes in our culture and in our lives.¹

On the side of the Starbucks cup, autism’s multiple meanings – individual meanings we endow it with, cultural meanings we ascribe to it and so on – are streamlined, simplified, made easily accessible and quickly transferable. Autism is distilled down to a series of ‘bad’ signs and ‘good’ responses, ‘too fast’ rates and ‘too slow’ bodies, punctuated statistical odds – highly consumable ‘facts’ that can rapidly be exchanged, bought, sold and circulated in and through a fast-paced consumer culture that is always seeking to increase the speed of exchange and circulation in the name of efficiency and, of course, profit. Drawing on the work of Bruno Latour, Briggs and Hallin (2007) note that “[the movement of ‘health information’] seems contingent on the status of biomedical ‘facts’ as ‘immutable mobiles,’ information that can go anywhere, jumping between genres, places, people, and scales without changing meaning” (p. 58). They go on to demonstrate how the mobility – the circulation – of these ‘facts’ works to constitute and define subjectivities; subjectivities that are, they write, “defined not by possessing knowledge per se but in participating in its movement: as producer, translator, disseminator, or receptor” (Briggs & Hallin, 2007, p. 58). Insofar as they are crucial components of the machinery of neoliberalism, such “hybrid” bodies must move in time

¹ For more about the ‘difference that disability makes’, see Michalko (2002).
with the ever-quickening pace of economic processes of production and consumption (Latour, 1993).

It is, therefore, hardly insignificant that a message informing us of autism’s developmental deviancy and the need for advocacy to assure autism’s more timely development through swift and early intervention, is delivered to us on the side of a paper coffee cup. The medium of the disposable consumer good, together with its message, in turn, delimits the normative contours of the ‘good’ advocate as one who moves through the world in a ‘timely’ way. The Starbucks cup anticipates a ‘good’ contemporary advocate subject who uses the commodity of time well – a ‘time efficient’ body that arrives on time (or even early) to its work and to its milestones. If time is understood as that quintessential commodity that puts us in touch with all other commodities, then to be on time is to assume a position where we might consume more, produce more. The ‘good’ advocate, then, is the timely subject of the ‘now’, ready and willing to act and, so, ready and willing to participate in – and even enjoy – the processes of consumption, production.

**Market Timing**

On December 17th 2007, the United Nations General Assembly adopted resolution 63/139, which declared April 2 to be ‘World Autism Awareness Day’ “in perpetuity” (Autism Speaks, 2011c, para. 1). The resolution (Fig. 5.2) makes it clear that raising public awareness about autism is tantamount to raising public awareness about it

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2 Declaring April 2 as autism awareness day ‘in perpetuity’ suggests a commitment to having autism in our midst forever. Yet, the promise of contemporary autism advocacy discourses – including the discourse surrounding World Autism Awareness Day – is that autism can be lessened/treated if not eliminated/cured. This disjuncture, of course, begs the question: is the search for better treatments and/or cure for autism a perpetual one?
as a biomedical problem in need of biomedical solutions. The resolution also hints at how a neoliberal ideology – an ideology grounded in the logic of the market – underpins discourses of autism advocacy, and governs the formation of the subjects permitted to dwell within these discourses. According to the resolution, the impetus for the creation of a designated day for autism awareness is premised on three other awarenesses. The first of these awarenesses is the:

Aware[ness] that autism is a lifelong developmental disability that manifests itself during the first three years of life and results from a neurological disorder that affects the functioning of the brain, mostly affecting children in many countries irrespective of gender, race or socio-economic status, and characterized by impairments in social interaction, problems with verbal and non-verbal communication and restricted, repetitive behaviour, interests and activities. (United Nations General Assembly 76 Plenary Meeting, 2008, para. 4)

In no uncertain terms, the document, quickly and concisely, states that we might recognize the need for increased autism awareness only once we become aware that autism is a “lifelong” biomedical problem, located in the (any) body of children (i.e., the document narrates an autism that freely transgresses borderlines of race, class and gender), attributable to biological blunder (i.e., it states that autism is caused by a malfunctioning brain) and which manifests itself through a series of developmental deficits or delays (i.e., autism is narrated as the sum total of its developmental ‘signs’ - impaired social interaction, restricted interests, problems with communication and so on). Once again, as in earlier chapters, we are confronted with the awareness of autism as a state of pathological underdevelopment. The autistic body, this passage suggests, is the
Resolution adopted by the General Assembly

[on the report of the Third Committee (A/62/435)]

62/139. World Autism Awareness Day

The General Assembly,

Recalling the 2005 World Summit Outcome1 and the United Nations Millennium Declaration,2 as well as the outcomes of the major United Nations conferences and summits in the economic, social and related fields,

Recalling also the Convention on the Rights of the Child3 and the Convention on the Rights of Persons with Disabilities,4 according to which children with disabilities should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community, as well as the full enjoyment of all human rights and fundamental freedoms on an equal basis with other children,

Affirming that ensuring and promoting the full realization of all human rights and fundamental freedoms for all persons with disabilities is critical to achieving internationally agreed development goals,

Aware that autism is a lifelong developmental disability that manifests itself during the first three years of life and results from a neurological disorder that affects the functioning of the brain, mostly affecting children in many countries irrespective of gender, race or socio-economic status, and characterized by impairments in social interaction, problems with verbal and non-verbal communication and restricted, repetitive behaviour, interests and activities,5

Deeply concerned by the prevalence and high rate of autism in children in all regions of the world and the consequent development challenges to long-term health care, education, training and intervention programmes undertaken by Governments, non-governmental organizations and the private sector, as well as its tremendous impact on children, their families, communities and societies,

Recalling that early diagnosis and appropriate research and interventions are vital to the growth and development of the individual,

1. Decides to designate 2 April as World Autism Awareness Day, to be observed every year beginning in 2008;
2. Invites all Member States, relevant organizations of the United Nations system and other international organizations, as well as civil society, including non-governmental organizations and the private sector, to observe World Autism Awareness Day in an appropriate manner, in order to raise public awareness of autism;
3. Encourages Member States to take measures to raise awareness throughout society, including at the family level, regarding children with autism;
4. Requests the Secretary-General to bring the present resolution to the attention of all Member States and United Nations organizations.

76th plenary meeting
18 December 2007

1 See resolution 60/1.
2 See resolution 55/2.
4 Resolution 61/106, annex I.
5 See International Statistical Classification of Diseases and Related Health Problems, tenth revision (subcategories F84.0 and F84.1), endorsed by the forty-third World Health Assembly in May 1990.

Figure 5.2: United Nations Resolution 62/139 “World Autism Awareness Day” adopted at the UN General Assembly 76 Plenary Meeting, December 18, 2007.
quintessentially late body: the body that does not arrive ‘on time’ to the milestones of social, emotional and behavioural development.

Next, the UN resolution makes us aware that a second impetus for the creation of a world autism awareness day is the awareness of the:

Deeply concern[ing]...prevalence and high rate of autism in children in all regions of the world and the consequent development challenges to long-term health care, education, training and intervention programmes undertaken by Governments, non-governmental organizations and the private sector, as well as its tremendous impact on children, their families, communities and societies. (United Nations General Assembly 76 Plenary Meeting, 2008, para. 5)

No longer understood as merely (!) a problem body, the UN resolution suggests that awareness of autism is also awareness of autism as a problematic (developmentally ‘too slow’) group of bodies, a “deeply concerning” “prevalent” population trend, occurring too quickly (at “high rates”), transgressing state borders and thus, threatening to slow down “development” in “regions all over the world”. Autism, the resolution indicates, “challenges” the fast-paced and forward moving work of social and economic development and modernization by negatively “impacting” its foundational institutional building blocks (families, communities, societies). Awareness of autism, the resolution hints, is awareness of autism as a social and economic ‘cost’ and, so, as a threat to neoliberal modernity.

The UN resolution, thus, demonstrates the dominant understanding that more autism awareness is needed only insofar as autism is understood as both a biomedical (neurological) problem that threatens the (good/timely) development of the body and as a
(prevalent) problem population trend that threatens the (good/timely) development of the state. What is more, the resolution tells us that the ‘solution’ to both the social and individual ‘problem’ of autism – the third and, perhaps the ultimate impetus for autism awareness – is to target and alter the body of the individual autistic person through ‘early’ diagnosis and ‘appropriate’ (read: biomedical) interventions aimed at catalyzing (normative/more timely) development. The resolution states:

...early diagnosis and appropriate research and interventions are vital to the growth and development of the individual. (United Nations General Assembly 76 Plenary Meeting, 2008, para. 6)

Yet, what follows from the resolution, and what it fails to address, is how the move to develop (speed up) autism’s untimely state of underdevelopment also and most significantly works to develop private and public economic interests in a number of interrelated ways (e.g., through the production of more time efficient subjects better equipped as consumers and producers, through the proliferation of microeconomies driven by the treatment and/or curing of autism and so on) (Lane, 2007; Rose, 1999). The relationship between the development of the individual body and that of the state was all too evident, just over 3 months after the General Assembly passed its resolution, on the first ever World Autism Awareness Day.

April 2, 2008 – the inaugural World Autism Awareness Day (WAAD) – was observed in cities across the globe as a day to, according to the official WAAD website: “[shine] a bright light on autism as a growing global health crisis” (Autism Speaks, 2008b). In New York City, Autism Speaks took this imperative quite literally when organization volunteers and supporters rang the opening bell of the New York Stock
Exchange and, amidst a multitude of flashing and scrolling lights, ushered in another trading day (Fig. 5.3). That the world’s largest autism advocacy organization spent the very first moments of the very first World Autism Awareness Day on the New York Stock exchange trading floor – perhaps the nexus of speed and consumption, *par excellence* – holds both material and symbolic significance. This is so, insofar as the stock exchange represents: (1) a substantial amount of (private and public) funds invested in, for example, biomedical research, treatment and intervention programs and (2) the potential economic productivity of autistic people, the desired ‘end-products’ of the latest in biomedical research and its early intervention programs. Finally, (3) the stock market also represents the cultivation of the speed-driven temporality of urgency where capital – biomedical capital (i.e., research and intervention therapies) and biological capital (i.e., the bodies produced by research and intervention) – are produced and circulated within increasingly narrow time margins.

Indeed, Autism Speaks’ ringing of the market bell in New York – now an annual event, which, in 2010, chimed in chorus with opening and closing trading bells around the globe[^3] - gestures toward an undeniable blending of dominant contemporary versions of autism advocacy with (increasingly global) economic imperatives and neoliberal market rationalities (New York Stock Exchange, 2010). To better understand the material and symbolic implications of this ‘blending’ of market rationalities with advocacy work, I turn to a consideration of three key market principles – investment, risk

[^3]: On April 2, 2010, the *Dutch Autism Association* rang the closing bell at the NYSE Euronext Amsterdam, *Autism-Europe* rang the opening bell at NYSE Euronext Brussels and Paris and the *Federação Portuguesa de Autismo* and the *Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo* rang the closing bell at NYSE Euronext Lisbon (New York Stock Exchange, 2010).
Figure 5.3: Autism Speaks employees and volunteers ringing the opening bell at the New York Stock Exchange in honour of World Autism Awareness Day 2010. © 2005-2011 Autism Speaks Inc. Autism Speaks Inc. and Autism Speaks It’s time to Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.
and security – principles that are commonly evoked, employed and, so, work to govern the field of autism advocacy today.

**Time to Invest**

In contemporary times, autism is commonly brought into conceptual association with notions of social and/or economic investment, where ‘investment’ is conventionally understood as the provision of resources (e.g., time, energy, money and so on) with the expectation of future ‘return’ or profit. And, as the association between autism and investment is made and re-made, autism itself, gets (re)invested, as we shall see, with very particular cultural meanings and values.

Returning, once again, to the UN World Autism Awareness Day resolution, we can note how its appeal for greater public awareness of autism is rhetorically framed in terms of an appeal for investment in our collective (global) future. Recall how the UN’s declaration of the need for greater awareness of autism is premised on several other awarenesses, namely, the awareness of autism as an individual problem body, the awareness of autism as a problem population that effects the social body, and the awareness of the need for biomedical solutions that target the individual body but work to secure a better future for both the individual and the social body. With this in mind, the document issues its resolution in four parts:

**The General Assembly,**

1. *Decides* to designate 2 April as World Autism Awareness Day, to be observed every year beginning in 2008;
2. **Invites** all Member States, relevant organizations of the United Nations system and other international organizations, as well as civil society, including non-governmental organizations and the private sector, to observe World Autism Awareness Day in an appropriate manner, in order to raise public awareness of autism;

3. **Encourages** Member States to take measures to raise awareness throughout society, including at the family level, regarding children with autism;

4. **Requests** the Secretary-General to bring the present resolution to the attention of all Member States and United Nations organizations.

(United Nations General Assembly 76 Plenary Meeting, 2008, para. 7-10).

Using enticing and coaxing verbs that invariably bestow upon the addressee the freedom to choose (e.g., the general assembly ‘invites’, ‘encourages’, ‘requests’ etc.) – and, so, mirroring the principles of freedom, liberty and choice that are so central to the logic and the functioning of the free market – the WAAD resolution calls on global nations, organizations – national and international, public and private, governmental and non-governmental – and, indeed, the whole of “civil society” to (“appropriately”) observe World Autism Awareness Day and to do this in the name of more timely (individual and social) development outcomes. While the resolution makes no explicit mention of ‘investment’ per se, it functions, nonetheless, as an appeal for both ideological and monetary investment by promising better (profitable) future ‘returns’.

The WAAD resolution makes an appeal for greater awareness and advocacy and, in so doing, is involved in the production of the (good) advocate subject. The good, aware,
advocate subject is delimited as s/he who must invest in the ideological presupposition that autism is a problem in need of a solution. *Invest time,* it hints, in becoming more aware of the problem of autism and its many solutions. *Invest energy* in raising others awareness about autism through the dissemination of informational facts about untimely arrivals to milestones, and too-slow rates of development. What is more, the, presumably ‘appropriate’, ways of observing World Autism Awareness Day – exemplified around the world by the appearance of various autism organizations at global stock exchanges, the lighting up of numerous iconic (and many corporate) buildings in autism’s ‘trademark’ blue color – made it clear that becoming aware of autism in contemporary times is not only an ideological investment, but also a monetary one.

As we invest in the understanding that autism is nothing more than a biological problem – a ‘too slow to develop’ body and a time consuming population – the efficient way to proceed necessarily becomes to invest in biomedical research that will bring about autism’s solution (i.e., intervention treatments that target the autistic body and work to speed up its untimely growth and development by diminishing and/or eliminating ‘too slow’ autistic ways of being). In this way, the resolution functions indirectly as an appeal to invest in the latest biomedical research focused on identifying autism’s biological pathologies, uncovering its neurological etiologies and developing effective treatments to diminish and/or eliminate autistic ways of being. *Invest money,* the document hints, but not indiscriminately. Under a neoliberal rule that abides by the logic of the market,

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4 The buildings that were lit up in blue included the Empire State Building, Madison Square Gardens, the Toys ‘R’ Us in Time Square, Fenway Park and Sak’s Fifth Avenue in the US, the World Trade Center in Bahrain, the CN Tower in Canada and the Kingdom Center in Saudi Arabia (Autism Speaks, 2011d).
money must be invested efficiently. Put differently, money must be invested in such a way that provides ‘good’ returns; in such a way that makes profit.

The UN’s call for a global and globalizing commitment to (investment in) (individual and social) development was heeded in the fall of 2009 when a newly elected US President Barack Obama – at the height of the so-called ‘World Economic Crisis’ – held a press conference at the National Institutes of Health (NIH) to announce his administration’s substantial monetary investment in health focused research as part of the American Recovery and Reinvestment Act (the so-called ‘stimulus package’) (Government of the United States of America, 2009a). The 5 billion dollars in research money – as president Obama quipped at the press conference, “...that’s with a ‘b’” – represented, in Obama’s words, “the single largest boost to biomedical research in history”\(^5\) (Government of the United States of America, 2009b, para. 6). The money was earmarked for studies that would apply knowledge and technologies derived from the Human Genome Project to “understand, prevent, and treat” cancer, heart disease, and autism; “diseases,” in his words “that have long plagued humanity” (Government of the United States of America, 2009b, para. 6). At the press conference, the president spoke, in particular, about this “largest-ever infusion of funding into autism research” – approximately 100 million dollars was specifically designated for autism research – where, said Obama, “grant recipients will have the opportunity to study genetic and environmental factors of a disease that now touches more than one in every 150 children” (Government of the United States of America, 2009b, para. 11). The research supported by the grants, Obama said, would “hopefully lead to greater understanding, early

\(^5\) For the full transcript of President Obama’s remarks at the NIH press conference, please refer to Appendix A.
interventions, more effective treatments and therapies to help these children live their lives and achieve their fullest potential, which is extraordinary” (Government of the United States of America, 2009b, para. 11).

To invest in something (or someone) is to commit an asset – e.g., money or capital – in the hope of securing a profit, a more valuable return. In this way, any notion of investment is premised, first, on some version of an economy of exchange.

If I was to invest in the stock market, for example, I might examine and appraise my investment options, weigh their potential risks against their potential benefits, and buy up those stocks that I think will, as time passes, go up in value so as to ensure that my initial investment will turn a profit. Applying this investment orientation to real estate, we might commit a certain amount of money ‘up front’ with the belief that, in time, the property value will grow and might be sold for a greater sum of money. Similarly, in contemporary times, this investment orientation is also commonly applied to education. Investing in higher education means paying high tuition fees now with the expectation of better employment opportunities later. We invest money, but we also invest other valuable resources with the expectation of return. We invest, for example, time, love and energy in children, in families, in friends, in partners and so on. In each of these examples, sacrifices are made in the present time (we part with valuable resources), but only with the expectation of rewards in the future time (we gain desired outcomes). A key implication of this investment orientation is that we do not necessarily invest in what is valuable now, but, rather, we invest in what could be valuable in the future. In this way, investments have precisely to do with the imagining of futures and desirable ones at that.

It is interesting and certainly revealing to note the emphasis on childhood in the UN
resolution as well as in Obama’s NIH press conference. Children are cited as the primary focus and motivation for the need to invest in autism research and awareness. For example, referencing “children with disabilities” and the need for the child’s “active” participation in the community and “full” enjoyment of human rights and freedoms, the UN resolution goes on to state that autism “mostly [affects] children”, that there is a “high rate of autism in children in all regions of the world” and, finally, that UN member states ought to take “measures to raise awareness throughout society...regarding children with autism” (United Nations General Assembly, 76 Plenary Meeting, 2008, my emphasis). Indeed, but for a single, brief mention of “all persons with disabilities”, the resolution makes it clear that the autistic child, and not the autistic adult, is the focal point of and driving force behind World Autism Awareness Day. Childhood is emphasized, again, recalling Starbucks’ ‘fact’ to-be-consumed: one in every 150 children receives an autism diagnosis. Returning to the example of the NIH press conference, Obama, too, reinforced the common cultural understanding that only children are “touched” by autism and that investment in autism research is necessary to ensure that these children can go on to live good lives and reach their “full” potential.

Indeed, it almost goes without saying that the figure of the child is conceptually bound to notions of futurity (Berlant, 1997). This sentiment is repeated time and again in our culture; we hear it in song lyrics [e.g., Whitney Houston’s declaration, “I believe that children are our future/ teach them well and let them lead the way...” (Masser & Creed, 1984)] and political speeches [e.g., Former president John F. Kennedy’s famous pronouncement that “children are the world’s most valuable resource and its best hope for the future” (Kennedy, 1963, para. 1)] we glean it from the commercials advertising
‘healthy’ food products (e.g., Pediasure’s corporate tagline ‘Feed kids potential’) and in the informational facts printed on the sides of paper coffee cups. As Lee Edelman (2004) notes, it is, indeed, almost impossible to conceive of future times without the figure of the child, for the child has come to embody the very telos of the social order itself (p. 11). In this way the figure of the child is, in Edelman’s words, the “preeminent emblem of the motivating end” (Edelman, 2004, p. 13) compelling and, so, propelling us toward ‘better’ future.

The, as we have seen, ubiquitous presence of the figure of the child (and the conspicuous effacement of the autistic adult) within discourses of autism advocacy is significant as it conjures a very particular – and highly functional – temporal environment where notions of futurity get collapsed with the immediate present; where we must invest ‘now’ for better ‘laters’. While the question of what childhood is, is surely open to endless theorizing, in this (western/ized) culture and in these (neoliberal) times, one way of understanding ‘childhood’ is to understand it as a time. The time of childhood – understood, simultaneously as a biological time of growth and development and a sentimental/nostalgic time of innocence, hope and vulnerability – is precisely that time of seemingly infinite ‘laters’. The child is positioned as ‘early on’ on the (normative) biological timeline and, therefore, is understood as having more time, more future yet-to-be-realized. In a neoliberal regime where ‘time is money’, the child is figured as ‘time-rich’ and so represents a good investment opportunity indeed.

Underscoring a logic of exchange, a logic so central to any conception of investment, both the UN resolution’s investment appeal and the Obama administration’s actual investment resonate with the promise of ‘better’ futures conceived of in terms of
investing in the child in exchange for more profitable future returns. In all examples, this ‘better future’ is characterized in terms of more timely economic development, both individual and social.

The WAAD resolution, as we have seen, paints a picture of a too-slow to develop child’s body that poses “consequent development challenges” to governmental and non-governmental initiatives and to the private sector. While the resolution does not explicitly say how the one (individual development) is connected to the other (social and economic development), we must assume its logic, as a matter of commonsense. We might assume – and it would seem, the resolution expects us to assume – that the logic goes as follows: the ‘too slow to develop’ body represents an excessively costly body and this excessive cost works to slow down the development of, to quote the resolution, “long-term health care, education, training and intervention programmes”.

The autistic body, the resolution suggests, represents the possibility of expensive social services, costly and ongoing medical evaluations and treatments, specialized education programs and so on. This dominant, commonsense understanding resonates throughout our culture as autism is so often framed as an excessive economic burden in, for example:

- **News headlines:** e.g., The New York Times’ headline, “Tug of War over Costs to Educate the Autistic” (Fairbanks, 2009); The Chicago Sun-Times headline, “Families confront stiff cost of autism” (Ritter, 2005) “Autism Costs Society An Estimated $3 Million Per Patient, According To Report” (Science Daily, 2007); "Fighting autism too costly, top court told court told" (Makin, 2004); “Autism a lifelong burden, study shows: Because few adults with the disorder can work, the
economic costs continue” (Picard, 2007).

• **Journal articles:** e.g., “Measuring the parental, service and cost impacts of children with autistic spectrum disorder” (Jarbrink, Fombonne & Knapp, 2003); “The Lifetime Distribution of the Incremental Societal Costs of Autism” (Gantz, 2007); “Economic cost of autism in the UK” (Knapp, Romeo & Beecham, 2009); “The costs of services and employment outcomes achieved by adults with autism in the US” (Cimera & Cowen, 2009)

• **Legal decisions:** e.g., Auton v. British Columbia (2004); Wynberg et al. v. Ontario (2006); McHenry v. PacificSource (2009)

• **Government reports:** The Centers for Disease Control and Prevention ADDM reports (CDC, 2006; CDC, 2010); Canadian Autism Research Agenda and Canadian Autism Strategy: A white paper (Autism Society of Canada, 2004).

Yet, the logic does not end with the conceptualization of the autistic body as an excessive cost. The WAAD resolution, for example, reminds us that the need to invest in autism awareness is motivated, at least to some degree, by the promise of a better future where individual autistic children’s bodies can be helped to “grow” and “develop” in a more timely way by “early diagnosis and appropriate research and interventions” and presumably, in this way, be placed in a better position to more “fully realize” and even “enjoy” their “human rights and fundamental freedoms”. Drawing on the UN Conventions on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, the WAAD resolution paints a utopic picture of a future where all individuals are free to lead a “full and decent life”, to be “self-reliant”, to “actively” participate in the community and so on.
Similarly evoking the utopic time of ‘better futures’, President Obama speaks of biomedical research holding “incredible promise for the health of our people and the future of our nation and our world”, a “promise” that, in his words, “we’ve only begun to realize”. Obama articulates that in investing in biomedical research (and, in relation to autism, this is most often constituted by research into “early interventions, more effective treatments and therapies”) we are also and necessarily investing in a “brighter future” – we are “build[ing]”, in his words, “a better world for ourselves, our children, and our grandchildren”. A world, in his words, where autistic children are free to “live their lives and achieve their fullest potential” (Government of the United States of America, 2009b, para. 11).

Obama’s remarks at the NIH press conference, together with the WAAD resolution, are suffused with a neoliberal rhetoric of potentiality, articulated in terms of the individual right and the freedom to become. As we realize our freedoms and “enjoy” our human rights, some crucial questions arise: what or who are we free to become? And, what rights must we enjoy along the way?

Rose (1999) points out, “only a certain kind of liberty – a certain way of understanding and exercising freedom, of relating to ourselves individually and collectively as subjects of freedom – is compatible with liberal arts of rule” (p. 62). There are, therefore, limited permissible ways of performing and exercising our rights and freedoms in neoliberal times. Drawing attention to the ways rights discourse works to regulate particular historically specific cultural values and ideals, including those market-driven values and ideals of the contemporary neoliberal state, Veena Das warns, that discourses of human rights and freedoms can be “a means of sanctioning cultural
authoritarianism” (as cited in Stephens, 1995, p. 39). Jo Boyden (1990) observes: “the norms and values upon which this ideal of safe, happy and protected childhood are built are culturally and historically bound to the social preoccupations and priorities of the capitalist countries of Europe and the United States” (p. 186). Far from being simply ‘fundamental’, ‘guaranteed’ or ‘naturally endowed’ to all humans, human rights and freedoms are granted or withheld or even revoked – they are, in other words, socially, historically, politically and economically determined. And, in this way, they function to determine the necessary shape of their bearer.

As the WAAD resolution explicitly states:

...children with disabilities should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community, as well as the full enjoyment of human rights and fundamental freedoms on an equal basis with other children. (United Nations General Assembly 76 Plenary Meeting, 2008, para. 2)

Rights and freedoms, here, are revealed as something other than what one simply ‘has’ as a matter of nature or even as a matter of law. Rights and freedoms are, rather, framed as something one ‘should’ ‘fully enjoy’. For a subject to be granted human rights and freedoms – and so to be regarded as living a “full” or ‘good’ life – the subject ought to enjoy his/her rights and freedoms in particular (limited) ways. Under neoliberalism, an individual is only recognized as enjoying his/her human rights and freedoms if s/he moves in time with neoliberal values and its market rationalities; if s/he “enjoys” or

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6 And, as Sharon Stephens (1995) points out, in an increasingly global and globalized world, “it is not only modern European national citizens who should have a particular sort of childhood, but populations around the world, in need of ‘civilization’ and ‘development’” (p. 16).
consumes goods – coffee, for example – and so participates the s/pace of production.

Pressing is the need for greater awareness of autism as a biomedical problem and for more biomedical research and corrective therapies, the WAAD resolution suggests, for all children, including children with autism, ought to be free/ have the right to lead and enjoy ‘full lives’, to achieve their “full potential” and to do these things – as per the refrain of liberalism – independently (to be “self reliant”) and efficiently (abiding by a timely tempo of development that invariably leads to “active participation” in the economic development of the greater global community). The child, in other words is made free, but only to, following Ruth Lister (2003), become a “cipher for future economic prosperity and forward looking modernization” (p. 433). This imaginary of the “future worker-citizen,” she points out is “the prime asset of the social investment state” (p. 433). The child ‘with’ autism, then, becomes framed as needing to be freed from his/her autism so as to be free to become a ‘good’ neoliberal subject well positioned to enjoy human rights by participating in and, indeed, enjoying a “full” life of production and consumption.

And, most interestingly, as the advocate heeds the UN’s ‘encouragement’ and becomes more aware of autism, as she accepts the WAAD resolution’s ‘invitation’ and chooses to “appropriately” observe April 2\textsuperscript{nd} (by ringing the bell at the stock exchange, for example, or by buying a WAAD a t-shirt) – as the advocate, in other words, exercises her freedom and realizes herself as a good advocate – she is also and simultaneously engaged in the realization of bodies that are less free - bodies that are characterized by the WAAD resolution as first requiring early diagnoses and interventions before being able to fully realize and “enjoy” their rights and liberties, bodies that, in Obama’s words, need
‘help’ to live their (good, neoliberal) lives and achieve their ‘full’ potential. And so, as the advocate realizes herself as an advocate, she also engages in the realization of herself as a good neoliberal subject – a timely (and so, necessarily, non-autistic) subject who consumes/enjoys products and goods while learning about the signs of “good” (developmental) timing; a subject, moreover, who is engaged in the work of producing the good neoliberal subjects of the future by working to develop/speed up autism’s ‘bad timing’. In this way, the freedom of autistic subjects is constructed as dependant (and thus contingent) upon the good choices of good advocates.

Investing in interventions that work to speed up too slow development and ensure the developmental timeliness of children’s bodies are investments with the expectation of “good” (profitable) return. In other words, the WAAD resolution suggests that we (‘civil society’) invest resources in the present to ensure the production of bodies both timely (developing on time) and time-rich (still have much time) of the future; bodies that, in consumer culture, are highly economically valuable for they are available to better participate in the global economy as producers and consumers. This not only assigns economic value to normative human development and, so, transforms the body of the normatively developing child into some kind of material asset; it also works to produce the non-normatively developing body as non-valuable and, perhaps even, as non-viable in the contemporary market-driven economy, a notion that I will explore in more depth for the remainder of this chapter.

The resolution reminds us, albeit indirectly, that a ‘good’ return on an awareness investment is the production of more profitable bodies – bodies, in other words, that arrive ‘on time’ to their milestones and so arrive ‘on time’ to ‘actively’ participate in
processes of production and consumption and otherwise contribute to (or, at least, do not slow down) the timely development (modernization) of the state. That autism’s too-slow development represents a significant economic burden to the public and private sectors, and so poses a threat to better futures, indeed seems to be a fact that the WAAD resolution takes for granted. Yet, if we attend carefully to Obama’s remarks at the NIH press conference, it would seem that the business of investing in better futures needs – is absolutely dependent upon – the untimely autistic body and the time sensitive response of advocacy. Indeed, we might note how good, neoliberal versions of advocacy – populated by advocates who participate in and even enjoy the work of noticing the differences between autistic and non-autistic comportments and who produce and consume treatments for such differences – already represent a ‘good’ and very profitable ‘return’ on an awareness investment.

Consider, for example, how the Obama administration’s 100 million dollar investment in autism research – a sizeable monetary investment, to be sure – was, almost counter-intuitively, announced in the midst of the greatest economic crisis since the Great Depression and that the money invested was sourced from the US recovery act – the stimulus package – the explicit purpose of which was to stimulate or ‘recover’ a faltering market economy (encourage spending, create jobs and so on). Investing in the business of treating and curing autism is explicitly framed by the president as an investment in

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7 It is interesting to note that this language of ‘recovery’ is also very commonly used in advocacy discourse as a way of articulating the work of treating and/or curing the autistic person. It is equally interesting to note how contemporary economic discourses use the language and concepts of childhood development to articulate processes of recovery (i.e. the success/progress of the American Recovery and Reinvestment Act is measured in terms of the economy’s “growth and development” and even in terms of its “recovery milestones”) (Government of the United States of America, 2009c).

8 See Albrect’s (1992) *The Disability Business: Rehabilitation in America.*
future economic prosperity; an investment that works to stimulate the economy by, in the
president’s words, ‘improving’ and ‘saving’ lives (of future producers and consumers),
but also by ‘creating’ and ‘saving’ jobs along the way. As Obama explicitly stated:

...we know that these investments in research will improve and save countless
lives for generations to come [...] But we also know that these investments will
save jobs, they'll create new jobs – tens of thousands of jobs – conducting
research, and manufacturing and supplying medical equipment, and building and
modernizing laboratories and research facilities all across America. (Government
of the United States of America, 2009b, para. 12)

Lofty appeals to the betterment of children’s futures through the development of
children’s bodies function as powerful and productive investment appeals. At once, this
kind of appeal functions to secure more and better neoliberal body-assets better able to
contribute to state and global economies as well as to entice the emergence of good,
productive and consumptive advocate-workers who realize their subjecthood by ensuring
the development (production) of better (time efficient and time-rich) citizen-workers of
the future. What is more, such an appeal also works to stimulate the development of
whole industries centralized on the production of the timely body, itself an economic
commodity to be bought and sold (Albrect, 1992).

**The Business of Autism**

Despite the constant lament that autism is just too costly, a significant or even,
"crippling" economic burden for the social whole, the production of the time-rich but not
time-efficient body of the autistic child has generated a multi-billion dollar ‘autism
industrial complex’ – public and private investment interests that benefit, economically from and, indeed, whose very fiscal survival is reliant upon, the existence of the late body that needs help catching up to its milestones and so, to its (and, apparently, everyone else’s) better future. While Obama references several of these investment interests explicitly – biomedical researchers, private and public biomedical research facilities, medical equipment manufacturers and suppliers and so on – there are surely many other economic interests that stand to benefit, directly and indirectly, from the president’s and the UN’s (as well as other major and minor players) re-articulation of the need to speed up autism’s developmental too-slowness.

Harlan Lane (2007) writes about the existence of what sociologist Joseph Gusfield calls the “troubled persons industries”, industries that, in Gusfield’s words, “bestow benevolence on people defined as in need” (as cited in Lane, 2007, p. 81). For example, in recent decades, there is an ever growing range of new and specialized jobs that have emerged that absolutely depend on the construction of an untimely autism in need of ‘speeding up’ (i.e., specialist/expert doctors, teachers, researchers, advocates, therapists, audiologists, psychologists, psychiatrists, social workers, counselors and so on). These and many other jobs are supported by a barrage of (mostly privately offered) intervention therapies and programs that aim to diminish autistic behaviours and/or ‘cure’ autism, including, but certainly not limited to: stem cell therapies; behaviour therapies (e.g., Applied Behavioural Analysis and Intensive Behavioural Intervention); craniosacral therapies; chiropractic therapies; relationship therapies (e.g., Relationship Development Intervention®, Son-Rise®, Floortime® and SCERTS®); detoxification therapies (e.g., chelation and hyperbaric oxygen treatments); diet supplement therapies; nutrition
therapies (e.g., casein-free and gluten-free diets); vitamin therapies; acupuncture therapies; massage therapies; music and art therapies; aromatherapy treatments; neurofeedback therapies; animal assisted therapies (e.g., dolphins, dogs and horses); occupational and physical therapies; communication therapies; shamanism therapies; electric shock therapies; and, of course, a wide variety of pharmaceutical based drug therapies.

While whole industries have cropped up around treating and/or curing autism, other industries have discovered it can also be profitable to take the prevention route, marketing products that aim to prevent untimely bodies altogether and/or to enhance timely bodies by stimulating normal fetal and infant brain development (e.g., BabyPlus Prenatal Education System®, Juicy Juice for Brain Development®) and a wide range of development toys (Nadesan, 2002). Other industries still, have honed in on the autism ‘niche’ market, marketing a plethora of communication tools and software (e.g., Dynavox Technologies®, as we saw on the ‘red flag’ poster in Fig. 4.1), informational books and “autism friendly” products marketed to help build ‘appropriate’ skills (e.g. Toys R Us® “Ten Toys that Speak to Autism” or the 2,000-square-foot retail store in California called Angels for Autism) (For a selection of autism products, see Fig. 5.4). Think your kid might be autistic? There’s an app for that! Want to encourage more normative behaviours? There’s an app for that too⁹.

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⁹ For example: you might take a quiz about your child’s behaviours with AutismTest®, or upload video footage to better track the progression of your child’s ‘symptoms’ on BehaviorTrackerPro®, Model Me Going Places® provides slideshows of images depicting smiling children modelling ‘socially appropriate’ behaviours, Look in my Eyes® is a game that rewards players for looking directly into the eyes of a person on the screen. Parents, teachers and anyone who works with or lives with autism can download behaviour modification tools such as ABA Flashcards©, Teach Emotions®, Everyday Social Skills© and so on.
Heeding the UN’s request that “all of civil society” (“including the private sector”) engage in autism awareness raising, even industries that have little or nothing to do with autism in specific or childhood development more generally – coffee chains, designer boutiques – have thrown their ‘philanthrocapitalist’ hats in the ring by promoting autism awareness on their paper coffee cups and in their window displays while, all the while, drawing a profit. Nowhere is the lucrative business of autism more apparent than on the Autism Speaks Marketplace website (Autism Speaks, 2011e) where patrons can learn about and purchase the latest autism products and therapeutic toys, choose from an expansive array of autism clothing and accessories, learn about the organizations multi-million dollar corporate partnerships (e.g., Toys R’ Us, T.J. Maxx, Chevrolet, Fox Sports, Home Depot, Zales Diamonds etc.), or participate in the “shop and give” initiative where they can buy non-autism related products (e.g., clothes from the Gap®, Old Navy®, Banana Republic® or Roots®, flights from Expedia®, books from Amazon®, music from iTunes® and so on) and have a portion of the proceeds of the sale (between 1-12.5%) go to Autism Speaks.

The sheer breadth of this ‘autism industrial complex’ gestures towards the cultural ‘fact’ that, under neoliberal rule, social and/or economic investment in the untimely autistic child – such as those investments articulated by the UN and by President Obama – is not just an investment in the realization of the ‘future-citizen-worker’ but in the potential for its realization. In one unbroken – and very lucrative – move, our market-driven times, at once, produce and regulate, create and constrain conducts beyond the norm.
Figure 5.4: A collection of consumer products and advertisements reflecting the corporatization of autism.

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Risk-Benefit Potentials

Throughout this chapter so far, I have been reading discourses of autism advocacy through the frames, logics and temporalities of ‘our times’, times that are characterized, primarily, in relation to the political and economic orientations of a global – globalized and globalizing – free market. I conclude this chapter by tracing how such free market orientations deliver us to commonsense understandings of worth and value (what and who constitutes a ‘good’ investment or ‘good’ stock’ and what and who gets recognized as investment ‘risk’) via particular and culturally specific narratives of potentiality.

Insofar as it resides at the nexus of the ‘now’ and the ‘later’ – the point of collapse between present and future – the time-rich figure of the child is the figure of potentiality, par excellence. If we imagine the child in terms of the biological, its body comes to represent the potential for growth and development, the potential for growing up, for getting older, becoming an adult and so on. But, as we have seen, the child’s body represents more than the potential for biological growth, it also comes to represent the potential for economic growth and development – it represents the potential for work, for achievement, for success – potential which is closely related to the potential of a society, a nation, an empire.

In his essay “On Potentiality”, Giorgio Agamben (2000) meditates on Aristotle’s writings on the concept. In *Metaphysics*, Aristotle writes: “Impotentiality [adynamia ἀδυναμία] is a privation contrary to potentiality. Thus all potentiality is impotentiality of the same and with respect to the same” (as cited in Agamben, 2000, p. 182). Unpacking these observations, Agamben (2000) writes: “to be potential means: to be ones own lack. To be in relation to one’s own incapacity. Beings that exist in the mode of potentiality
are capable of their own impotentiality; and only in this way do they become potential” (p. 182). For Agamben, then, potentiality is the presence of an absence and the relation between the two. This centralization of the absent-present character of potentiality – that potential is both absent insofar as it is an imagination of ‘not yet’ future times but is also and, therefore made very present, actively structuring the present time – is crucial for critiques of development discourses as it permits an analysis of the ways in which children’s bodies, themselves, become understood as both absent and present. These are present and ready-to-hand bodies-to-be-managed, bodies managed always in relation to their status as could-be but not-yet bodies of the future. Evans (2010) writes, “children’s bodies are absent-presences within hoped-for utopias” but also, she continues, within, “threatening dystopias” (p. 34).

Echoing one of the most rudimentary of stock market principles: the potential for gain bears within it the seed of potential loss. While potentiality is often oriented toward desired outcomes – the potential for ‘better futures’, economic gain and so on – it is also and because of this vulnerable to risk. Time-rich and, thus, as we have seen, ripe with the potential for ‘good return’, the figure of the child also comes to represent the potential for loss: the child might not grow in the ‘right’ direction\(^\text{10}\); the child might fail to grow ‘up’, might not move ‘forward’ on the developmental timeline fast enough, might not ‘go far’ in life. The child might squander his/her (temporal) riches with the time inefficiency of “developmental delays”, and so, ‘wasting’ ‘full’ potentials for culturally determined – and, as we have seen, in these neoliberal times, this often comes to mean economically determined – notions of ‘success’ and achievement.

\(^{10}\) For a compelling discussion of growing ‘sideways’, see Kathryn Bond Stockton’s book *The Queer Child, or Growing Sideways in the Twentieth Century* (2010).
Just as the ways imagined utopias reflect the political commitments, values and interests of a particular culture at a particular historical moment – as is exemplified in both the WAAD document and in Obama’s appeal to ‘better futures’ – imagined dystopias, too, are marked by the particularities of culture and history. As Erikson & Doyle (2003) remind us: “risk [...] is a cultural code for expressing and defending interests. Nothing is inherently risky but anything can be treated as a risk if the party claims that it has the potential to adversely affect their interests and values” (p. 16). Culturally and historically specific investments call into being particular kinds of fears and, thus, particular conceptualizations of risk. As the time-rich and time-efficient body of the child gets inaugurated as the primary site of neoliberal investment, autism gets cast as a risk, a variable that might divert potential gain into potential loss. Autism, in other words, is understood as potentially causing the time-rich figure of the child to squander his temporal ‘riches’ by being non-efficient with his time: by ‘wasting’ or ‘losing’ time, by not ‘spending’ time in (morally coded) normative ways, by arriving late (or not at all) to ‘milestones’ and so, falling behind on an economic timetable of production and consumption. Recalling the WAAD resolution, this process creates ‘development challenges’ for nation states and global communities.

Yet, we cannot forget that, following Aristotle and Agamben, ‘all potentiality is impotentiality’ – the one contains the other and vice versa. Put differently, without the potential for loss, there can be no potential for gain. To make an investment is to live with risk and, in a market economy, invest we must. Simons (2006) notes: “risk is not immediately understood as the chance that some problems will arise, but is instead a chance or opportunity” (p. 533). Risk is, thus, not necessarily something to be avoided
altogether (recall, for example the extent to which the market is dependent on the ‘troubled person’). And so, rather than something to be eliminated altogether, risk – and this, of course, includes those bodies constituted as ‘risky’ or ‘at risk’ – becomes something (someone) to be managed with the aim of maximizing gain; something that must be measured, monitored, calculated, strategized about, manipulated, and above all, controlled.

These times have witnessed the emergence of scores of tools and techniques aimed at assessing and managing the perceived risk of autism (e.g. empirical studies examining epidemiology or risk factors, informational ‘facts’ about early warning signs, assessment tools, technologies and checklists and so on). I now turn to a consideration of but one of these techniques: the systematic production and circulation of statistics that tell of autism’s presence or, perhaps more accurately, its prevalence.

Before I delve into some of the productive effects of statistics, it is important to first note, how these are accomplishing something more than simply relaying information about a given risky phenomenon. They are, following Erikson & Doyle, “not simply conduits through which knowledge of risk is transferred” (Erikson & Doyle, 2003, p. 2). Rather, to borrow from Titchkosky, “to put disability into [statistical] text […] is to enact its meaning” (Titchkosky, 2007, p. 76). In other words, statistical techniques of assessing and managing risk provide the conditions of possibility for the appearance of a given risky phenomenon and are, thus, involved in the very constitution of what (who) gets recognized as risky in the first place. In order to examine the productive effects of notions of investment within contemporary autism advocacy discourses, it becomes necessary to look to the ways in which understood risk get communicated. To do
this, let us return, once again, to the central usages of this chapter: Bob Wright’s Starbucks coffee cup statement, the UN World Autism Day resolution, and president Obama’s 100 million dollar investment in biomedical autism research.

Advocacy in a Time of 'Epidemic': The S/pace of the ‘NOW’

Weaving together epidemiological narratives of prevalence and proximity and citing increasing odds in collapsing times, each of the three central examples from this chapter communicates and, indeed, actively works to constitute autism as a very specific kind of risk: particular usages of autism statistics in contemporary times invoke autism as a risky pathology threatening the benefit outcome (or, perhaps the ‘health’) of neoliberal investments. In this way, as we shall see, autism gets transformed into a risk-to-be-managed, while non-autism (normalcy) is reified as an investment-to-be-protected.

“Every 20 minutes – ” whispers your morning coffee, “ less time than it will take you to drink your coffee – another child is diagnosed with autism”. Be “concerned” with your child’s development, Wright instructs, for autism’s untimely development is “much more common than people think, with one out of every 150 children diagnosed”. Obama, too, cites the 1 in 150 statistic, as he reminds the American public that autism is “a disease that now touches more than one in every 150 children”. While the United Nations World Autism Awareness Day resolution does not cite the ‘1 in 150’ statistic, it nonetheless references it, as the resolution states that the assembly is “deeply concerned by the prevalence and high rate of autism in children in all regions of the world” (my emphasis). More than simply or transparently informing us of empirically derived numbers of individual autism diagnoses or the rates at which these diagnoses occur (processes that are, themselves, historically, politically and economically mediated, to be
But it is, perhaps, more interesting to ask the question: what kind of risk does autism represent? One way that autism gets statistically represented as a growing sub-population is through the listing of numbers; climbing statistics meant to reflect the number of individual bodies being diagnosed at a given time. These kinds of statistics are most often found in scientific journals, in advocacy organization reports or in government documents. For example, the *Centers for Disease Control and Prevention* (CDC) report from the Autism and Developmental Disabilities Monitoring (ADDM) Network entitled “Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2004 and 2006” (2010), published a summary of its research findings that included statistical ‘facts’ that showed autism’s growing numbers in the US during the two years studied:

- Number of 8 year olds identified with an ASD [2004]: 172,335
- Number of 8 year olds identified with an ASD [2006]: 308,038

(Centers for Disease Control and Prevention, 2010, p. 8)

Recalling Erikson & Doyle, techniques of measurement and modes of communication “are not simply conduits”. The kinds of statistics deployed work to shape the kinds of risk that are and can be recognized. Particular kinds of statistics shape ‘autism populations’ into very particular kinds of risk.

The statistics above make a few things clear: counting up numbers of (risky) individuals with autism diagnoses, comparing these numbers over time and
communicating these measurements through statistical facts such as those seen in the ADDM report functions to depict autism as a growing population: a population trend and, as we have seen, a risky one at that. More specifically, the risk that autism represents in these statistics is the risk that its growth might not be stoppable; that it might grow beyond available techniques of management, that its growth is out of control.

Yet, it is significant, to note that, at least in popular autism advocacy discourse, growing numerical figures are not so commonly cited. While these kinds of statistics might be found buried somewhere in an advocacy organization’s annual report or as a bullet on a government ‘fact’ sheet, rarely are we confronted with the refrain: “In the past two years, incidence of autism in eight-year-olds has increased from 172,335 to 308,038”: we do not encounter these statistics on the streets, in our living rooms, at the coffee shop.

What we are confronted with is the extensive – excessive even – repetition of autism represented as a simplified ratio, a statistical ‘odd’ (i.e., ‘autism affects 1 in 110’ as opposed to ‘autism affects 308,038’). And, as we go about our daily lives, odds are, we’ll encounter them. We might encounter autism ‘odds’, for example, in the middle of a Sunday afternoon football game as the most up-to-the-minute stat flies by on the news ticker at the bottom of the screen. We might be struck by these numbers as we flip through magazines as we wait in line at the grocery store or as we listen to the car radio driving along the highway.\(^\text{11}\) These odds are prominent in:

\(^\text{11}\) See, for example, Autism Speaks 2006 ‘Learn the Signs’ Campaign, where print advertisements and public service announcements present statistical information about the probabilities of something occurring (‘odds of a child getting hypothermia’: 1 in 66,000, ‘odds of becoming a top fashion designer’: 1 in 7000) in contrast with the probabilities of a child being
• **Newspaper headlines:** e.g., the *New York Time’s* headline “Study puts rate of autism at 1 in 150 US children” (Carey, 2007); the Washington Post headline “1 in 150 Children in US have Autism, New Survey Finds” (Weiss, 2007); a headline from Reuters India “With autism at 1 in 110 kids, treatment in demand” (Fox, 2009)

• **Sweeping news coverage:** e.g., MSNBC and NBC News’ week-long coverage “Autism: The Hidden Epidemic?” (Autism Speaks, 2005); CNN’s day-long special, “Autism: Unravelling the Mystery” (Autism Speaks, 2008).

• **Advocacy campaigns:** e.g., Autism Speaks ‘Learn the Signs’ campaign (Autism Speaks, 2006), Autism Speaks’ ‘Times have Changed’ PSA (Autism Speaks, 2010); National Autism Association’s “Never Give Up” PSA (National Autism Association, 2010) feature autism ‘odds’ prominently, but they are cited in almost every mainstream autism advocacy campaign of the moment.

Presidential addresses. Celebrity interviews. And, of course, we might also encounter these ‘odds’ as we are on the go with our morning coffee.

What different kinds of work are accomplished by these two similar yet divergent ways of statistically representing autism’s presence (i.e., as a growing number vs. as a statistical odd)? Statistics that represent autism as a growing number count up individual untimely bodies, stack them up, one upon the other, growing them into towering bar graphs. And, as these teetering numbers (and the bodies they represent) shoot up and up

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diagnosed with autism (‘1 in 150’) (For a more detailed discussion on the particular strategies and techniques deployed in this campaign, see McGuire, forthcoming).
and up again – 172, 335…308, 038 … – they, symbolically, grow further and further away from us. The towering numbers are indiscriminate, faceless; they are someone else in some other place. And, what is more, as they continue to grow away from us they seem to move beyond the purview of the everyday; out of reach, beyond our control.

Statistics, though, that represent autism as an ‘odd’, count up untimely bodies only to divide them out, distilling the numbers down to the most simple\(^{12}\) of ratios. Rather than growing away, statistical odds grow inwards. They close in: as the odds go up, the ratio gets smaller. 1 in 500; 1 in 166; 1 in 150; 1 in 110. Like a countdown, increasing odds grow towards us. Where growing numerical figures are abstract, faceless, distant and deeply impersonal, increasing odds are close, specific, personal, intimate.

It bears notice that with the ‘odd’, the number ‘1’ – perhaps, the most intimate of numbers – never changes over time. Autism’s 1 never grows (we never are confronted with odds like, say, ‘2 out of every 150’). As odds change over time, the variable number is the second number in the ratio – the number representing the population as a whole. According to the ADDM report released in the winter of 2010, autism no longer affects 1 in 150 children, but 1 in 110 (Centers for Disease Control, 2010). While increasing numbers function to expand out, increasing odds conjure an atmosphere of enclosure and confinement, they tell an allegorical story of a circle that is closing in, zeroing in on the ‘1’, which is, inevitably, your ‘1’. To borrow the tagline from a 2010 Autism Speaks PSA entitled “Times have Changed”\(^{13}\), “autism is getting closer to home” (Autism Speaks, 2010c).

\(^{12}\) Recall, here, the functional importance of the simplified and therefore highly-consumable ‘fact’ in a neoliberal economy of that relies on, as we have seen, the existence of the untimely body to be made timely

\(^{13}\) See Chapter 6 for a full description of this PSA
Autism, Obama stated at the NIH press conference, is “a disease that now touches more than one in every 150 children”. Autism touches. Close. Recalling Wright, “It’s much more common than people think”. So ‘close to home’ is autism that it no longer waits on doorsteps but penetrates thresholds. Its touching us, making contact, grazing the borderlines of our bodies and those of our children. And the intimate borderlines of the skin are not the only frontiers that autism is understood to be penetrating. Autism is narrated as leaky and indiscriminate, transgressing bounded spaces of identity and identification: as the WAAD resolution states, autism “affect[s] children […] irrespective of gender, race or socio-economic status”. And, it is seeping across state lines with neither restriction nor restraint: autism is, according to the WAAD resolution, “affecting children in many countries” and is “deeply concerning” because of its prevalence and high rates amongst “children in all regions of the world”. And, as the ‘odds’ count down towards us, as the numbers close in and our borders are breached, each of these examples agrees on the necessary course of action: Do something and do it quickly. “Learn the early warnings signs” says Wright, “early intervention could make a big difference in your child’s future”. “Early diagnosis” says the WAAD document, and “appropriate (read: biomedical) research and intervention is vital to the growth and development of the individual”. More biomedical research, declares the Obama administration in chorus, research that leads to, in the words of the president, “greater understanding14, early interventions, more effective treatments and therapies to help these children”.

Insofar as these examples draw upon epidemiological tropes of “high rates” of contact and indiscriminate spreading – not only is autism “touching” us, according to

14 And it is clear that ‘understanding’ here refers to the understanding of the nature of autism’s problem, which must not be confused with greater understanding of autism as a way of being in the world, or understanding of autistic people.
Obama, it’s “plaguing” us – they put together a story of autism that might be characterized in terms of what Priscilla Wald (2008) refers to as an “outbreak narrative”, a narrative that, in her words, “follows a formulaic plot that begins with the identification of an emerging infection, includes discussion of the global networks through which it travels, and chronicles the epidemiological work that ends with its containment” (p.2).

This ‘outbreak narrative’ is a familiar one; it is, indeed, a real ‘sign of the times’, as it were, and this is evidenced by a vast variety of contemporary artifacts du jour that take up this narrative including:

- **Films and television:** e.g., *Outbreak* (Petersen, 1995); *Quarantine* (Dowdie, 2008); *The Andromeda Strain* (Salomon, 2008); *The Stand* (Garris, 1994); *28 Days Later* (Boyle, 2002); *Carriers* (Pastor & Pastor, 2009) and HBO’s *The Walking Dead* (Darabont, 2010)

- **Video games:** e.g., *Resident Evil* (Mikami, 1997), *Pathologic* (Ice-Pick Lodge, 2006), *Left 4 Dead* (Turtle Rock Studios, 2008) and *Dead Nation* (Housemarque, 2010);


To quote Harold Varmus of the *New York Times*, “microbial plagues have displaced nuclear winter in the public’s mind of the way the world will end” (as cited in Lavin & Russell, 2010, p. 66).

The predictable worry-laden storyline of a-dangerous-and-threatening-contagion-
to-be-stopped often, if not always, underpins and, indeed, organizes (ever popular)
discussions of contemporary viral diseases (e.g., AIDS, SARS, West Nile, Avian Flu,
HIN1, the range of diseases/illnesses associated with ‘bioterrorism’): how we orient to
these, how we understand them, how we fear them, how we react to their presence and so
on. What is more, the ‘outbreak narrative’ also serves as a metaphoric way of
understanding and orienting contemporary ‘social problems’ – disruptive phenomena,
morally constructed as undesirable and even threatening.

In contemporary times we often hear talk of, for example, an ‘obesity epidemic’, a
And so on and so forth, ad infinitum. As Lavin and Russill (2010) point out, Americans
[and I think here we can also include all of us residing in the western and westernized
countries] have become increasingly prepared to view the world through the lens of
infection and contagion” and adopt a kind of, in their words, “‘epidemiological
imaginary’ in which individuals make sense of a time of spatial disruption through the
terms of infectious disease” (p. 66, my editorial). And so, it comes as no surprise that

autism, too, is widely articulated and so understood in contemporary times, as not only a
risk, but a particular kind of risk: a risk of epidemic proportions.

Prior to the winter of 2009-2010, the often cited ‘odd’ of having a diagnosis with
autism was, as we have seen, ‘1 in 150’. Over the course of that winter, however, two
major scientific studies were released with more timely statistical odds. According to a
major study published in Pediatrics, autism is now as common as ‘1 in every 91’
children, while according to a study published by the CDC, ‘1 in 110’ children have autism (Centers for Disease Control and Prevention, 2010; Kogan et. al., 2009). While the two studies did not agree on the precise ‘odds’, they did agree on some things: the odds of autism are increasing and this increase is undesirable. Around the globe, news of increasing odds was (and continues to be) reported as ‘shocking’, ‘staggering’, ‘striking’, ‘alarming’; sending ‘waves’ through autism communities everywhere. Just what is ‘shocking’ or ‘staggering’ about these numbers is not in question. Vis-à-vis these statistics, we know, immediately – tacitly even – that what is alarming is that autism’s prevalence is high, that its prevalence is too high, that its getting higher. It’s getting closer, it’s closing in. ‘Epidemic!’ advocates cried.

Responding to increasing prevalence statistics, Kelly Vanicek, boardmember of the National Autism Association, said "we hope these new numbers will create an immediate shift in priorities [...] this nation's children need the CDC's full attention, and we are again asking President Obama to declare autism an epidemic and a national health crisis” (National Autism Association, 2009, para. 3, 5). According to the CDC, “[Autism Spectrum Disorders] are conditions of urgent public health concern,” warranting a “coordinated response” (Center for Disease Control, 2010, p. 27). “Well these are staggering numbers,” said Autism Speaks co-founder Suzanne Wright, “it’s really incomprehensible [sic] to think that so many families...so many families...in our country are suffering with autism [...] this is a whole generation of children being lost to autism. This is not acceptable” (Autism Speaks, 2009d).

That autism is sweeping in on us, spreading through the population, immediately threatening to breach the thresholds of our loved ones is, often, underscored in dominant
discourses of autism advocacy through comparison and analogy. Critiquing the CDC’s failure to declare autism a national emergency, Ann Brasher, Vice-President of the National Autism Association evokes the 2009 H1N1 influenza outbreak, stating: "The focus on the propaganda-driven swine flu 'pandemic' is outrageous considering the very real epidemic of autism" (National Autism Association, 2009, para. 5). Similarly, in response to the release of the Kogan et al. study, Bob Wright (of Starbucks fame) stated: “The statistical aspect of autism is just staggering. If we had 1 in 58 boys getting swine flu, the country would be crazy” (Brooks, 2009, para. 3). Far from being merely examples of ‘bad’ analogies or instances of hyperbole – everyone knows autism is neither contagious nor fatal – we can trace out a kind of logic that permits their ‘sayability’, that permits us, in other words, to understand and refer to autism as an epidemic in everyday speech (Titchkosky, 2008). This logic ties us back to the contemporary ruling logic of the global(ized) free market.

In Empire, Michael Hardt and Antonio Negri (2000) write that: “along with the common celebrations of the unbounded flows of the new global village, one can still sense also an anxiety about increased contact and a certain nostalgia for colonialist hygiene” (p. 136). We can, perhaps, glean this so-called ‘nostalgia’ in the contemporary neoliberal fixation with (and production of) a vast variety of risky ‘social problems’ ranging from (including the ‘social problem’ of untimely individual and social development). If, in colonial times, problem bodies were understood and devalued via discourses of pathology (as we saw in chapter 4), in a fast-paced, always moving, border-hopping, forward-thinking, globalized and globalizing neoliberalism, problem bodies are, quite fittingly, understood via the logic of a moving pathology, the logic, in other words,
of the epidemic. In this way, following Hardt and Negri (2000), “the age of globalization is the age of universal contagion” (p. 136).

To consider this further, let us return to an important interpretive effect of the odd. As we have seen, functionally, a ratio is a relation: the 1 is not a one on its own, but rather exists in relationship with the 150 or the 91 or the 110. In this way, the statistical odd underscores the relationship between autism’s 1 and the whole of the population, touching these oppositions together. This is, indeed, the etymological root of contagion. Con-tagion: to touch together. In the ratio, as autism rates are understood to be increasing, the autistic ‘1’ stays the same, it is, rather, the non-autistic population that seems to getting smaller – 149, 109 and so on. The ratio works, in effect, to structure a rivalry or competition – a kind of foucauldian ‘agon’ or contest – between constructed oppositions: autism/non-autism, pathology/health, underdevelopment/ development, cost/benefit (Foucault, 1980, p. 207).

The logic of the ratio goes as follows: as an (undesired) autistic population gets bigger, the (desired) non-autistic population is compressed. As autism demands (costly, timely) resources, those valuable resources of the whole are diminished. As autism arrives late, the whole is held back. Autism, the logic continues, becomes some ‘thing’ that ‘for the ‘good’ of (or even, in some rhetoric, the ‘health’ of) the (normative) whole – “civil society”, perhaps – must be suppressed. In this way, the work of advocacy in contemporary times often gets taken up as the work of protecting, preserving or recovering non-autism; the normative and normativizing work, in other words, of (biological) securitization.

The logic of (free) competition – a logic that is shared, incidentally, by both global
capitalism and contemporary discourses of contagion – delivers us security as a necessary response (Foucault, 2009, p. 48). Faced with the risk of a spreading contagion that threatens the health of the body, we take (security) measures to lower our risk. We wash our hands, sneeze into our sleeve, wear a condom and so on. Faced with a risky stock, we also take measures. We lower our risk portfolio, protect our investments. What is more, when we are working to secure something – be it bodies or assets or body-assets – we do not wait until tomorrow, next week, next year. The flailing-armed, blackberry wielding, fast-talking traders on the floor of the New York Stock Exchange cannot be accused of taking it easy. The World Health Organization did not inform the public that they would figure out how to respond to H1N1 when they got back from their summer holidays. When confronted with a free roaming, fast-acting, uncontrolled risk, we install security measures. And we do it, now.

As is evidenced in the examples throughout this chapter, discourses of autism advocacy are often situated, in contemporary times, at the point where the logics of contagion and the market converge\textsuperscript{15}. And as the story of autism gets grafted onto the times of capitalism and outbreak, autism’s meaning gets transformed into a too-quickly spreading epidemic of too-slow bodies to be left behind by an accelerated liberal modernity. This hybrid story of autism conjures a very particular temporality that, in turn, works to speed up the s/pace of autism advocacy, producing a frenzied sense of urgency: a temporality that sweeps advocate and advocated for up, shapes their meanings, endows them with particular im/possibilities

\textsuperscript{15} Nowhere is this more clear than in the words of one parent: "Our son has been on a 4 year recovery journey that was not like a ramp but more like the stock market, with times of plateaus and regressions, usually preceding advancement" (Autism Speaks, 2010a).
Within dominant discourses of autism advocacy, the autistic subjectivity – located, simultaneously, in the perpetual past (e.g., developmentally too-slow and always late), and the future (e.g., yet-to-be developed) – is discursively foreclosed from being in the privileged and agentive time of the ‘now’. Via a kind of time-sensitive investment logic, autism is understood not as a being but as a happening – a costly body, a disruptive threat, a risky trend and so on – a happening, moreover, that is happening fast. Every 20 minutes. Vis-à-vis understandings of drawn out pasts and dwindling futures, the neoliberal ‘now’ becomes the time for responding to autism’s perceived ‘happening’. It is a time for action and reaction. Yet, paradoxically and as we have seen throughout this chapter, such timely actions and reactions are regulated (and regulating) – surveil particular kinds of behaviours, notice particular behaviours as signs of ‘deviance’, discipline and restrict these behaviours, seek out biomedicine to ensure timeliness – but they are also entrepreneurial, creative (and creating) – uncover more ways of noticing and charting the minutia of human difference, generate more ways of classifying behaviours as ‘abnormal’ or ‘deviant’, come up with more and more ways of treating or preventing autism, more and more ways of raising awareness about its pathological state of underdevelopment. As it, both, stimulates and regulates conducts beyond the norm, the neoliberal ‘now’ is a (lucrative) time for autism advocacy par excellence16.

But, this is not the only demand of the urgent imperative. To follow Slavoj Zizek (2008): “there is a fundamental anti-theoretical edge to […] urgent injunctions. There is no time to reflect: we have to act now” (p. 6). Now is a temporality that forecloses the,

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often slow, or not time-efficient, possibilities of contemplation, critical thinking, debate, deliberation and, in so doing, functions to normalize and even naturalize neoliberal discourses in which notions of rights and understandings of (good) life are mediated and even determined by one’s timely ability to “fully” partake in and “enjoy” market-driven processes of production and consumption. Moving more slowly – being untimely as it were – permits us to notice still another risk; a risk that is, itself, animated by understandings of autism as a risk to be secured. What the examples in this chapter present to us is the risk of ‘better futures’ where bodies must keep pace with the unyielding tempo of the market or be left behind. And, most significantly, the ‘better futures’ being envisioned are futures without autism’s difference. Throughout this chapter, we have seen how – to borrow from Roger Stahl’s (2009) discussion of evocations of urgent temporalities in the US ‘war on terror’ – “dominant voices use temporal rhetorics to shape a public environment hostile to deliberative possibilities”, creating a temporal environment of control that is, he argues, a central characteristic of war discourses (p. 74). I turn now to a critical consideration of the strategies and tactics of representation that have emerged out of what has often been referred to as advocacy’s ‘war on autism’.
CHAPTER SIX

“We Have Your Son...”: Frames of Terror in Advocacy’s ‘War on Autism’

We are a community of warriors.


This way of life is worth defending.

- George W. Bush (March 19th 2004), Remarks on the Anniversary of Operation Iraqi Freedom

Whose lives count as lives?

- Judith Butler (2004), Precarious Life: The powers of mourning and violence, p. 20

I begin this chapter with a story of the production, circulation and the subsequent retractions of three high profile contemporary autism advocacy campaigns. I engage in this process of re/telling so as to collect these seemingly isolated enactments of autism advocacy into a kind of autism advocacy ‘genre’ and to expose an underlying logic that binds the genre together: a global and globalizing logic of terror and terrorism particular to the contemporary historical moment. Admittedly, the three central campaigns I cite – and the discourses of terror and terrorism that follow these – are born of a US context.
However, as was evidenced in Chapter 5 and as we shall see again in this chapter, under neo/liberalism, US discourses of autism – and, of course, terror – are relentlessly and meticulously being exported around the globe.

**Terrorizing Autism**

In the summer of 2005, the Autism Society of America (ASA) unveiled a “new arm to fight autism”, a “jarring new initiative” entitled “Getting the Word Out” that was, according to a press release, aimed at “combat[ing] the rising statistics of autism diagnosis” by “talk[ing] about the harsh realities of living with Autism Spectrum Disorders” (Autism Society, 2005a, para.1). To this end, an elaborate new website was launched, complete with a dramatic opening *FLASH* sequence that features a tragically grayscale photograph of what appears to be a small child with his parents (Fig. 6.1). To the far left of the photographic frame, two adults – a man and a woman, both people of colour – appear with their backs facing one another. Their postures and the expressions on their faces suggest upset, worry, exhaustion and concern. To the far right of the frame is a young, racialized child with his head resting in his hand. The boy stares pleadingly at the viewer: his body deflated and hopeless, his eyes wide with sadness.

The *FLASH* sequence begins as a small tear is made in the top edge of the photograph. And then, the following statement appears: “1 in 166 children are born with it”. The photograph tears a little more, and then the words: “24 000 will be diagnosed with it this year”. The tear extends deeper into the photograph, now beginning to cleave the parents from the child. “It is more common that multiple sclerosis, cystic fibrosis and childhood cancer. Combined”. Tear. ”It is growing at a rate of 10-17% each year”. Tear. “Currently there is no cure for it”. And as the tear reaches the bottom edge of the
photograph, the words: “It can tear a family apart.” The sequence ends as the left side of the photograph – the side with the image of the parents – is completely torn off and discarded. Only the torn image of the boy remains, and the words: “It is...autism” (Autism Society, 2005a). This opening sequence delivers us into the website’s inner pages, which provide further details about the presumed origin of torn families and ripped photographs, information about, in other words, autism.

The section ‘Autism 101’ (Fig. 6.2) provides readers with information quite similar to the likes featured in other advocacy campaigns examined in previous chapters (Autism Society, 2005b). Reminiscent of the ‘red flag’ campaigns explored in Chapter 4, the webpage presents readers with biomedical ‘evidence’ of autism’s pathology. Readers are informed, for example, that, “autism is a neurological disorder that effects the functioning of the brain impacting the normal development of the brain in the areas of social interaction and communication skills” and “children and adults with autism typically have difficulties in verbal and non-verbal communication, social interaction and leisure and play activities...” (Autism Society, 2005b, para. 1). And, much like the ‘odds’ campaigns explored in Chapter 5, the site cultivates a growing sense of urgency by offering viewers statistical evidence of swelling numbers of autism diagnoses in collapsing temporal/spatial frames. “Roughly 1 out of every 166 children is diagnosed with Autism Spectrum Disorder” the text from the webpage tells us, “that’s 66 children per day, nearly three an hour, one every 20 minutes...” (Autism Society, 2005b, para. 2).

Next to this biomedical and statistical information – facts that, as we have seen, work to frame autism as nothing more than a common deficit and a spreading pathology – another key piece of information is entered into evidence. The webpage features one
Figure 6.1: Detail of Autism Society of America’s (2005) ‘Getting the Word Out’ campaign website. Photograph by Eduardo Trejos. Reprinted with the artist's permission.
Figure 6.2: Detail of ‘Autism 101’ webpage from the Autism Society of America’s (2005) ‘Getting the Word Out’ campaign website. Photograph by Eduardo Trejos. Reprinted with the artist's permission.

Figure 6.3: Detail of Autism Society of America’s (2005) poster for the ‘Getting the Word Out’ campaign. Photograph by Eduardo Trejos. Reprinted with the artist's permission.
half of a torn black and white photograph – much like the one from the opening sequence – of what appears to be a young, white (presumably autistic) girl\(^1\). The girl in the photo is collapsed into a ball, her bare toes curled inward and her face obscured, buried in her knees. She is pictured cowering against a non-descript wall and tightly clenching a stuffed toy. Based on the opening animation, we must assume that this terrified, crumpled girl in the torn image has been wrenched away from those who love her, and – corralled within the tight confines of the photographic frame – she appears held captive by an unknown, but not unnamed, aggressor. Recalling the opening sequence, “it is autism”\(^2\).

The text adjacent to the photograph confirms her captors identity, providing viewers with a kind of behavioural profile: “Autism knows no racial, ethnic or social boundaries” the text reads, “it doesn’t care how much money you make, what kind of lifestyle you lead or what your education level is. For more information on understanding autism, treatment and/or education, please visit [the ASA website] autism-society.org” (Autism Society, 2005b, para. 3). Finally, at the very bottom of the page, the statement: “Helping to get the word out”.

In the ‘Getting the Word out’ campaign – which belongs, as we shall see, to whole genre of similar campaigns – autism is not, strictly, characterized as some ‘thing’ – a series of pathological behaviours, for example, or a risky statistic – and is surely not understood as a some ‘one’ – a viable embodiment, a way of being, an identity. Out of a normative background image of (heterosexual, nuclear) family and childhood innocence,

\(^1\) And, as Kathleen Seidel importantly notes in *Neurodiversity: A Weblog*: “We do not know whether the girl is afraid of the photographer, or whether she wishes to be photographed. We do not know whether she has been paid for the use of her image” (Seidel, 2005b, para. 8).

\(^2\) The notion of autism as captor permeates the ‘Getting the Word Out’ campaign materials. For example, Fig. 6.3 displays a poster from the campaign featuring a young, shirtless boy seemingly cowering in the shadows with a gag over his mouth. Additionally, the typography used in the ‘Getting the Word Out’ logo is reminiscent of the piece meal composition of a ransom note.
autism emerges as a threatening ‘Ripper’ figure, a ‘tearer’ of photos and families. And as it tears, this figure of autism terrifies and terrorizes: pulling apart families, isolating children from their loved ones, holding (what we must presume to be otherwise non-autistic) kids captive. Autism is made faceless, hidden and ubiquitous, lethal and out of control. One part biology – striking at the body indiscriminately and spreading quickly (“Roughly 1 out of ever 166 children is diagnosed with Autism Spectrum Disorder. That’s 66 children per day, nearly three an hour, one every 20 minutes...”). One part (a)morality – cruel and uncaring, unmoved by the fiercely guarded social boundaries of privilege and position (“Autism knows no racial, ethnic or social boundaries. It doesn’t care how much money you make, what kind of lifestyle you lead or what your education level is”). Autism is delivered to us, then, as an anthropomorphized threat. Half metaphor. Half corporeal. And very real.

This terrifying and terrorizing figure of autism solicits the emergence of still another figure, and an oppositional one. Out of the metaphorical scene of the tear, and in opposition to the tearing, terrifying and terrorizing figure of autism, materializes a very particular figuration of autism advocacy. In the ASA’s ‘Getting the Word Out’ campaign, the figure of the advocate – the viewer of the photograph – is framed as witness to autism’s terrible deeds, a neutral (and so, necessarily non-autistic) bystander who happened upon the scene of autism’s crime. Vis-à-vis captive children and torn up families, the figure of the advocate is therefore framed as he who should help, she who should intervene, they who ought to defend innocence and protect families by ‘getting the word out’ about this threatening figure of autism: what it looks like, how it behaves, where it hides, how to treat it.
The campaign, which was powerfully met with cries of protest by many autistic activists and bloggers\(^3\), ended in the summer of 2007. Though it was never formally retracted, its controversial website was taken down from the web.

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In the winter of 2007, a few months after the ‘Getting the Word Out’ campaign was dismantled, New York University’s Child Studies Center (CSC) launched another controversial public awareness campaign, entitled ‘Ransom Notes’. Appearing on billboards, kiosks and in various online and print media sources, the campaign materials were aimed to “[alert] Americans to the silent public health epidemic of children’s mental illness” (New York University, 2007b, para. 1). Fig. 6.4 depicts the ‘umbrella advertisement’ released by the CSC, which displays a towering urban billboard in the form of a large ransom note. The note’s text – composed of words that appear to have been cut out from a variety of different print sources and pasted hurriedly together – delivers the message, “12 million kids are held hostage by a psychiatric disorder” (New York University, 2007a). The campaign referenced various ‘psychiatric disorders’ including Attention Deficit and Hyperactivity Disorder, bulimia, depression and Obsessive Compulsive Disorder. Autism, too, was featured in the ‘Ransom Notes’ campaign, appearing in two separate advertisements.

\(^3\) Most notable of these campaigns of protest was, perhaps, Amanda Baggs’ brilliantly disruptive counter campaign ‘Getting the Truth Out’ (Baggs, 2005). Baggs’ launched a website that, via a slideshow of words and photographs, draws out the representational modes and tactics used to characterize autism in the ASA campaign and politicizes these images by bringing them into a tense contact with self-portraits and personal narrative, an approach which effectively worked to unsettle the ASA campaign by exposing its representational tactics as both oppressive and stigmatizing.
Figure 6.4: Detail of New York University Child Study Center’s (2007) ‘Ransom Notes’ campaign umbrella advertisement, photograph by Eduardo Trejos. Reprinted with the artist’s permission.

Figure 6.5: Detail of New York University Child Study Center’s (2007) ‘Ransom Notes’ campaign poster, “Autism” and “Asperger’s Syndrome”, photograph by Eduardo Trejos. Reprinted with the artist’s permission.
“We have your son.”, declares one such print advertisement (fig. 6.5). The advertisement, which was designed to look like a typed ransom note, continues:

“We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” The note is signed: 'autism' (New York University, 2007a). Fig. 6.5 also depicts another NYU CSC advertisement. Similar to the previous one, this advertisement is also made to look like a ransom note and begins with the terrifying pronouncement “we have your son”. Its message, which appears to have been hastily scrawled by hand, continues: “we are destroying his ability for social interaction, and driving him into a life of complete isolation” (New York University, 2007a). This time, the note is signed: “Asperger’s Syndrome”. Superimposed at the bottom of both ransom note advertisements is the NYU CSC logo and the statement: “Don't let a psychiatric disorder take your child. The NYU Child Study Center is dedicated to giving children back their childhood by preventing, identifying, and treating psychiatric and learning disorders” (New York University, 2007a).

In ‘Ransom Notes’ we encounter, once again, the anthropomorphized threat from the ‘Getting the Word Out’ campaign. The terrifying and terrorizing figure of autism has struck again: Still aggressively ripping apart families. Still faceless, still hidden, still lethal and still out of control. And, as such, still generating the need for an oppositional figure of the advocate who should take action not for autism, as the term “autism advocacy” might seem to suggest, but against it. Yet, the background story out of which these two figures emerge has been slightly altered in the ‘Ransom Notes’ campaign, alterations that invariably work to shape and re-shape the figures of autism and advocate anew.
In ‘Ransom Notes’, autism’s crime hits closer to home, its more personal now, more intimate. The ransom notes are addressed to a ‘you’. No longer a third party bystander merely witnessing autism’s crime, the figure of the advocate is now framed as one of autism’s many victims. “Your” (presumed non-autistic) child has been ripped away from you and is now in the grasp of a masked villain (autism) who means him great harm, who intends to leave him isolated and alone, starving him of social interaction for as long as he lives. And, “this is”, promises the figure of autism, “only the beginning”.

Vis-à-vis a threatening and violent figure of autism that is attacking and attacking close – tearing apart not just any family but your family, taking not just any child but your child – the figure of the advocate can no longer be s/he who should act, but is reformed and reborn as s/he who has no choice but to act. In ‘Ransom Notes’, the viewer is confronted with a veritable ultimatum issued by the NYU CSC4: “Don’t let a psychiatric disorder take your child”. With “your” child’s life on the line, it is no longer enough to merely “help” to “get the word out” about autism’s pathology or its rates of growth, the figure of the advocate is now positioned to embark upon a kind of reconnaissance mission aimed a ‘recovering’ a ‘taken’ child - a, necessarily, non-autistic child – from behind autism’s (enemy) lines. As a way of “giving children back their childhoods”, the advocate must, according to the campaign, search autism out, ‘identify’ it, ‘treat’ its pathology and ‘prevent’ any future harm its presence invariably promises.

Shortly after this campaign was launched, and following political action from an outraged autistic community, the NYU CSC decided to retract the campaign (New York University, 2007c).

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4 Interestingly and most ironically, the NYU CSC’s demand is the only demand made in these ransom notes...
In the fall of 2009, a year and a half after the ‘Ransom Notes’ campaign was taken down, Autism Speaks produced a strikingly similar initiative, this time in the form of a short film entitled “I am Autism” (Cuarón, 2009). The film, which was written by Grammy-nominated songwriter Billy Mann and directed by Academy Award-winning director, Alfonso Cuarón – both parents of autistic children – premiered to an audience of 150 first spouses and dignitaries from across the globe gathered for the Second Annual World Focus on Autism to raise greater awareness about the global “autism epidemic” (Autism Speaks, 2009c). The film is divided into two carefully choreographed parts.5

The first part of the film features home video footage of individual autistic children, each filmed alone. A small boy sways at home plate, looking around without apparent focus or purpose with a blue plastic baseball bat idly propped on his shoulder. Another boy is at the beach, buried up to his chest in sand. A young girl repetitively runs her hands back and forth over a placemat. A man at the beach stands still looking down on a village of sandcastles and so on. The isolated images are tied together by an ominous horror-film style soundtrack – complete with hollow echoes of children’s cries – and the

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5 In an Autism Speaks press release entitled “Do you want to be in a World Autism Video?”, the organization makes an appeal to families who have autistic children to submit home video footage of themselves and their children for potential inclusion in Cuarón’s film. The press release issues very detailed instructions (complete with sketched illustrations) as to what kinds of scenes the organization will accept. “We need three video clips per submission,” the press release states, “The first clip is: A person on the spectrum wearing a plain white t-shirt filmed alone in a place that is special to your family. It can be landmark (Eiffel Tower, Big Ben, etc.) skyline, town square, backyard, schoolyard, amusement area or somewhere else of your choosing, The second clip we need is: Have the same person stand in the same spot this time surrounded by family members. All the people in the shot should be wearing white T-shirts. Please film both shots in the same camera angle. The third clip we need is: Film closer angles of the family – interacting, smiling, holding hands, hugging etc.” I highlight the carefully choreographed nature of the film so as to emphasize the extent to which meanings of autism are made in this and, indeed, any advocacy initiative (Autism Speaks, 2009b)
deep and sinister voice of “autism”. The voice rumbles:

I am autism. I’m visible in your children, but if I can help it, I am invisible to you until it’s too late. I know where you live, and guess what? I live there too. I hover around all of you. I know no color barrier, no religion, no morality, no currency [...] I move very quickly. I work faster than pediatric AIDS, cancer, and diabetes combined [...] And if you are happily married, I will make sure that your marriage fails. Your money will fall into my hands and I will bankrupt you for my own self-gain. I don’t sleep, so I make sure you don’t either. I will make it virtually impossible for your family to easily attend a temple, a birthday party, a public park, without a struggle, without embarrassment, without pain [...] I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope. I will plot to rob you of your children and your dreams [...] And the truth is, I am still winning, and you are scared, and you should be. I am autism. You ignored me. That was a mistake. (Cuarón, 2009, for full transcript of the ‘I am Autism’ film, see: Appendix B)

We can recognize, immediately, this disembodied voice. We have ‘heard’ it before in typed words and in torn up images. This, we know, is the terrifying inflection of the ‘tearer’ of family photographs, the architect of ransom notes and it is still threatening the family, still hiding in the shadows. Like the ‘Ransom Notes’ campaign and the ‘Getting the Word Out’ campaign before that, ‘I am Autism’ evokes a familiar background story ripe with childhood innocence and the purity of (normative versions of) family and it is out of this pleasant scene that the figure of autism emerges as a threat. Yet, let us note,
once again, the key changes in the telling of the story of this terrorizing figure and its terrifying transgressions.

‘I am Autism’ is narrated from autism’s own perspective and, so, the viewer is offered an intimate glance at the inner machinations of the mind of this monstrous figure. Still ensuring a personal tie with the viewer advocate – still addressing a ‘you’ – the figure of autism draws ‘you’ closer still. Unlike previous campaigns, in the film, the figure of autism speaks (pun intended). And, while photographs and notes tell us little of proximity, the voice is always near by. Autism lurks close. Maintaining the shape of a hostage taker, as seen in previous campaigns, autism, thus, takes on the added dimensions of a kind of stalker: autism is next door or, even, in your very home. It is watching your family movies, intimately, malevolently plotting its next transgression.

And, most disturbingly, in ‘I am Autism’, we are confronted with an autism that is growing bolder, its words are not merely addressing the viewer advocate but are taunting him/her. ‘Happily married?’ Autism jeers, ‘I’ll fix that’. ‘Have money?’ it hisses ‘not for long.’ “I’m still winning”, provokes autism, and you can’t stop me. In this way, the figure of autism formulates a kind of challenge, shaping up a novel version of advocacy that takes up the role of adversarial opponent, the role of warrior. As the terrifying and terrorizing figure of autism devolves, the figure of the intervening advocate evolves. And necessarily so.

The second part of the ‘I am Autism’ film shifts dramatically in tone and tempo. The hollow children’s cries are replaced with full-bodied giggles, the eery percussion traded for an upbeat tempo of a guitar being plucked, the singular menacing voice called
“autism” silenced by a chorus of voices called “advocacy”. Those same children who, moments earlier, appeared alone, are now seen surrounded by family. As she is tickled by her mother, the little girl’s hands stop their repetitive movement; a brother or a friend drapes his arm around the boy buried in the sand; the kid playing baseball, now focused and smiling, is seen with a whole family behind him, cheering him as he readies himself to hit the ball. Accompanying these happy images is a medley of voices of advocates that seem to recollect the CSC’s admonition, “Don't let a psychiatric disorder take your child”. And take it further still:

And to autism, I say: I am a father, a mother, a grandparent, a brother, a sister. We will spend every waking hour trying to weaken you [...] I am a parent riding toward you, and you can push me off this horse time and time again, but I will get up, climb back on, and ride on with the message [...] Autism? You forget who we are. You forget who you are dealing with [...] We are Qatar. We are the United Kingdom. We are the United States. We are China. We are Argentina. We are Russia. We are the European Union. We are the United Nations [...] We are coming together in all climates. We call on all faiths. We search with technology and voodoo and prayer and herbs, genetic studies and a growing awareness you never anticipated [...] We speak the only language that matters: Love for our children. Our capacity to love is greater than your capacity to overwhelm [...] We are a community of warriors. We have a voice. You think that because some of our children cannot speak, we cannot hear them? [...] You think that because my
child lives behind a wall, I am afraid to knock it down with my bare hands? [...] Autism, if you are not scared, you should be. (Cuarón, 2009, for full transcript of the ‘I am Autism’ film, see: Appendix B)

As the figure of autism is seen to be devolving in the three campaigns described above – as it is depicted as an entity that is growing bolder, hitting harder, moving closer – let us also note how the figure of the advocate, too, is changing; its own oppositional figure shaped anew. Over the course of the three campaigns, we have watched as this figure has shifted from the shape of a neutral witness charged with the task of helping to spread the word about autism’s criminalized deeds, to an invested victim who has no choice but to protect and defend against this figure, and now finally, to a victim-no-longer; to, in other words, a militant warrior who not only (reactively) defends and protects, but who is (actively and, even, pre-emptively) engaging in battle. I would like to mark out these latest – and very related – figural incarnations of a terrorizing-autism and its advocate-warrior, for further exploration in the pages to follow.

As with the first two campaigns detailed earlier, the premiere of the ‘I am Autism’ film was met with an eruption of protest from the Neurodiversity movement. A petition circulated by the Autism Self-Advocacy Network (ASAN) accumulated thousands of signatures, a grass-roots internet protest against Autism Speaks swept around the globe and ASAN president Ari Ne’eman’s condemnation of the film was discussed in Time Magazine (Wallis, 2009). A YouTube video parodying the film – “I am Autism Speaks” – was circulated across the internet (“I am autism speaks”, 2009). In response to this negative reaction, Autism Speaks, almost immediately, removed the video link from their website.
Offense and Apology

In the three autism advocacy initiatives detailed above, we are introduced, re-introduced and introduced again to a terrifying and terrorizing figure of autism. Indeed, the ‘Getting the Word Out’ website, the ‘Ransom Notes’ advertisements and the ‘I am Autism’ short film work to sketch out a kind of ‘composite image’ of a dangerous figure, highlighting various key characteristics to facilitate quick and easy recognition and identification. The campaigns assert: ‘Look at this figure of the ripper, this hostage-taker, this stalker. Observe its malevolent ways, scrutinize its immoral intentions, witness its devastating wake: this IS autism’. As we have seen, vis-à-vis such assertions, various interested and implicated folks came together in response to these campaigns and importantly declared this figuration of autism to be inaccurate, inflammatory, oppressive and, even, dangerous.

In resistance to the propagation and promotion of a figure of autism who terrifies and terrorizes, we said: autism is not and should not be likened to a morally maligned villain stealing children and ruining lives. This is not what autism is. Autism is not kidnapping a child, *autism is a child* (or an adult, for that matter!). It is not “destroying” a person’s ability for “social interaction”, social interaction is precisely that: a social occurrence negotiated between people, autistic and non-autistic alike. Such figurations of autism are wholly inaccurate and all wrong: these are not what...who autism is. Autism is, rather, a viable and valuable way of being in the world: a legitimate perspective, a meaningful way of communicating, an identity. These campaigns represent, we argued, a case of mistaken identity. Autism is going down, in other words, for a crime it did not commit.
Yet, to say that the figuration of autism in these campaigns is merely inaccurate – a case of mistaken identity – places us squarely in the middle of an empirical debate. And, interestingly enough, both Autism Speaks and NYU’s Child Studies Center oriented to and, indeed, relied upon this notion of public debate as a tactic to quickly and effectively diffuse and depoliticize the critical responses to their respective campaigns. For example, in a press release announcing the retraction of the ‘Ransom Notes’ advertisements issued by the CSC (see, Appendix C), the center’s director, Dr. Harold Koplewicz, framed up the campaign as nothing more or less than a hotly debated ‘topic’: “While many people praised the campaign and urged us to stay the course” Koplewicz stated, “others were troubled by it” (New York University, 2008, para. 2). Autism Speaks executive president Peter Bell took a similar approach in framing the critical responses to the ‘I am Autism’ film. In an interview with Time Magazine, Bell is quoted as saying that while the video received many “positive” responses from the autism community, “we realized it did hurt a certain segment of the population, which is why we removed the video link from our website” (Wallis, 2009, para. 6).

Such is the nature of an empirical debate: Some are ‘for’, while others are ‘against’. Some consider autism to be terrorizing children and families while others believe it to be a valuable and viable way of being in the world. Some have been empowered by the “jarring” advocacy initiatives, while others were offended. And, the logic extends, in the end, we are all entitled to our opinion. Yet, we must note, how this notion of equal opinion and debate frames up dominant ideologies and acts of resistance to these ideologies as if on even political terrain, an interpretive move that both effaces the uneven nature of the power structures grounding dominant ideologies and discourses
of autism and depoliticizes acts of resistance to such ideologies and discourses. This strategy castes critical voices of dissent as, merely, ‘opinions’ that we may or may not agree with, thus making it possible to dismiss them entirely.

Political acts of contestation and resistance – acts of contestation and resistance that were (and continue to be) led, we must note, by autistic people, for autistic people – were, thus, transformed in the campaign retractions into mere ‘opinions’, a ‘side’ in a good old fashioned debate. And while generating debate was, certainly, a central objective of these and similar campaigns – as Koplewicz stated, “we wanted a campaign that would grab people’s attention, break through the clutter, and serve as a wake up call to what we believe is America’s last silent public health crisis” – the decision to dismantle the campaign was taken as (too) “much of the debate centered on the ads instead of the issues” (New York University, 2008, para. 1, 2).

Following Koplewicz’s line of reasoning, the central problematic of these campaigns was not the moral figuration of autism as a vicious and violent hostage-taker, it was not the problematic discursive figuration of autism as somehow separate from the autistic person, nor was it the repetition and propagation of a dominant ideology that re/asserts that life with autism’s difference is a terrifying and terrible life indeed. Rather the problem with the campaign was understood as nothing more or less than an instance of poor delivery. As Koplewicz suggests with respect to ‘Ransom Notes’, what was creating ‘too much debate’ was the advertising vessel carrying the campaign’s message – the posters and billboards, their bold new design etc. – and not the message itself. This understanding, of course, works to re-iterate and affirm the campaign’s central message – that autism is taking away the lives of children and terrorizing loved-ones – as, itself,
non-debatable. It, thus, became possible to, simultaneously, announce the campaign’s retraction, express regret about the “hurt” and “offense” it caused “a certain segment”, while all the while repeating the message: ‘psychiatric disorders’ rip children away from their families. This message is quite evident in the NYU press release as it concludes by stating: "we would like to move forward and harness the energy that this campaign has generated to work together so that we do not lose one more day in the lives of these children" (New York University, 2008, para. 4, emphasis mine). And so, even as the billboards were taken down and the advertisements plucked from circulation, it was, to use the language of the ransom note ‘too late’: very particular figures of autism and advocacy were, once again, fortified and released into our culture. And, as we have already seen, we continue to encounter these figures again and again, in slightly altered form.

Faced with figurations of autism that, at once, pathologize, dehumanize, criminalize and stigmatize autistic people, direct opposition is, of course, absolutely necessary. We must condemn these campaigns, point to their deficiencies, and unequivocally demand that they be taken down. Yet, as crucially important as such strategies of resistance are, it is evident that something is not quite working. As I described earlier, just as the Autism Society of America took down their ‘Getting the Word Out’ campaign, the ‘Ransom Notes’ campaign was put into circulation. As NYU very publicly retracted their ‘Ransom Notes’ campaign, the ‘I am Autism’ Film saw its first screening. And even after the link to the ‘I am Autism’ film was removed by Autism Speaks from their official website, that film, along with other advocacy initiatives using explicitly similar tactics, remain in
circulation at the time of this writing⁶.

The critical question becomes: in the midst of repeated cycles of reaction and retraction, offense and apology, what new strategies of resistance can be adopted so as to both contest and permanently dislodge this damaging figuration of autism? One way to proceed is to not only point out the glaring mischaracterization of autism but to also and simultaneously engage in an analysis of how such a mischaracterization has been and continues to be made possible. If autism is, indeed, going down for a crime it did not commit, we must then ask: how is autism being ‘framed’?

**Framing Autism**

Frames direct our gaze, guide our perception. The ‘frame’ is that which marks the limits of a scene, it is all that lies along the edges of a “phenomenal field”, to borrow Merleau Ponty’s term (Merleau Ponty, 2002, p. 60). In this way, ‘to be framed’ is a prior condition of any appearance. “Whatever appears” writes Titchkosky (2007), does so only and always insofar as it is “conditioned by the possibility of appearance” (p. 17). There can be no appearance, no image, no phenomenon, no figure in the absence of a conditioning frame; that (shifting, contingent) scaffolding that comes before and rests beneath a phenomenal field – that which anticipates it, collects it, renders it intelligible.

Let us take the example of a classical painting. In classical painting, the frame demarcates, for the viewer, an essential whole of the painting. The painting is all that is

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⁶ We can look to, for example, a recent Public Service Announcement put into circulation by the Australia based *Autism Awareness Society*, which, once again, explicitly frames autism as a kidnapper of children (Autism Awareness, 2010).
collected inside the frame. In a 1639 letter, French painter, Nicolas Poussin, presents a theory of the classical frame. In a letter to a patron, he writes:

Once you have received your painting, I beg you, if you think it a good idea, to adorn it with some framing, for it needs it: so that when gazing at it in all its parts, the rays of the eye are retained and not scattered outside in the course of receiving the espèces of the other neighboring objects, which, being jumbled with the depicted things, confuse the light [or the space: confondent le jour]. It would be very fitting that the said frame be gilded, quite simply, with mat gold, for it unites very sweetly with the colors without clashing with them. (Poussin, 1639 quoted in Lebensztejn, 1988, p. 37)

For Poussin, the classical painting is not composed, in any essential way, of that which lies outside of the limits of the frame. The meanings that are attributed to its depicted image, in other words, are fundamentally not made of, in or by the spaces that display it, for example, or the viewers who find themselves before it, or the histories it was born of or the culture in which it invariably dwells. To the contrary, for Poussin, that which lies outside the limits of the framed painting is nothing more than a distraction that ‘jumbles’ and ‘confuses’ an originary image and its static meaning. If you wish to ‘look’ at the painted representation, Poussin suggests to his patron, look here, within the frame, and not elsewhere. The classical frame, then, as Poussin conceives of it, functions normatively by gathering and directing the ‘scattered’ gaze of the viewer. It is a construct that tames and regulates our lines of perception, guides our modes of recognition.
As he reminds us how processes of classical framing function normatively, Poussin also reminds us something of the character of such normative functions. He informs his patron that, while the frame is absolutely necessary to regulate the gaze, not just any frame will do. For Poussin, the frame must be self-effacing, inconspicuous. It should be, he writes, “gilded quite simply, with mat gold”. It must blend, in other words, with the background image of the painting itself, ‘sweetly uniting’ with its colors. Conceived of in this way, as Lebensztejn (1988) writes: “the [classical] frame acts as a scaffolding: once it has helped to build the depicted space, it should disappear as much as possible, so that the depicted space appears naturally self-contained” (p. 37). Thus, Poussin’s frame appears only to disappear. It normatively regulates space and perception, only to efface its own construct. And, as the frame is obscured, the image it frames and the organized character of our lines of perception and our modes of recognition are forgotten, reified as natural.

Much like the scene of a painting, or, indeed, like any scene at all, the ‘scene’ of autism advocacy is surrounded by (multiple) frames – historical frames, geo-political frames, economic frames, moral frames, frames of charity and frames of biology, frames of love and frames of war – frames that are integral to the scene they frame and that, as in Poussin’s version of the classical frame, function to direct and so regulate the ways in which we come to regard autism and advocacy. And, much like Poussin’s frame, the cultural frames encasing discourses of autism advocacy, too, very often escape our attention, ‘sweetly uniting’ with – and so disappearing into – the colorful, taken-for-granted landscape of everyday life. As interpretive frames dissolve and disappear,
dominant ways of regarding autism and advocacy are, very often, rendered natural, transforming from socio-political construct to, very simply, the way things are.

“To call the frame into question” Butler writes, “is to show that the frame never quite contained the scene it was meant to limn, that something was already outside, which made the very sense of the inside possible, recognizable” (Butler, 2009, p. 9). In the midst of disappearing frames and naturalized, taken-for-granted understandings, the critical task, then, according to Butler, is to connect the scene before us – the scene of autism advocacy, for example, or the figures that dwell in this scene – to the oft taken-for-granted interpretive frames that contain these and give them shape and possibility.

While, as we have seen, ‘to be framed’ is a prior condition to any appearance – recall Titchkosky’s assertion that “whatever appears, is conditioned by the possibility of appearance” – we must, nonetheless, give an account for the kinds of frames that are installed around certain scenes or certain figures and for how these frames differentially allocate and deny power and privilege. Judith Butler (2009) reminds us:

‘To be framed’ is a complex phrase in English, a picture is framed, but so too is a criminal (by the police) or an innocent person (by someone nefarious, often the police), so that to be framed is to be set up, or to have evidence planted against one that ultimately ‘proves’ ones guilt […] if one is ‘framed’, then a frame is constructed around ones deeds such that one’s guilty status becomes the viewer’s inevitable conclusion. (Butler, 2009, p. 8)

While contesting the validity or accuracy of a given figuration often provokes, as we have seen, the infinite regress of an empirical debate, thinking of the figure as framed – to
‘frame the frame’ to borrow from Trinh Minh-ha (1992) – both accounts for the situated ways in which certain bodies are produced as always and already guilty and opens up space for critically attending to and engaging the multiple social processes, or interpretive social frames, that work to regulate our perceptions and structure our modes of recognition such that, from Butler, a ‘guilty status’ becomes an ‘inevitable conclusion’ (Butler, 2009: 8). One such interpretive frame is the frame of liberal biopolitics.

**Frames of Life**

Michel Foucault observes that liberal rule is, firstly, characterized by and invested in life; its promotion, management, securitization and optimization (Butler, 2004a; Butler, 2009; Foucault, 1997; Rose 2007). In the first volume of *The History of Sexuality* (1990), and later, in a series of lectures at the Collège de France in the mid-seventies (1997), Foucault turns to a consideration of the unique properties and tensions associated with modern liberal technologies of rule and the simultaneous emergence of a particular form of modern power: biopower. He begins this consideration by tracing out how liberal ruling relations are distinct from previous technologies of rule, namely, the rule of the sovereign.

Foucault observes that under sovereign rule – a social system of governance where power is possessed by a singular ruler or group of rulers and is negatively wielded over subjects – a ruler’s power is defined by a “right of seizure: of things, time, bodies, and ultimately life itself” (Foucault, 1980, p. 136). Endowed with the right to, in Foucault’s words, “let live” or “take life” (Foucault, 1997, p. 241), the sovereign ruler ultimately exercises his power by deciding which of his subject’s lives must be taken, a
power which also and indirectly decides which of his subjects lives might be let alone, permitted to thrive. The subject’s relation to the sovereign, then, writes Foucault:

...is, by rights, neither dead nor alive. From the point of view of life and death, the subject is neutral and it is thanks to the sovereign that the subject has the right to be alive, or, possibly the right to be dead. In any case, the lives and deaths of subjects become rights only as a result of the will of the sovereign (Foucault, 1997, p. 240).

However, this seeming equilibrium, Foucault reminds us, is not a balanced one: the rule of the sovereign over his subjects is a rule always and inevitably “tipped” in favour of death (Foucault, 1997, p. 240). The power to “let live” is, in other words, defined by and reliant upon the sovereign’s power to “take life”. The power invested in the sovereign, in other words, is a morbid power ultimately defined and determined by the sovereign’s right to kill. Under sovereign rule, life is not assured, but is, rather, something that is permitted. One lives because the sovereign (power) has not yet exercised his endowed right to kill; one lives because one is allowed to live.

Conversely, Foucault argues that the 18th century witnessed an important transformation in the way power came to be exercised over the subject. Though it has not been altogether replaced, sovereign power is, in modern times, complimented by a new biopolitical exercise of power. “The right of sovereignty was the right to take life or let live” writes Foucault, “and then this new right is established: the right to make live and to let die” (Foucault, 1997, p. 241, my emphasis). The distinction Foucault makes between the sovereign power to “let live” and the biopolitical power to “make live” is an important one. Where, under sovereign rule, to (be permitted to) live was, in some sense,
a privilege of the subject shaped by and contingent upon the sovereign’s exercise of power, life has now become that which is and must be regulated (and so innovated) by power. In the here and now of liberalism, power targets “life itself” (Rose, 2007).

As a way to regulate life – as a way to secure it, amplify it, optimize it and above all ensure it – liberal technologies of biopower take as their referent the living, biological being. Such biopolitical forms of power, Foucault notes, no longer take direct aim at the ‘individual-as-body’, are no longer precisely concerned with the discipline and regulation of the individual corporeal body (although, of course, as is evident in Chapter 4, this does not do away with normative processes that work to discipline individual bodies). Rather, this new kind of biopolitical power takes aim at, in Foucault’s words, a “new body” – a “multiple body”, he writes, “a body with so many heads that, while they might not be infinite in number, cannot necessarily be counted” (Foucault, 1997, p. 245).

“Biopolitics” he continues “deals with the population as a political problem, as a problem that is at once scientific and political, as a biological problem and as power’s problem” (Foucault, 1997, p. 245).

Biopower is concerned with populations. In other words, power is principally concerned with the living biological individual, but only insofar as this individual lives in relation to – and thus alters and effects – the overall life of a greater living biological entity: the life of a species. It is a “biopolitics” writes Foucault, “of the human race” (Foucault, 1997, p. 243). Biopower, thus, invests in the cultivation, management and the overall securing of “life” – or ‘more’ life or ‘better’ life – for the greater whole of the species and does so by measuring, monitoring, evaluating, intervening in and manipulating those elements understood to be ‘coefficients of life’: birth and mortality
rates, statistics and systems of classification regarding health, hygiene, illness, disability, reproduction and so on, averages of life expectancy, calculations of the determinants of quality of life, environmental factors and so on.

In the name of life, biopolitical power is exercised not by killing – not by ‘taking life’ – but by shaping life, improving it, optimizing it and so on (i.e., in terms of efficiency or normative notions of ‘health’). This power has, effectively, transformed life into a spectrum: there are now many gradients of life, many ways in which life can be lived – more and more ways to better it, more and more ways to extend it, more and more ways to make it more efficient. And, as it takes ‘life’ as its target, biopower also makes life the rule.

Here and now, ‘to live’ (and, of course, here we must read: to live ‘better’ and ‘more’ according to normative liberal standards and values) is the rule; ‘to live’ is compulsory. As life comes under rule in liberalism, and, indeed, as life is made the rule, what of life’s opposite: what of death? Not only is biopower exercised by optimizing and improving life, it is also, and ultimately, exercised by ensuring it, and so, by thwarting death, by preventing it for as long as is possible. Indeed, Foucault describes a “gradual disqualification of death” under biopolitical rule (Foucault, 1997, p. 247) and, along with this disqualification he identifies a shift in the overall conceptualization of the category of death. “Death” he writes “[is] no longer something that swoop[s] down on life”, it is, rather, “now something permanent, something that slips into life, perpetually gnaws at it, diminishes it, weakens it” (Foucault, 1997, p. 244). Death is no longer conceived of as that which takes life all at once, but rather as that which penetrates life’s frontiers,
infiltrates it – *terrorizes* it, even. And so, as biopolitical power shapes a spectrum of life, it also, and necessarily, gives us many shades of death.

Death is no longer conceived of as a thing unto itself, but is, rather, redefined in terms of a threatening pathological relation to the living. It is the murky underbelly of vitality, the expression of life’s absences, a kind of biopolitical non-life or, “necropolitics”, to use Achille Mbembe’s (2003) term. To borrow from Puar (2007), death has become nothing more than “a negative translation of the imperative to live, occurring only in through the transit of fostering life” (p. 32). With life as the rule, then, the threat of this relationally negative space of non-life is (and, indeed, must be) understood and articulated in and through the terms and tropes of vital (biological) invasion, in and through discourses of pathology.

Of course, of primary importance to any discussion of liberal life, is the question: what (who) constitutes ‘life’? As life is installed as a governing rule of liberal society, what (whose) life comes to be understood as securing or even optimizing the overall vitality of the species and what (whose) life gets read as inherently threatening to species life? Conceptions of life are, as Foucault emphasizes, always normatively defined, measured and organized (Foucault, 1997). Dillon and Reid observe:

> If you wish to make life live, as Foucault teaches us that liberalism does, you must embark on a rigorous and continuous assaying of life. What are the properties of the species? Which properties are compatible with the welfare of the species? Which properties endanger the species? How do these life processes work? (Dillon and Reid, 2009, p. 43)
This hyper-attention to and meticulous taxonomy of species life – this, following Foucault, “fragmenting” of “the field of the biological” into sub-species populations – is a necessary function of a biopolitical regime for it allows for the identification of those forms of life that promote or optimize the life of the species and those forms of life that inhibit or threaten it. Yet, what often escapes attention is how this process of ‘fragmenting the biological’ (e.g., splitting the field of the human into developmentally ‘normal’ and ‘abnormal’ species ‘types’) is a process that is at once, politically determined (i.e., determined or motivated by, for example, social, historic and/or economic factors) and morally coded (i.e., certain ‘types’ are coded as “good” or “beneficial”, while others are coded as “bad” or “threatening”) (Titchkosky, 2007). What also, and very commonly, escapes attention is how such divisions inaugurate certain lives as non-vital: lives that – while technically alive – are not recognized as performing the normatively defined process of living and so are cast as pathologically life-threatening, as draining the life of the normative whole (Butler, 2009).

Returning to the scene of autism advocacy, a contemporary scene that is born of and so is, invariably, framed by this liberal imperative of life, let us note how autism is being discursively transformed into a pathological threat to life. Autism is ‘framed’, as we have seen, as a kind of morbid public enemy – a ‘tear’ of families, a stalker of the innocent, a stealer of children. In the campaigns detailed above, autism is, always and already, cast as guilty of terrorizing and terrifying: guilty, in other words, of not necessarily taking away life, per se, but infiltrating it, destroying it, ruining it, ‘spoiling’ it (Goffman, 1963). Indeed, a ‘life with autism’ – conceived of in the sense of both a
person ‘with autism’ as well as a collective ‘with autism’\(^7\) – is being ushered into contemporary intelligibility as a kind of biopolitical death. Autism is found guilty, time and again, of pathologically ‘gnawing’ at life, guilty of ruining life, of lowering ‘quality of life’, of diminishing life’s viability and so on.

Considering the three examples of advocacy initiatives described in the beginning of this chapter, as well as other campaigns and initiatives detailed in earlier chapters, autism is, time and again, conceived of as nothing other than an undesirable and even dangerous individual biological pathology. The evidence is in and it is damning: bad biology, mis-wired brains, devolving development, histories of red flags. It is, as was explored in chapter 3, ‘bad’ genes or damaged pathways leading to, as examined in chapter 4, abnormal behaviours and underdeveloped bodies and minds. It is preventing, as in chapter 5, the full enjoyment of liberal rights and freedoms. Autism is dominantly conceived of, in other words, as a pathological threat to (normative, liberal versions of) individual life and is even framed as actively spoiling/wasting away this life.

At the same time as dominant enactments of advocacy narrate autism as a threat to \textit{individual life}, they also and simultaneously depict an autism that is infiltrating the frontiers of the (normative) \textit{life of the whole}, wasting it away, bit by bit. As we have seen in both this chapter and the previous one, autism is represented in epidemiological terms, a spreading epidemic moving through the ‘greater’ population, working faster, to borrow a very commonly evoked phrase, “than AIDS, cancer, and diabetes combined”. Such an epidemic not only spoils individual lives, but threatens the life of the whole. First, it’s the diminishment of the “good life” of the liberal (middle class, heteronormative) nuclear

\(^7\) In chapter 7, I conduct a more detailed analysis of this conflation of meaning.
family – high rates of divorce, depleted banks accounts, disrupted leisure activities, ruined birthday parties – and then it’s the erosion of the vital life of the liberal society as a whole – disappearing independence, (too) costly social supports and so on. With such frames, autism’s “guilty status” is, surely, *made* an “inevitable conclusion”. And, there is plenty of guilt to go around.

Insofar as autism and its advocate are invariably tied together in discourses of advocacy, the frames that present autism as always and already guilty of acts of terrorizing life, shore up the advocate as always and already suspect. Recalling the red flag campaigns from Chapter 4 and the Starbucks cup from Chapter 5, the advocate is continuously being framed as *potentially guilty*: potentially guilty of not learning the signs, potentially guilty of not being vigilant in watching for ‘red flags’, potentially guilty of, in other words, being a ‘bad’ advocate and, so, aiding and abetting an already guilty autism and becoming complicit in autism’s crimes against life.

In the face of guilty and potentially guilty figures who threaten the frontiers of normative life, a whole host of security mechanisms must be erected so as to safeguard it, protect it and, indeed, ensure it by keeping non-normative life at bay. Foucault writes:

> Regulatory mechanisms must be established to establish an equilibrium, maintain an average, establish a sort of homeostasis and compensate for variations within this general population and its aleatory field. In a word, security mechanisms have to be installed around the random element inherent in a population of living beings so as to optimize a state of life. (Foucault, 1997, p. 246)

We have encountered such ‘security measures’, time and again, throughout the previous chapters. In contemporary times, the perimeters of normative life are clearly staked out
Autism is prevalent
- 1 out of 6 children are diagnosed with a developmental disorder and/or behavioral problem
- Approximately 1 in 150 children are diagnosed with an autism spectrum disorder
- Developmental disorders have subtle signs and may be easily missed

Listen to parents
- Early signs of autism are often present before 18 months
- Parents usually DO have concerns that something is wrong
- Parents generally DO give accurate and quality information
- When parents do not spontaneously raise concerns, ask if they have any

Act early
- Make screening and surveillance an important part of your practice (as endorsed by the AAP)
- Know the subtle differences between typical and atypical development
- Learn to recognize red flags
- Use validated screening tools and identify problems early
- Improve the quality of life for children and their families through early and appropriate intervention

Refer
- To Early Intervention or a local school program (do not wait for a diagnosis)
- To an autism specialist, or team of specialists, immediately for a definitive diagnosis
- To audiology and rule out a hearing impairment
- To local community resources for help and family support

Monitor
- Schedule a follow-up appointment to discuss concerns more thoroughly
- Look for other conditions known to be associated with autism (eg, seizures, GI, sleep, behavior)
- Educate parents and provide them with up-to-date information
- Advocate for families with local early intervention programs, schools, respite care agencies, and insurance companies
- Continue surveillance and watch for additional or late signs of autism and/or other developmental disorders
- Continue to provide a medical home

For More Information: www.medicalhomeinfo.org

by ‘red flags’ (e.g., the posters from chapter 4: figs. 4.1, 4.2 and 4.3) and systems of early warning (e.g., the CDC-sponsored ‘Autism A.L.A.R.M.’ document in fig. 6.6 that unmistakably resembles a kind of ‘emergency procedures’ document). We calculate and re-calculate the ‘odds’ of a security breach (e.g., the discussion of ‘odds’ in chapter 5). And, when breaches in security happen, as they invariably do – when the flags go up, when the alarm sounds, when the odds close in – when, in other words, the imagined frontiers of normative life are penetrated and normative life is understood to be under attack, we go to war.

The War on Autism

...
Public Law 109–416
109th Congress

An Act

To amend the Public Health Service Act to combat autism through research, screening, intervention and education.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Combating Autism Act of 2006”.

SEC. 2. CENTERS OF EXCELLENCE; IMPROVING AUTISM-RELATED RESEARCH.

(a) CENTERS OF EXCELLENCE REGARDING RESEARCH ON AUTISM.—Section 409C of the Public Health Service Act (42 U.S.C. 284g) is amended—

(1) in the section heading, by striking “AUTISM” and inserting “AUTISM SPECTRUM DISORDER”;

(2) by striking the term “autism” each place such term appears (other than the section heading) and inserting “autism spectrum disorder”; and

(3) in subsection (a)—

(A) by redesignating paragraph (2) as paragraph (3); and

(B) by striking paragraph (1) and inserting the following:

“(1) EXPANSION OF ACTIVITIES.—The Director of NIH (in this section referred to as the ‘Director’) shall, subject to the availability of appropriations, expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder, including basic and clinical research in fields including pathology, developmental neurobiology, genetics, epigenetics, pharmacology, nutrition, immunology, neuroimmunology, neurobehavioral development, endocrinology, gastroenterology, and toxicology. Such research shall investigate the cause (including possible environmental causes), diagnosis or rule out, early detection, prevention, services, supports, intervention, and treatment of autism spectrum disorder.

“(2) CONSOLIDATION.—The Director may consolidate program activities under this section if such consolidation would improve program efficiencies and outcomes.”.

(b) CENTERS OF EXCELLENCE GENERALLY.—Part A of title IV of the Public Health Service Act (42 U.S.C. 281 et seq.) is amended by adding at the end the following:

Figure 6.7: United States public law 109-416, the "Combatting Autism Act of 2006", signed by President George W. Bush on December 19, 2006.
Figure 6.8: "In the Name of the Normal" (2011), digital collage by Eduardo Trejos. Reprinted with the artist's permission.
to win the war against autism”, echoed federal lobbyist Craig Snyder in *Newsweek* magazine, “and it’s now the law of the land” (Scelfo & Kantrowitz, 2006, para. 6).

In a contemporary moment when autism is officially legislated in the US as an outlaw at large – a-state-enemy-to-be ‘combatted’, ‘assaulted’, ‘battled’ – many disparate soldiers are taking to the trenches of a war. “Progress is slow in war against autism” screams a 2009 CNN headline (CNN, 2009), “Pediatricians are receiving new marching orders in the war against autism” reports a CBS medical correspondent (CBS, 2007). Larry King discusses it (Douthit, 2009). Oprah endorses it (Winfrey, 2007). The pentagon funds it (Kirby, 2008). And, having had a change of heart, Yoko Ono has decided to give this war a chance (Autism Speaks, 2009a).

Indeed, we find ourselves in a contemporary social context where doctors, professional athletes, celebrities, politicians, journalists, parents, ‘stakeholders’ and concerned civilians from around the world are coming together “against autism”; where we can walk, run, row, fish, shop or take a cruise to "fight autism"; or read up on the latest research study “taking aim at autism” (York University, 2010). In these (war) times, it is possible to pass a stranger on the street wearing a t-shirt with the image of an armed child in military fatigue and the words: “welcome to my war on autism” or attend a “Defeat Autism Now!” workshop or conference. And, we might flip on the TV and tune in as celebrity advocate Jenny McCarthy - author of the *New York Times* best-selling book on parenting autistic children called 'Mother Warriors' - teams up with *World Wrestling Entertainment* for an 'autism smackdown'. There can be little doubt: we are living in the midst of a global (and globalizing) war on autism (Fig. 6.8 depicts
Eduardo Trejos’ digital collage, “In the Name of the Normal”, which offers a visual sampling of this war and its linguistic and representational targets and tactics).

But, of course, our times have not only given birth to this ‘war on autism’ but also and most glaringly to the ‘war on terror’. But there are many other wars still. We are living in the midst of a “war on child abuse”, a “war on obesity”, a “war on mental illness”, and an (ever ironic) “war on bullying”. Indeed, in contemporary times, war has been declared on such disparate targets as cars, poverty, bed bugs, crime, ignorance, greed, drugs, germs, cancer and, of course, on war itself. And, while it seems almost reasonable to assert that, these days, there is, as Richard Ericson puts it, a “war on everything” (Ericson, 2007, p. 214), we know that this is not exactly so. Even as the ‘war on’ lexicon is applied and applied liberally to a whole gamut of disparate targets, war is never waged indiscriminately. War is never waged, for example, on that which is desired and valued in a culture. Government reports are not calling for a war on literacy and doctors are not waging a battle against mental health. Indeed, as Dillon and Reid (2009) observe: “forms of war and forms of life are intimately related [...] Wars have always been fought in the name of whatever different forms of life have been made sacred” (p. 35). In this way, war performs the dual function of protecting that which is desired and valued in and by a culture by targeting that which is perceived as threatening to this.

Under biopolitical rule, (a normative liberal version of) life is what is of primary value; it must be accounted for and monitored, protected and secured against a terrifying and pathological non-life. And, when it is threatened, life must be battled for. I turn now, and for the remainder of this chapter to a consideration of the existence and persistence of two significant contemporary wars – the war on autism and the war on
terror – and I suggest that the fact that these two wars are appearing at the same moment
is not mere historical happenstance. To the contrary, the war on terror and the war on
autism – and their resonant oppositional figures of terrorist/warrior – are intimately
connected, dependent upon one another, even, for they both share a very particular
(liberal, biopolitical) war frame.

**War Frames**

As we attempt to better understand these war frames, it becomes necessary to,
first, ask: how is it possible to wage war – any war, be it a war on autism or a war on
terror – and so to expose *life* to the possibility of harm – under a biopolitics *where life is
what is of primary value?* Under a politics that privileges and even enforces life, war
seems counterproductive, itself a transgression of the vital rule. Foucault asks:

> How can [biopower] kill[^8], if it is true that its basic function is to improve life, to
> prolong its duration, to improve its chances, to avoid accidents, and to
> compensate for failings? How, under these conditions, is it possible for a political
> power to kill, to call for deaths, to demand deaths, to give the order to kill, and to
> expose not only its enemies but its own citizens to the risk of death? (Foucault,
> 1997, p. 254)

In response to his own questions, Foucault suggests that liberal war – and the harm it
invariably causes – is and can only be made possible when waged in the name of life

[^8]: Foucault emphasizes, elsewhere, that “killing” can and must be broadly conceived. He writes:
“when I say ‘killing’, I obviously do not mean simply murder as such, but also every form of
indirect murder: the fact of exposing someone to death, increasing the risk of death for some
people, or quite simply, political death, expulsion, rejection, and so on” (Foucault, 1997, p. 256).
(Foucault, 1997, p. 256). As (normative) life itself comes to be understood, under liberalism, as both what is of value and what is at stake, war, and its inherent violence, emerges, almost counter-intuitively, as a kind of ‘vital’ force charged not with the taking of life but with the protecting, promoting and ensuring of it. Following Foucault, liberal wars are “no longer waged in the name of a sovereign who must be defended, they are waged on behalf of the existence of everyone; entire populations are mobilized for the purpose of wholesale slaughter in the name of life necessity: massacres [have] become vital” (Foucault, 1990, p. 40).

What is more, Foucault asserts that this vital technology of liberal war must be conceptualized in racist terms. Indeed, he asks: “how can one not only wage war on one’s adversaries but also expose one’s own citizens to war [...] except by activating the theme of racism?” (Foucault, 1997, p. 257). Here, Foucault conceptualizes racism not as an ideological commitment, per se, but rather as, in his words, “a way of introducing a break into the domain of life that is under power’s control” (Foucault, 1997, p. 254). Indeed, this “break” in life’s continuum, this constitution of a “negative ontology” (Patterson & Hughes, 1997; Kumari Campbell, 2005, p. 108), this liberal process of breaking up and marking out vital and pathological ‘types’ through the organization of ‘superior’ and ‘inferior’ ways of being human or, perhaps more accurately, ‘viable’ and ‘non-viable’ ways of living humanness, is, for Foucault, the primary technology of contemporary racism. “The first function of racism” he writes, “[is to] to fragment, to create cesuras within the biological continuum addressed by biopower” (Foucault, 1997, p. 255).
It is this racist organization that is, Foucault argues, an essential feature of liberal war, a kind of war not premised on military confrontation, per se, but is, rather established as a kind of ‘biological-type relationship’ where inflicting harm or even death on an individual life (or, even, on many individual lives) is rendered intelligible as necessary for the preservation of the overall life of the whole. Via biopolitical frames of racism, certain bodies are coded as ‘non-vital’ types and emerge as always and already guilty of crimes against life. Such ‘types’ are thus rendered vulnerable as necessary casualties of (liberal) war. “Enemies who have to be done away with” writes Foucault, “are not adversaries in the political sense of the term; they are threats, either external or internal, to the population and for the population” (Foucault, 1997, p. 256).

Gleaned from the vantage point of biopower as a pathological threat to (normative) species life, autism – and indeed disability more broadly – is racialized (Erevelles, 2002; Watts & Erevelles, 2004). Biopolitical versions of disability are always, to borrow from Rey Chow’s discussion on the coterminus condition of race and sexuality, “racially and ethnically inflected” (Chow, 2002, p. 7). Under the biopolitical rule of life, the frames with which we come to recognize disability and race run continuous, the one implicated in the other, supporting the other, helping it to function, rendering it possible. This implication is made all the more evident as we piece apart and analyze liberal discourses of war, discourses which are not only, essentially, racist, but are also and, simultaneously, ableist. This insipid presence of racist/ableist war frames is very evident if we consider the ‘war on terror’ and the ‘war on autism’, not as separate but continuous phenomena committed to defining, preserving and securing borders of a
Life worth Defending

I dedicate the remainder of this chapter to a consideration of how the biopolitical imperative to ‘make life live’ has come to frame contemporary acts of war in both racist and ableist terms. More particularly, I consider how such racist/ableist war frames are concurrently animating and animated by discourses of the global ‘war on terror’ and discourses of advocacy’s ‘war on autism’. To better glean these overlapping frames I turn now to a look at something truly terrifying, the words of the former US president, George W. Bush.

In a speech marking the one-year anniversary of the US-led war in Iraq – a particularly bloody year of war with a death toll well over 100,000 (Roberts et al., 2004) – George W. Bush offered the American public a few remarks about the value of life. On March 19, 2004, the then president stated:

...there is a dividing line in our world, not between nations, and not between religions or cultures, but a dividing line separating two visions of justice and the value of life. On a tape claiming responsibility for the atrocities in Madrid, a man is heard to say, "We choose death, while you choose life." We don't know if this is the voice of the actual killers, but we do know it expresses the creed of the enemy. It is a mind-set that rejoices in suicide, incites murder, and celebrates every death we mourn. And we who stand on the other side of the line must be equally clear and certain of our convictions. We do love life, the life given to us and to all. We believe in the values that uphold the dignity of life, tolerance, and
freedom, and the right of conscience. And we know that this way of life is worth defending. There is no neutral ground – no neutral ground – in the fight between civilization and terror, because there is no neutral ground between good and evil, freedom and slavery, and life and death. (Bush, 2004, p. 411)

In his speech, Bush divides up many things. His words work hard to create caesuras: splitting outside from inside, limit from possibility, death from life. In her discussion of representational frames delimiting the field of appearances in the ‘war on terror’, Butler (2009) characterizes these ‘war frames’ as, in her words, “the ways of selectively carving up experience as essential to the conduct of war” (Butler, 2009, p. 26). For Butler, the frame is made through a carving up of the field of experience, the sculpting of the field of phenomena. The meaning of such a field, for Butler, is not self-evidently there, as it was for Poussin, but is rather conditioned by and conditional to a process of framing.

Let us examine how Bush engages in the ‘carving up’ of a field of experience he calls ‘the world’. Let us examine, in other words, how he is engaged in the work of framing understandings of the world anew. Rejecting other familiar (and equally artificial) ways of carving up the world (e.g., as a series of nation states, or along the lines of religion), Bush’s speech cuts yet another dividing line deep into the world, carving it up into two parts – allies and enemies, an ‘us’ and a ‘them’ – distinguished, not coincidentally, by oppositional ‘visions’ and ‘values’ with respect to life.

One world – the ‘we’ of America, we must presume, and its ‘allies’ – is sculpted by Bush as an essentially vital world, populated by thriving figures who, “love life, the life given to us and to all”, figures who demonstrate their vitality, moreover, by adhering to liberal norms and values (i.e. “life” is constituted in Bush’s speech as not merely living
but as “civilized”, “free”, “tolerant” and so on). Meanwhile, the other world – the ‘they’
of al-Qaeda, collected by a figuration of a Muslim who is always and only a terrorist – is
framed as having fallen outside of the frame of liberal norms and values or, even, as
existing in opposition to these frames (i.e., where Bush’s “we” are “civilized”, his “they”
are “terrorists”; where his “we” are “good”, his they are “evil”; where his “we” are
“free”, his “they” are “slaves” and so on). And so, out of a racist act of inserting a break
in the continuum of ‘life’ comes a middle eastern “death world” (Mbembe, 2003; Puar,
2007) populated with pathologically morbid Muslim terrorists who “[rejoice] in suicide,
[incite] murder, and [celebrate] every death we mourn”. Following Foucault, where
Bush’s “we” ‘makes live’, his “they” ‘takes life’, and, so while his “we” is always (or at
least until expelled) inside the rule of life, his “they” is always, firstly, guilty of
transgressing it.

Making reference to a tape that was released by a group claiming responsibility
for the 2004 train bombings in Madrid, Bush presents us with evidence to support this life
world/death world frame. He states that a man’s voice is heard on the tape as saying:
"We choose death, while you choose life". “We do not know if this is the voice of the
actual killers”, the then president admits, and, ultimately, he reminds us, this does not
matter. It does not matter whether or not this is the voice belonging to the actual culprit
behind the Madrid bombings, for, within Bush’s liberal frame of life and death, the voice
on the tape, cathected to death, materializes from the start as breaking the rule of life. It
is the life-draining voice of the already-guilty and it is speaking, a (racially inflected)
“creed of the enemy”. Under a liberal biopolitics, where transgressions of the rule of
(normative) life are encoded not only as deviance, but as a pathologically oppositional
threat, it is a voice that, Bush implicitly suggests, requires immediate intervention in the form of American military invasion and occupation.

In Bush’s speech we encounter yet another instance of a malignant voice issuing terrifying threats of biopolitical death. Faceless. Hidden. Lethal. Out of control. In contemporary autism advocacy campaigns such as the three I referenced earlier, the terrifying and terrorizing figure of ‘autism’, too, appears always and firstly as ‘speaking’ threats to the normative (social and individual) body. In so doing, this figure is conjured into existence as a pathologically terrorizing figure, always and already guilty of speaking non-vital threats: a (racially inflected) “creed of the enemy”. In this way, the figure of autism comes into being as always, and necessarily, war-able.

I conclude this chapter by explicitly listening for the ableist and racist resonances that are tying together the figure of autism in dominant contemporary advocacy discourse and the figure of the Muslim terrorist in Bush’s presidential pronouncements (insofar as this is representative of US foreign policy more generally). I seek to highlight the discursive continuities that are tying together the ableist and racist underpinnings of the emergence of both the figure of autism that we have been tracking through contemporary advocacy discourse, as well as the contemporary figure of the Muslim terrorist. In drawing out these resonances my intent is not to make a simple analogy or comparison (as intriguing as such an analogy and comparison is!) but to attend to the overlapping, and even shared, racist/ableist war frames that pull together these figures and allow them to appear as they do.

Contemporary discourses of autism advocacy and terror share a (liberal, biopolitical) frame, a frame that conditions into possibility the very particular appearance
of pathologically terrifying and terrorizing enemy-figures and, in so doing, delimits the range of possible reactions and responses to those bodies marked as/conflated with such figurations.

Vis-à-vis this life threatening/life draining enemy figure – be it the figure of autism or the figure of the Muslim terrorist – a very particular and historically specific kind of response is naturalized as obvious and necessary. In the face of terror, what is required is immediate militarized acts of intervention and rehabilitation, invasion and occupation. In the name of life, the figure of death must be stopped up, silenced, eliminated at all cost. I turn now to the former president’s characterization of the contemporary “terrorist” enemy and read this characterization against the narrative put forward in the dominant enactments of autism advocacy described throughout this chapter.

**Wars on Terror**

Just a day after September 11 2001, in what was a watershed moment in the crystallization of contemporary understandings of terrorism, the then president of the United States delivered a now infamous speech characterizing the figural shape of the terrorist. Bush stated:

We are facing a different enemy than we have ever faced. This enemy hides in shadows, and has no regard for human life. This is an enemy who preys on innocent and unsuspecting people, runs for cover. But it won't be able to run for cover forever. This is an enemy that tries to hide. But it won't be able to hide forever. This is an enemy that thinks its harbors are safe. But they won't be safe forever (Bush, 2001, p. 1100).
And, out of and in relation to this (ostensibly) different kind of enemy – this figure whose threatening character is understood in terms of a particular kind of pathological threat, a threat that hides, spreads, circulates, infiltrates, gets closer to home – emerged a different kind of allied response. “The United States of America...” Bush continued:

...will use all our resources to conquer this enemy. We will rally the world. We will be patient, we will be focused, and we will be steadfast in our determination [...] We will not allow this enemy to win the war by changing our way of life or restricting our freedoms. America is united. The freedom-loving nations of the world stand by our side. This will be a monumental struggle of good versus evil, but good will prevail. (Bush, 2001, p. 1100)

Let us note, at the onset, the striking resonances between the rhetorical devices that have and continue to give shape to both the ‘war on terror’ and the ‘war on autism’, as well as to the particular ally and enemy figures generated by these war stories. Yet, the similar rhetorics and striking resonances do more than merely sound the same; they are continuous. The ‘war on terror’ and the ‘war on autism’ (and their respective figures of enemy and ally) are tied together by a tale of terror drawn from, and made intelligible within, an historically specific discursive formation ruled by life. Indeed, what, in part, makes the figure of autism and the figure of the Muslim terrorist so utterly terrifying – and what marks them as historically particular terror figures – is the notion that the pathology that threatens the frontiers of the neo/liberal (life) world might not be immediately apparent. Such enemy figures are framed as possessing the dangerous combination of a (near) normative outward appearance and a pathological death-driven
inner impairment – a “mindset” of terror. Such figures of terror “hide in shadows” says Bush; they are “invisible” says Autism Speaks, “until it is too late”.

Bush references a terrorist “enemy” that could be anywhere, blending in, moving unnoticed through borders in diffuse global networks, laying low in deviant ‘cells’. This figuration of the terrorist that travels in, to borrow from Puar’s (2007) genealogy of the terrorist subject, “rhizomic, cell driven, non-national, transnational networks that have no self-evident beginning or finite end” (p. 52), is understood not only by way of racist/orientalist notions of infiltration and contamination but also and, necessarily by way of an inherently ableist conception of biological contagion.

Puar demonstrates how the common mode of characterizing the movement of terror along the representational lines of cellular contagion is, in her words “often sublimated (against the foil of the western liberal rational subject) through the story of individual responsibility and personal pathology” (Puar, 2007, p. 52). The cellular, epidemic-like movement of the terrorist is reified, in other words, by the notion that the terrorist subject possesses (is possessed by?) a pathological biomedical impairment. Acts of terror are dominantly framed – explicitly and implicitly – as nothing more or less than the destructive effects of the individual (psycho)pathology of the Muslim terrorist as well as the collective (psycho)pathology of a Muslim ‘death world’. As Bush articulates in his 2004 speech quoted earlier, the “creed of the enemy” is not a doctrine or an ideology, per se, but a death-driven and death-loving “mind-set”.

Indeed, the minds and movements of the terrorist have been psychologized through and through. This is evidenced in the proliferation of a vast variety of books, articles, reports and whole academic disciplines that embark on a (familiar) search after the

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9 For a more detailed unpacking of this logic of contagion, please see chapter 5.
pathological origins of a terrifying mind or ‘mind-set’ and that relentlessly engage in the
never-ending project of observing and classifying its deviant/dangerous behaviours.
Examples of explorations into the psychological foundations of terrorism include but are
certainly not limited to:

- *Crusaders, criminals, crazies: Terror and terrorism in our time* (Hacker, 2007);
- *Origins of terrorism: Psychologies, ideologies, theologies, states of mind* (Reich, 1998);
- *Psychology of Terrorism* (Horgan, 2005);
- *The Mind of the Terrorist: The psychology of terrorism from the IRA to al-Qaeda* (Post, 2008)
- “The psychology of terrorism: A case for the 21st century” (Crenshaw, 2000);
- “Psychology of terrorism” (Borum, 2007);

One US Federal report, entitled “The Sociology and Psychology of Terrorism: Who Becomes a Terrorist and Why?”, provides a literature review of a whole host of contemporary research examining the pathological psycho-social origins of terrorist behaviours (Hudson, 1999). The report cites, for example, a model for the genesis of terrorist inclinations, developed by psychologist Eric D. Shaw. Shaw’s ‘Personal Pathway Model’ suggests that terrorist behaviour originates from:

...a selected at risk population who have suffered from early damage to their self-esteem [...] who appear to have been unsuccessful in obtaining a desired traditional place in society, which has contributed to their frustration. The
underlying need to belong to a terrorist group is symptomatic of an incomplete or fragmented psychosocial identity. (Hudson, 1999, p. 25)

The report continues by presenting a great many other theories of the psychology of terrorism. The research cited in the report argues that terrorism might be caused by:

- ‘Mental illness’ [e.g., Post’s postulation of a “terrorist psychologic” or the linking of “depressive aspects” of an individual’s personality with “the terrorists’ death-seeking or death-confronting behaviour” (Hudson, 1999, p. 28)].
- Lack of empathy [e.g., Strentz’s postulation that leaders of terrorist organizations are marked by their “oblivious[ness] to the needs of others and [are] unencumbered by the capacity to feel guilt or empathy” (Hudson, 1999, p. 37)].
- An unsettling, and, it seems, equally pathological, ‘extranormativity’ [e.g., Crenshaw’s allegation that “the outstanding common characteristic of terrorists is their normality” (Hudson, 1999, p. 30) or Fried’s suggestion that the terrorist “may be perfectly normal from a clinical point of view [...] he may have a psychopathology of a different order” (Hudson, 1999, p. 31)].

Of course, the figure of autism, too, is framed as possessing/possessed by a wide range of pathological impairments – biomedical pathologies like ‘mis-wired’ brains, as we have seen, or bad genes that lead to deviant behaviours. And, like the figure of the terrorist, the figure of autism, too, is understood to derive its terror from a purported “lack of empathy” or “mindblindness” (Baron-Cohen, 1995). And, time and again, the threat of autism is narrated, precisely, in terms of its invisibility. Awareness campaigns repeatedly tell us that the ‘disorder’ of autism may be hard to notice for it lies in otherwise
normative bodies. As per the terrorist narrative, the story of autism is told as a kind of ‘spreading’ pathology, infiltrating normative populations in an epidemiological, cellular fashion: an epidemic “work[ing] faster than pediatric AIDS, cancer and diabetes combined”. Knowing no borders or barriers, autism is framed as learning languages, infiltrating homes, moving next door and hiding in otherwise normative bodies.

Betrayed by pathological movements and behaviours, the contemporary figure of terror – be it the terrifying figure of the Muslim terrorist or the terrorizing figure of autism – emerges as a “racially inflected” (species-life threatening) figure whose pathological character is not only understood as biologically abnormal but also as essentially amoral. While, for example, a pathological inner impairment drives the figure of the Muslim terrorist to perform acts of, in Bush’s words, “evil”, to “[prey] on innocent and unsuspecting people” – to “rejoice in suicide” and “celebrate death” – notions of autism as neurological disorder give shape to a figure who stalks families, plots to rob (liberal) hopes and dreams, takes and holds kids hostage and does so with, as per “I am Autism”, “no interest in right or wrong“, “no morality”.

As discourses of terror shape the biopolitical enemy as both life threatening and amoral, they also work to delimit the terms of its response as both necessary and moral. Vis-à-vis a death-driven enemy, a life loving and life-saving allied warrior is born. Confronted with an enemy that hides in plain sight, the ‘ally’ must increase its surveillance techniques, fortify its borders and hone its technologies of war. Said Bush to terrorism: “The United States of America will use all our resources to conquer this enemy”, “we will be patient, we will be focused, and we will be steadfast in our determination”. We will watch were you “run”, find where you “hide”, and uncover your
“safe harbours”. Said the autism advocates to autism: “We will not rest until you do”, we will search for you “with technology and voodoo, prayer and herbs genetic studies and a growing awareness you never anticipated”, we will “knock down” your “walls” with our “bare hands”, and “if you are not scared, you should be”.

And, of course, when confronted with a biopolitical threat to a (normative) life world, a fiercely normativizing (racist/ableist) patriotism is born – a ‘love’ for, in other words, the ‘patris’...the fatherland, the vital bloodline. Faced with a life-threatening global network of enemies – a moving and hidden pathology that contaminates and spreads – allied soldiers and civilians draw together as a homogenous, normative, normativizing and, necessarily, vital ‘we’. In the face of spreading networks of terror (or the ‘terror epidemic’, to borrow a commonly used phrase), Bush stated: “America is united and we will rally the world”, “the freedom-loving nations of the world stand by our side”. In the face of autism, said the Autism Speaks advocates: “We are a community of warriors”, “we are coming together in all climates, we call on all faiths”. “We are Qatar. We are the United Kingdom. We are the United States. We are China. We are Argentina. We are Russia. We are the European Union. We are the United Nations”.

Faced with the life-threatening figuration of a terrifying and terrorizing enemy (be this enemy the figure of the terrorist or the figure of autism), the ‘ally’ – the good advocate, the good citizen, the good soldier – is constrained. The ‘ally’ takes the shape of a militant warrior, a fiercely loving protector and defender of the borders a kind of normative ‘homeland’ (be it a political paradigm, a nation, a family or a child) and is charged with the task of securing and, indeed, ensuring normative life no matter the cost and, as I will explore in Chapter 7, irrespective of the casualty.
And so, I end this chapter – and begin the next one – by acknowledging how the creation of enemy ‘figures’ is, itself, a productive move that ushers particular bodies (read: actual disabled and/or racialized people) into recognition as always and already guilty of terrorizing life. While biopolitical war frames function to govern the ways in which we come to regard all embodied movements and behaviours as potentially terrifying and terrorizing, some ‘racialized disabled’ bodies and/or ‘disabled racialized’ bodies are differentially positioned within such frames so as to appear as always and already deviant: death-driven and life-threatening (Watts & Erevelles, 2004). Such ways of regarding bodies as legible sites ever in danger of betraying the profile of the terror figure lead to increased security and to the installment of a wide range of surveillance techniques\(^\text{10}\) at normative borderlands and state frontiers – security checkpoints and pre-natal screening\(^\text{11}\), ‘behavioural assessment repots’ and ‘threat assessment reports’, offender registries and identity cards\(^\text{12}\). In this way, biopolitical frames, thus, render particular bodies differentially and disproportionately vulnerable to intervention,

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\(^{10}\) This intermingling of frames is made most evident, for example, in a recent research initiative – led by Rutger’s University Psychology researcher Dr. Maggie Shiffrar and Dr. Kent Harber and funded by an almost half-million dollar research grant from the Department of Homeland Security – that studies autistic subjects “lack of empathy” (what the Rutger’s press release refers to as autism’s “lens devoid of emotion”) as a way to develop better screening techniques to use for profiling potential terrorist subjects (Rutgers University, 2008).

\(^{11}\) Michalko, 2010

\(^{12}\) A great many autism organization have begun to put together training workshops and materials geared toward police officers, emergency responders and security guards to better enable quick and easy recognition of autism’s ‘red flag’ pathological traits (see, for example, Autism Speaks’ Family Services Autism Safety Project). Other advocacy organizations have lobbied local governments to institute ‘autism registries’ where parents can register autistic individuals to be ‘flagged’ in the 911 system (see, for example, the Autism Society of America’s ‘Take Me Home’ program or the Autism Society of Ontario’s ‘Autism Registry’ in Ottawa, Ontario). Other advocacy organizations, still, offer ‘Autism Alert’ identity cards, to be presented by the autistic person to the authority in event of a detention or encounter. The cards, typically, list the signs and symptoms of autism (see, for example, the NAS “Autism Alert” card).
detention, incarceration as well as other violations and violences enacted in the name of life (Butler, 2009; Puar, 2005).

In the summer of 2010, less than a year after the “I am Autism” film was removed from the Autism Speaks’ website, the organization launched their new Public Service Announcement entitled “Closer to home” (Autism Speaks, 2010c). The PSA, which was designed, pro bono, by the advertising conglomerate BBDO – the same agency that, three years earlier, came up with the NYU ‘Ransom Notes’ campaign – begins with the appearance of a young, middle-class white man wearing a jean jacket who appears to be in a college dorm room. Against the whining background music of a violin, he speaks:

“I think someone in my friends’ school has this thing called autism...”

Before the eyes of the viewer, the man’s face changes. He appears older now – a young professional with a smart haircut and a crisp polo shirt. He speaks:

“...my friends’ brother’s son has autism...”

The man ages once again, his hairline receding slightly, his polo shirt replaced with a crisp dress shirt:

“...my neighbor’s son has autism....”

The man now makes a final transformation, his hair dusted with grey:

“...my son has autism.”

With this proclamation, the camera pans out and a young child, a boy, enters the frame. Against the backdrop of a middle-class living room, the two embrace. A voice-over says:
“Autism is getting closer to home. Today, 1 in 110 children is diagnosed with autism. That’s a 600% increase in the last 20 years. Learn the signs at autismspeaks.org”

The figure of autism is completely disappeared from this advertisement. And, the truth is, we no longer need gory threats or menacing confessions. We are well aware of the pathological character of this, now prominent, cultural figure. We have been educated. And, so we know this: its invisibility and its quietness, only means it is all the more dangerous. “Autism” – still figured as terrifying and terrorizing – “is getting closer to home”.

Banal by comparison, but consistent in message and meaning, “Closer to home” did not follow the same trajectory as “Getting the word out”, “Ransom Notes” and “I am Autism”. It did not elicit any kind of widespread public outcry and, at the time of this writing, the campaign remains in circulation.
CHAPTER SEVEN

Collateral Damage: Normalizing Violence and the Violence of Normalcy

She was a tough nut to crack…


In contemporary times and in neoliberal western/ized spaces, there seems to be a collective, cultural fixation on – or, perhaps even, obsession with – ‘life with’ autism (Broderick & Ne’eman, 2008). Indeed, these words, ‘living’ and ‘with’, are so commonly strung together in relation to autism in everyday life that they appear everywhere from newspaper articles to government reports, from scientific studies to celebrity appeals, from fundraising initiatives to self-help books. Consider but a few of a vast number of recent examples:

- A Vancouver Sun Headline: “Living with Autism” (McMartin, 2007)
- A BBC Headline: “Living with Autism in the UK” (Guerry, 2008)
- A common phrase: ‘1 out of every 110 children is living with autism’
• A parent resource: *Living with Autism: Practical Strategies for Supporting People with Autism Spectrum Disorders* (Autism Association of Western Australia, 2007)

• An *Evening Herald* headline: “Breakthrough brings fresh hope for families *living with autism*” (Connor, 2010).

• Kathleen Dillon’s (1995) book: *Living with Autism: The parents’ stories*

• An oft repeated ‘fact’ that ‘1 to 1.5 million Americans *live with Autism Spectrum Disorder*’

• A 2008 Easter Seals Study “*Living with Autism*”

• A Daily Press article: “*Living with autism disconnects kids from the world*” (Freehling, 2001).

• An edited collection of stories: “That’s *Life with Autism: Tales and tips for families with autism*” (Ross & Jolly, 2006)

• The common biomedical observation: ‘many persons *living with autism* have significant communication challenges’


• A talk show episode “*Living with Autism*” (Winfrey, 2007)

Given the sheer ubiquity of the understanding that autism is a condition that is not ‘lived’ but ‘lived with’ and as this way of articulating the condition of autism seems to roll so quickly off the tongue and drift so easily across the page, I want to conclude this dissertation with a discussion of the meaning of the condition of ‘living with’. And so, I ask, once again, the same question I have been asking throughout the previous pages but
in a different way: what does it mean to be ‘living with’ autism and autistic difference in neo/liberal times?

**Living ‘with’ Autism**

Perhaps the most literal way of reading the meaning of the phrase ‘living with autism’ is as an instance of ‘person first’ language – a dominantly used and widely accepted system of naming disability that places the ‘person’ before the ‘disability’ (“person with a disability”, for example, or “people with autism”). When confronted with the phraseology ‘living with autism’, we might reasonably and literally understand it as referencing an individual (life) ‘with’ autism, as referencing, in other words, ‘a person with autism’. Indeed, there are many instances where the ‘living with’ phraseology is evoked precisely in this way. To draw on a few examples from the list above: “1 to 1.5 million people in the US live with an Autism Spectrum Disorder” or ‘many persons living with autism have significant communication challenges’ or “living with autism disconnects kids from the world”. Each of these statements suggests that the condition of “living with autism” is a condition of the individual ‘with’ it.

As Tanya Titchkosky (2001) observes in her critical reading of ‘person first’ language: “Wherever and however this [‘person-first’] lexicon appears, it always recommends that disability should be spoken of as something that comes along ‘with’ people” (Titchkosky, 2001, p. 126). If 1 out of every 110 children is a child with autism, it follows that autism – at least in some sense – can only be located ‘with’ that 1 child. It is, in other words, discursively forbidden from being ‘with’ the other 109 children. Statements such as ‘many persons living with autism have significant communication challenges’ suggest that communication challenges do not, in any essential way, belong
to all of us - to the realm of social interaction – but, rather, belong to persons afflicted
‘with’ a biomedical condition, persons with autism (McGuire & Michalko, 2011). Far
from being merely a politically correct system of words or names, as many disability
studies scholars have demonstrated, the “Person first” lexicon functions to systematically
organize disabled people as “just people” – regular, ordinary people who happen to have
a disability (Michalko, 1999; Overboe, 1999; Titchkosky, 2001). In organizing disability
(and so autism) in this way, the ‘person first’ lexicon also functions to localize disability
squarely in the individual, thereby forbidding any conceptualization of its existence
outside of the individual (in the socio-cultural environment, for example, or in
intersubjective relations).

The solidification of disability’s status as an individual condition is not,
however, the only interpretive move made by ‘person first’ language. As Titchkosky
(2001) and others have pointed out, this way of naming disability underscores it as an
individual condition only and simultaneously to inaugurate it as somehow separate from
the individual (Titchkosky, 2001, p. 135; Sinclair, 1999). Examining, for example, the
phraseology ‘person with autism’, the preposition ‘with’ – wedged between person and
autism – functions, discursively, to separate the ideological category of ‘person’ from a
biomedical condition of ‘autism’. It creates an artificial disconnect between the
individual person and the autism that comes to be associated ‘with’ it as an add-on to this
person. To be ‘with’ autism (and not, for example, to be of it, or in it), is to locate autism
‘with’ the individual while asserting its essential separation from it (Michalko, 1999).
The ‘with’, thus, performs a paradoxical act of separation and association. As a ‘person
first’ lexicon organizes autism into some ‘thing’ located squarely in the individual, it
also, and simultaneously forbids it from being understood as entwined with or integral to a person’s personhood (Michalko, 1999; Overboe, 1999; Titchkosky, 2001; Sinclair, 1999).

Yet, as we analyze the social significance of the ‘living with’ phraseology in terms of a ‘person first’ lexicon, we must account for the meaningful slippage between the expression ‘person with autism” and its vital permutation, ‘person living with autism’. While these two expressions are certainly related linguistic technologies that seem to be utilized interchangeably in everyday talk, they are not, precisely, equivalent formulations and, as such, the interpretive work they perform is not identical. While, in the former phraseology, the word ‘with’, alone, is wedged between the person and the autism, in the latter, two words – ‘living with’ – are wedged between and this difference is significant. While the ‘with’ posits autism as some kind of a personal possession or appendage that has become associated with or tied to an individual person, the ‘living with’ underscores autism as an appendage that has become attached to the life of the person. Where the phrase ‘person with autism’ renders autism as some (undesirable, pathological) ‘thing’ some people happen to ‘have’, the phrase ‘person living with autism’ renders autism as some (undesirable, pathological) ‘thing’ some people have to ‘live with’.

Most interestingly, let us note how the vital permutation of ‘person first’ language has opened up the condition of being ‘with’ (the individualized pathology of) autism to not only include ‘persons living with autism’ as this is conceived of in the strictest sense, but also to include, people who, quite literally, have autism in their lives. Indeed, we are, for example, seemingly, constantly confronted in the media, in advocacy initiatives as well as in everyday conversation with parent narratives that characterize their relationship
with their autistic child in terms of a ‘life with autism’ (McGuire, forthcoming). Families as well as communities, nations and, indeed, (the) united nations are, as we have seen in earlier chapters, all commonly understood – both implicitly and explicitly – as ‘living with autism’. In fact, while each of the examples in the long list above succeeds in confirming autism’s taken-for-granted status as an individual condition, very few of them articulate ‘living with autism’ as a condition of the individual alone.

To better glean this, let us note how Dillon’s (1995) book *Living with Autism* does not recount stories of ‘individuals living with autism’, as it would seem to suggest, but rather tells the stories of individuals (parents, in this case) living with individuals living with autism. Oprah’s (2007) “Living with Autism” episode focused on the narratives and perspectives of relationally non-disabled parents, siblings, advocates and physicians who, in some way, had autism in their lives. Likewise, the Easter Seal Study “Living with Autism” surveyed over 1600 parents of autistic people about their ‘life with autism’ (Easter Seals, 2008). With these examples, it becomes quite evident: another way the phrase ‘living with autism’ comes to be employed and understood in contemporary times is as a way to describe a collective condition of ‘life with’ the individualized condition of autism. This vitalized ‘people first’ system of meaning produces autism (as is, invariably, embodied by an individual autistic person or a group or sub-population of individual autistic people) as a condition afflicting the whole, as some (pathological) element separate from this whole, that has, as a matter of misfortune, attached to collective life.

The hegemonic conceptualization of autism as some pathological ‘thing’ that is not ‘lived’ but ‘lived with’ – where ‘living with’ autism is understood as something done
by both individuals and collectives – points to a significant and central *animus*
underpinning and orienting dominant neo/liberal versions of autism produced and
circulated within the field of advocacy. Moreover, this vital *animus* is generating
particular and significant consequences, both ideological and material.

Going along with the grain of linguistic technologies that characterize autism as
something that is not lived but ‘lived with’, dominant representations of autism produced
and circulated within the contemporary field of autism advocacy singularly depict autism
as an undesirable pathological ‘condition’ of the (social and individual) body, a
‘condition’ that is conditional to particular (unfortunate) individuals and their (equally
unfortunate) families, communities and nations. This pathologization of autism is
endemic to dominant enactments of autism advocacy: in fact, it is by no means an
exaggeration to assert that every mainstream advocacy initiative explored in this
dissertation has been premised on the assumption that autism is some 'thing' one ‘has’
and not someone who ‘is’ (McGuire, forthcoming).

Autism is not a person, we are assured, time and again, although some people do
‘have’ it. It is not a person....it is a puzzle, as we gleaned in Chapter 2. Autism is having
one’s puzzle out of order – a puzzling dis-order that ‘handicaps’ and ‘isolates’, prevents
‘fitting in’. Autism is not a person; it is, as shown in Chapter 3, a series of
‘tendencies’. It is a characteristic “trait” declared Bleuler back in 1911. It is a collection
of “symptoms” calculated Kanner in 1943, it is ‘echolalia’, ‘stereotypy’, ‘literalness’. It
is ‘extreme aloneness’. Autism is not a person, promised a 1960s era Bettelheim, it is a
prison, a shell. It is a “withdrawal” from “humanity”. A chilling effect of a cold mother.
Autism is not a person said Lovass, it is an exhibition of “inappropriate behaviours”. It is
a mind blind to intentionality, according to Baron Cohen. A lack of emotion. A ‘misfiring’ of neurons. A ‘miswired’ brain. It is too high levels of mercury. It is to be in possession of ‘bad’ genes. Autism is, as we were informed by the examples in chapters 4 and 5, to have a body that develops, too slowly, unnaturally, undesirably. Autism is not a person but a red flag.

And, so, it is repeated in posters and slogans, in newspaper articles and in media broadcasts, in novels, in blockbuster films, in advocacy initiatives, in scientific studies and on fast food containers; to ‘live with’ autism (whether it be collectively or individually or both) is to bear pathology. As the living ‘person’ or, perhaps ‘life’ more broadly, is, discursively, made to come before and so to exist as separate from ‘autism’, and as ‘autism’ is transformed into some pathological ‘thing’ that is not of the living person but has, as a matter of misfortune, come to be affixed to this life, we can observe how the vital category of the living person – the vital category of life itself – is emptied, in some essential way, of any possibility of being autistic.

Autism is not an essential part of life, as per the repeated refrain of advocacy. It is, rather, a condition of life; it is that which life must ‘live with’. It is, as we saw in Chapters 4 and 5, that which threatens the “good life” of neoliberal development, that which prevents children, adults, communities and nations from living “fully”. It is, we are promised by world leaders and structures of international governance, that which gets in the way of production and consumption. Autism is not life; it is afflicting life, a disease of epidemic proportions. It is that which infiltrates life’s borders. It is not life, as per the advocacy campaigns analyzed in Chapter 6, it is that which grabs hold of life, builds a wall around life, holds it hostage. It is ruining birthday parties, bankrupting nations,
causing divorce. Autism is not life, it rips life apart; it is scrawled threats writ large on the living. It is, we are told by advocacy over and again, life’s terrifying and terrorizing opponent. Autism is not life, it is nothing more than the ticking sound of life running out.

Life, in other words, is being made a condition of non-autism. And while life is always life, the condition of ‘life with’ autism comes to be immediately understood as a life that bear’s the origin of its own undoing. It is a life under threat and so, is no kind of life at all.

As it ‘lives with’ this maligned and malignant version of autism – an autism that is not a person but a pathogen afflicting a person, an autism that is not lived but is threatening to life – how can advocacy not come into being as that which, as we witnessed in the previous chapter, must wage a (life-saving) war against autism? How can advocacy be anything other than, as in Chapter 4, that which must “watch out” for autism’s presence and work to eliminate its signs of difference? How, in other words, can advocacy live anything other than a (good, neoliberal and, necessarily, non-autistic) life of fighting for – and so securing, attaining, recovering – the vital ‘being’ of non-autism? How, when any alternative to the non-autistic life is so carefully and so thoroughly framed as not life at all?

When autism is not a person but a puzzle, advocacy must (at least try to) solve ‘it’, put order to its inherent dis-order. It must fund, seek out, support and conduct studies to better ‘know’ its pathological origins so as to eliminate these origins, and neutralize their puzzling effects. When autism is not a person but a puzzle, advocacy must not dwell or desire or deal in puzzling uncertainties. Advocacy becomes that which deals with and in the uncomplicated certainty of neat ‘fits’ and good fitness. The
advocate is, as in Chapter 4, the surveiller of bodies and the noticer of red flags. It is that which must be aware, be wary and beware of particular behaviours, certain ways of moving, of acting, of reacting. When autism is not a person but a flag, advocacy becomes that which sees autism and, of course, sees red.

Yet, advocacy ‘sees’ more than ‘just’ red. When autism is not a person but a ‘sign’ or a ‘symptom’, advocacy can ‘see’ red but also is positioned to see beyond it, to see beyond the appendage of autism to the vital promise of an underlying non-autism. When autism is not a person but a ‘sign’ or a ‘symptom’, advocacy can reasonably understand and orient to autistic ways of being as naturally occurring unnatural human deviances that can and must be identified, corrected and unlearned. Advocacy becomes, in other words, that which intervenes early and teaches (or, at least, ensures the teaching of) the moral conduct of ‘proper’ human development.

When autism is denied status as a living ‘someone’ and when those lives that ‘live with’ a (life threatening) autism come to be understood as wasting away and so get cast as ‘at stake’, advocacy therefore and necessarily goes to war and does so, moreover, in the name of the normative promise of non-autism. When autism is not coterminus with life, when it is, rather, understood as a drain on the (good, neo/liberal) processes of living, the work of advocacy becomes the vital and vitalizing work of first protecting/defending the normative borders of non-autistic life and, second, rescuing and recovering those (otherwise non-autistic) individuals or collectives that ‘live with’ autism. When autism is not a life but a spreading epidemic – a terrifying network of pathological cells – advocacy becomes, as in chapters 5 and 6, the search for ways to eliminate autism. Advocacy is redirection, rehabilitation, restraint, recovery or “cure”. It
is security measures and preemptive strikes. When autism is not a life but a partition blockading life, the mission of advocacy becomes to tear autism down with hands bare. When autism is not a cohesive ‘living person’ but a fragmented condition of a ‘person living with’, advocacy can see underlying bodies without ‘symptoms’, minds without ‘blindness’, brains that don’t ‘misfire’. When autism is not a life but a shell surrounding life, advocacy is positioned to see normal kids, as per the opening epigraph, that need to be ‘cracked’ out.

What sensibility of life do such contemporary representations of autism permit us to think, or better, what do they inaugurate? Vis-à-vis all that is recounted in the paragraphs above and all that has come in the pages before, one thing is clear: in our contemporary culture, to ‘live with autism’ is not to dwell in it, or be of it, it is not to desire it, cultivate it, or love it. It is not to advocate for it. Within dominant contemporary discursive spaces of advocacy, to live with autism is to long for life without it. As (normative) acts of “living” as well as living people are relentlessly and meticulously made and kept separate from an extraneous and pathologically threatening “autism”, advocacy is delivered to us, as we have seen, time and again, as that which can – and should – ensure autism’s minimization or, even, its eradication from collective and individual life. And, as I have also suggested throughout this work, this way of conceptualizing and reproducing autism and advocacy – and the relationship between the two – is thick with danger.

**Life without Autism**

As a way to address and assess this danger, I turn next, to a critical consideration of fatal acts of violence against autistic people that have been reported and circulated
through the popular western/ized news media in the past decade, instances that include but are certainly not limited to those that follow:

**Willie Wright**, 15 years old. Willie was asphyxiated on March 4th 2000 while being restrained by hospital staff at Southwest Mental Health Center in San Antonio, USA (“Child Restrained”, 2000).

**Justin Malphus**, 5 years old. Justin was severely beaten to death by his mother, Joyce Malphus, on April 12th 2000 in Georgia, USA. Malphus, then, threw his body into the family pool (Lowery, 2002).

**Wayne Winter**, 39 years old. On the 15th of January 2001, Wayne was asphyxiated while being restrained by three employees at a residential facility in Ontario, Canada (Churchill, 2001).

**Gabriel Britt**, 6 years old. Gabriel was reported missing on March 3rd 2001. His body was found eight days later in a pond near his family’s home in South Carolina, USA. Terrence Britt, Gabriel’s father, was convicted of his death (Ferrell, 2004).

**Mark Owen Young**, Age 11. Mark was murdered on September 17th 2001 in Durham, UK. His mother, Helen Rogan, gave her son and herself prescription drugs, slashed both of their wrists and jumped off a bridge in Derwent Valley (“Mother killed herself and son”, 2002).
**Brahim Dukes**, 18 years old. Brahim was starved to death on December 29th 2001 in the home of his step-mother, Audrey McDaniels, in Philadelphia, USA (Soteropoulos, 2002).

**Matthew Goodman**, 14 years old. Matthew died on February 6th 2002 of respiratory complications and blood infection caused by physical and chemical restraints used by his residential program in New Jersey, USA (Peterson, 2002).

**Lillian Leilani Gill**, 4 years old. Lillian was murdered in March of 2002, by her mother, Sharon Michelle Gill, in Big Bear City, USA (Berry, 2006).

**Dale Bartolome**, 27 years old. Dale was murdered on July 29th, 2002 in California, USA. Dale was shot by his father, Delfin Bartolome in a van in a parking lot outside his school. His father then turned the gun on himself (Tran & Anton, 2002).

**Craig Sorger**, 13 years old. Craig was beaten and stabbed to death on February 15th 2003 in Ephrata, Washington, USA by two of his playmates, 13-year-olds Drake Savoie and Jake Lee Eakin (Dininny, 2006).

**Eric Bland**, 38 years old. Eric starved to death on February 24th 2003 in California, USA by his sister and caregiver, Delores Johnson (Nelson, 2004).
Nozomu Shinozaki, 22 years old. Over the course of three hours on February 25th 2003, Nozomu – a Japanese student going to school in New Zealand – was beaten to death by a mob of nine or more of his schoolmates ("Autistic student killed in three-hour gang attack", 2003).

Jason Dawes, 10 years old. Jason was strangled to death by his mother, Daniela Dawes, in New South Wales, Australia on August 4th 2003 (Lamont, 2004a).

Terrance Cottrell, Jr., 8 years old. On August 22nd 2003, Terrance – "Junior" – was asphyxiated to death in Milwaukee, USA by the Reverend Ray Hemphill at a faith healing ceremony at Faith Temple Church of the Apostolic Faith. Hemphill was attempting to release "demons" from the boy ("Conviction upheld for man who killed boy at church", 2006).

Angelica Auriemma, 20 years old. Angelica was killed on December 5th, 2003 by her mother, Ioanna Auriemma, in Brooklyn, New York. Auriemma drowned her daughter in the bathtub and then attempted to kill herself (Gallahue & Messing, 2003).

Scarlett Chen, 4 years old. Scarlett was drowned in a bathtub by her mother, Xuan Peng, on July 12th 2004 in Toronto, Canada (Small, 2007).
Patrick Markcrow, 36 years old. Patrick was killed by his mother, Wendolyn Markcrow, on March 29th, 2005 in Buckinghamshire, UK. Markcrow drugged and suffocated her son and attempted to kill herself. (Johnston, 2005).

Tiffany Pinckney, 23 years old. Tiffany died on April 2nd 2005 in an upscale neighborhood in Mississauga, Canada due to starvation and gross neglect at the hands of her sister, Allison Cox and Cox’s husband, Orlando Klass (Mitchell, 2008).

Abubakar Nadama, 5 years old. Abubakar died of a heart attack on August 23rd 2005 following a radical experimental ‘chelation therapy’ procedure that was intended to “cure” him of his autism in Pennsylvania, USA (Smith, 2005).

Hansel Cunningham, 30 years old. Hansel died after being tasered and restrained on November 17th 2005 by Des Plaines Police officers at his residential treatment facility in Illinois, USA (Higgins, 2006).

Hevin Dakota Jenkins, 2 years old. Hevin was killed in December 2005 in Huntington, USA by his aunt, Tonya Sloan. Sloan and her boyfriend, Anthony Milam, then, placed Hevin’s body in a trash bag and threw it into a river. The boy’s body was never recovered (Long, 2007).
Ryan Davies, 12 years old. Ryan was murdered in Humberside, England, on April 12th 2006, by his mother, Alison Davies, who also committed suicide. CCTV cameras show Davies took Ryan with her as she jumped off a 100-foot bridge in Humberside, England (Fernand, 2006).

Katie McCarron, 3 years old. Katie was suffocated to death with a plastic garbage bag by her mother, Dr. Karen McCarron, in Illinois, USA on May 13th 2006 (Sampier, 2008a).

Sean Miles, 35 years old. Sean was beaten with a golf club, stabbed in the head and then drowned in the Thames River in Oxford, England in May of 2006 by Edward Doyle, Terry McMaster and Karen Fathers (Wilkinson, 2007).

Marcus Fiesel, 3 years old. Marcus was murdered in September 2006 in Cincinnati, USA by his foster parents, Liz and David Carroll Jr. The couple pinned the boy’s arms behind his back, wrapped him in a blanket, bound him with tape and left him in a closet as they went on vacation (Hassert & White, 2007).

Ulysses Stable, 12 years old. Ulysses was murdered in the Bronx, USA on November 22nd 2006 by his father, Jose Stable. Police officers found Ulysses’ naked body in the bathtub with his throat slit. Said Stable to police: "I terminated the life of my autistic son" (Burke, Gendar & Moore, 2006).
Jonathan Carey, 13 years old. Jonathan died on February 15, 2007 in upstate New York, USA while being restrained. Two employees of the residential facility where he lived, Edwin Tirado and Nadeem Mall, were charged with manslaughter (Morgan Bolton, 2007).

Brandon Williams, 5 years old. Brandon died in Arizona, USA at the hands of his mother, Diane Marsh, and her friend, Flower Tompson. On March 21st 2007. The two fed Brandon a cocktail of sleeping pills and painkillers. An autopsy later revealed that the cause of Brandon’s death was a skull fracture (Smith, 2008).

William H. Lash IV, 12 years old. William was shot to death in July of 2006 in Fairfax County, USA by former assistant secretary of commerce with the Bush administration, William H. Lash, III (Jackman & McCrummen, 2006).

Unnamed girl, 7 years old. Died in November of 2007 in Hawk’s Nest, Australia. The girl was grossly neglected by her parents and was found, starved to death in her own excrement (“Starvation murder trial: girl was autistic”, 2009).

Mohammad Usman Chaudhry, 21 years old. Mohammad was shot three times in the chest by LAPD officer Joseph Cruz on March 25, 2008 in Los Angeles, USA. Mohammad was unarmed (Rubin, 2011).
**Gabriel Poirier**, 9 years old. Gabriel suffocated to death on April 17th 2008 at his school in Quebec, Canada. Gabriel was making loud noises in the classroom when his teacher wrapped the boy four times in a weighted blanket, and left him immobilized on the classroom floor for 20 minutes (Alphonso, 2008).

**Jacob Grabe**, 13 years old. Jacob was shot several times, including once in the head, on September 11th 2008 by his father, Allen Grabe, while he was sleeping in his home in Colorado, USA (Shockley, 2010).

**Kyle Dutter**, 12 years old. Kyle was shot to death in Wisconsin, USA by his father, Ryan Dutter, on November 18th 2008. Dutter, then, shot and killed himself ("Father accused of killing son served in navy, former firefighter", 2008).

**Terrell Stepney**, 19 years old. Terrell was murdered on February 27th 2009 in Chesapeake, Virginia by his grandmother, Constance Stepney, who gave him an overdose of prescription pills. Stepney also committed suicide (Davis, 2009).

**Jeremy LaBrie**, 9 years old. Jeremy died in March of 2009 in Salem, USA after his mother, Kristen Labrie, withheld at least five months of chemotherapy treatment ("Mom sentenced to 8-10 years", 2011).
David Cox, 18 years old. David was beaten to death in the street in June 2009 by a group of teenage strangers in Doncaster, UK (Taylor, 2009).

Michael Vonheath Becht Jr., 10 years old. Michael was killed on July 6, 2009 in St. Paul, USA by his mother, Patti Becht, who gave him a drug overdose. Becht also attempted, unsuccessfully, to kill herself (Simons, 9).

Unnamed Edmonton boy, 11 years old. Killed on September 27th 2009 in Edmonton, Canada by his 39-year-old father, who then killed himself (“Dad in murder-suicide had sought help for autistic son”, 2009).

Unnamed Crestline boy, 9 years old. On October 18th 2009, an unnamed boy from Crestline, California, USA was shot to death by his grandmother and caregiver Denise Snyder. Snyder also shot herself (Pinion-Whitt, 2010).

Tony Khor, 15 years old. Tony was murdered on October 25th 2009 in Mississauga, Ontario, Canada by his mother, Seow Cheng Sim, in a hotel room (Tambar, 2009).

Fabián Duque, 16 years old. Fabián was fatally shot on November 9th, 2009 in a car in Philadelphia, USA by his father Segundo Duque. Duque then shot and killed himself (Farr, 2009).
Walter Knox Hildebrand Jr., 20 years old. Walter died on November 19th 2009, malnourished and assaulted, in California, USA, allegedly, at the hands of his brother and caregiver, Stuart Allen Hildebrand (“Man arrested in death of brother”, 2010).

Timothy Aleshire, 27 years old. Timothy died January 1st 2010 after being restrained by four individuals at his state operated workplace in Eden Prairie, Minnesota, USA (Walsh, 2010).

Jude Mirra, 8 years old. Jude was murdered on February 5th 2010 by his mother, Gigi Jordan, in a room at Fifth Avenue's Peninsula hotel. Jordan allegedly gave Jude a cocktail of ground-up prescription pills and then attempted, unsuccessfully, to kill herself (Baker & Hughes, 2010).

Ajit Singh, 12 years old. Ajit died in London, England, in February 9th 2010 after being forced by his mother, Satpal Kaur-Singh, to ingest a cup of bleach. Kaur-Singh also attempted to kill herself (Gill, 2010).

Steve Eugene Washington, 27 years old. On March 21st 2010, LAPD gang enforcement officers Allan Corrales and George Diego reported that Washington ‘looked suspicious’ and appeared to be removing something from his waistband. Corrales and Diego both fired shots at Washington; one bullet hit him in the head. He was unarmed (Rubin, 2011).
Roland Campbell, 21 years old. Roland died, suddenly, on April 18\textsuperscript{th} 2010 while in police custody in Kentucky, USA. It was ruled that there would be no further inquest in the cause of his death (Kegley, 2010).

Benjamin McLatchie, 22 years old. Benjamin was shot and killed on April 27\textsuperscript{th} 2010 in Portland, Oregon, USA by his father, Daniel McLatchie. McLatchie, then, shot and killed himself (Hench, 2010).

Rylan Rochester, 6 months old. Rylan was smothered to death in Colorado, USA on May 31\textsuperscript{st} 2010 by his mother, Stephanie Rochester, when Rochester began noticing ‘early warning signs’ of autism (McGhee, 2010).

Christopher Melton, 18 years old. Christopher was murdered by his mother, Tracy Hawks, on June 4\textsuperscript{th} 2010 in Howard County, USA. Hawks used a gas generator to suffocate herself and her son (Carson, 2010).

Zain Akhter, 5 years old. Zain was trangled with a wire in Irving, Texas by mother, Saiqa Akhter in July 19\textsuperscript{th} 2010. Akhter then called 9-11 and said: “I killed my kids […] both are autistic. I don’t want my kids to be like that […] I Want normal kids…” (Golstein & Eiserer, 2010; “Mother to 911 - 'I Killed My Kids’”, 2010).

Faryaal Akhter, 2 years old. Faryaal was strangled with a wire in Irving, Texas by mother, Saiqa Akhter. Faryaal died in hospital a day the death of her brother, Zain (above), on July 20\textsuperscript{th} 2010 (Goldstein & Eiserer, 2010).
Kenneth Holmes, 12 years old. Kenneth was shot and killed on the 28th of July 2010 in New York, USA by his mother, Michaela Jackson, who subsequently shot herself (Schram & Bain, 2010).

Jawara Henry, 27-years-old. Jawara was asphyxiated on December 5th 2010 at New York state-run South Beach Psychiatric Center on Staten Island, USA. Henry’s death has been ruled a homicide (Karoliszyn, Parascandola & Paddock, 2010).

Each of these names is a trace of a violence that belongs to a culture…our culture ‘against’ autism: our culture that wars against autism, fights it, combats it, smacks it down. Our culture – of which advocacy is an influential part – that imagines and treats life as conditional and autism as (one of) its condition(s).

Yet, the list is misleading: it is an artifice of cohesion, a singular and uniform gloss for many differences, departures and incongruencies. The many-ness of these names and their stories span countries and continents, a vast breadth of material and social differences and uneven vulnerabilities, all of which I have uneasily – and perhaps even unjustly – brought together into a single column of violence. Indeed, there are many ways we could (and reasons we should) consider these cases individually, examining and weighing their similar or dissimilar properties and thinking through the ways violence is differentially structured by material and social differences. However, in

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1 In chorus and in solidarity with other interested and implicated people who are noticing, documenting and organizing around these deaths on online forums and blogs such as Joel Smith’s (2006) This Way of Life website (2006), Amanda Bagg’s (2008) Ballastexistenz blog, Kristina Chew’s (2009) Autism Vox blog, Michelle Dawson’s (2011) online forum, The Misbehaviour of Behaviourists, and Kathleen Seidel’s (2005a) Neurodiversity website.
strategic resistance to the many ways that both autism and violence against autistic people are systematically and repeatedly splintered and effaced through discourses of individualization, the towering column above and the analysis to come seek not to simply or easily compare or contrast one individual story against another. I attempt, rather, to curate these stories against a backdrop of culture, to let them touch in such a way that neither conflates them into one singular and monolithic story of violence, nor permits us to forget the dangerous repetition and aching frequency with which such violences are occurring in the contemporary west. In the pages to follow, then, I examine how dominant cultural systems of understanding and practices of organizing difference – systems and practices that, always and invariably, as we have seen, structure inequity in unequal and so racist, sexist, heterosexist, classist and ableist terms – provide for a particular, contingent and often near imperceptible shared cultural backdrop that shapes the boundaries of life and the differential acceptability of acts of violence.

However similar or dissimilar these individual stories are, each belongs to and is born of a global and globalizing culture of puzzling threats and eclipsing futures, a culture of red flags and global epidemics, a culture, where we are told, time and again, that the only way that non-autism and autism can ‘live with’ one another is if we believe ourselves to be cleanly split, respectively, into “living people” and “threatening pathologies”, into warriors and enemies.

Vis-à-vis a culture fixated on notions of ‘life with’ autism, I turn, now, to three particular stories of life without it. I look at the murder of 10-year-old Jason Dawes, killed by his mother, Daniela Dawes in 2003, to the murder of 4-year-old Jia Jia “Scarlett” Cheng, killed by her mother, Xuan Peng in 2004 and to the murder of three-
year-old Katherine “Katie” McCarron, killed by her mother, Karen McCarron in 2006. Each are stories of an ‘individual living with autism’ who was murdered by a non-autistic individual ‘living with’ an ‘individual living with autism’. In all three of the stories, ‘autism’ was articulated as the target of – and the underlying reason for – violence.

The Murders of Jason Dawes, Scarlett Chen and Katie McCarron

On the 4th of August 2003, 10-year-old Jason Dawes was suffocated in New South Wales, Australia. His mother, Daniela Dawes, admitted to holding the boy’s mouth and nose shut until he was dead (Lamont, 2004). She then attempted to kill herself, but was discovered and revived. Dawes was subsequently arrested and charged, initially, with murder, a charge that was soon reduced to manslaughter when the Crown accepted that the defendant was experiencing depression at the time of the killing. To this charge of manslaughter due to diminished responsibility, Dawes pled guilty.

Following a series of articles covering Dawes’ sentencing hearing that ran in the Sydney Morning Herald, autism was exposed at the center of this case. “She was a good mother” Herald reporter Leonie Lamont writes, “Dozens of people said so. From her teenage daughter and estranged husband, to the staff at the bank and local video store...” (Lamont, 2004a, para. 1). “How then” Lamont continues: “could this good mother, Daniela Dawes, grip her child's nose and mouth shut, and hold the struggling child until his last, terminal, breath?” How? Autism, it is suggested. “Jason Dawes had severe autism,” reports Lamont, and Dawes – described in the article as a “a crusader for her son” – “battled doggedly for years to get the educational, behavioural and medical support her son needed. The family left Ballina, and returned to Sydney in search of better services – which they didn't get” (Lamont, 2004a, para. 8-9).
The notion of Jason’s potentiality and his future outlook became central to the focus of the articles reporting on the Dawes hearing and its aftermath. Senior Councillor James Bennett spoke at the hearing about a mother growing increasingly concerned about her son’s impeding adulthood. He is quoted in the *Herald* as saying: "In the exchanges between the offender and her husband in weeks preceding these events they both expressed their despair at the future – how were they going to care for this young boy as he entered puberty?" (Lamont, 2004a, para. 23).

On the 2nd of June, 2004, the Parramatta District Court ruled that Dawes be immediately released on a 5-year good behaviour bond for the manslaughter of her 10-year-old son. “Her son died at her own hand” reports the *Herald*, “but a judge ruled yesterday that Daniela Dawes had been through too much to be sent to jail” (Lamont, 2004b, para. 1). As the sentence was handed down, Justice Roy Ellis told the court:

This offender has suffered enough and the circumstances of this offence are so exceptional as to justify the imposition of a non-custodial sentence. All the evidence leads to the inevitable conclusion that this offender will punish herself significantly for the rest of her life [for] taking the life of her beloved son [...] This offender was required to educate, feed, toilet, bathe, entertain and love Jason. She [also] loved and cared for her daughter. She constantly lived with the fact that her son had lost his best chance of acquiring greater life skills because of the failure of authorities to provide appropriate intervention during his early formative years (Lamont, 2004b, para. 3, 10).

Addressing Daniela Dawes directly, Justice Ellis then said: "I wish you all the best” (Lamont, 2004, para. 2).
On the 12th of July 2004, 4-year-old Jia Jia “Scarlett” Chen was drowned in her family’s bathtub in Toronto, Ontario Canada. Nearly six months later, the Toronto police arrested the child’s mother, Xuan Peng, charging her with the first-degree murder of her daughter, a charge which was dropped to second-degree before the case was tried (Huffman & Keung, 2005, p. B01). At her trial, which began in November 2007, Peng pled not-guilty.

A series of Toronto Star articles covering the Peng trial described the case made by the prosecution as a case of autism: “a mother increasingly frustrated with caring for her autistic daughter deliberately drowned the 4-year-old in a bathtub in the family home,” writes Star reporter Peter Small of the prosecution’s allegations (Small, 2007, p. A8). Addressing the Superior Court, Crown Prosecutor Joshua Levy is quoted as saying: “Scarlet was a child that required constant supervision [...] a child in her own world” – a child who was described by her mother, according to the Star, as having “no sense of danger, [a child] who would run into traffic, jump from high places and would only communicate with gestures” (Small, 2007, p. A8). The court heard of a mother with “health problems” – later described as severe depression – who was having trouble managing the care of her daughter.

In a key moment of the trial, the prosecution revealed that mere hours before Scarlett was drowned, the family attended a follow-up appointment with pediatrician Dr. James Leung to discuss the results of some tests Scarlett had had regarding her “developmental delays” (Small, 2008a, p. A16). According to the Star, “Leung told the court the results of the CT scan were normal […] he told the family there was nothing to
be done for the girl surgically” (Small, 2008a, p. A16). Leung told the court that “Peng and her mother peppered him with questions […] asking whether there was any hope” (Small, 2008a, p. A16). "They were disappointed, he said, adding that was a typical reaction for families” (Small, 2008a, p. A16). In the cross-examination, the defense pressed the doctor, who emphasized that he never suggested to the family that there was no hope for Scarlett. "There are all kinds of programs," he said, to help her adjust to the reality that she would always be developmentally delayed” (Small, 2008a, p. A16).

According to Star reporter Donovan Vincent: “her parents were informed that while Scarlett would never function normally, she was only mildly autistic and there was potential for major improvement” (Vincent, 2009, p. GT4). Still, Scarlett was found two hours later, drowned in the bathtub, her body naked and covered in vomit (Vincent, 2009, p. GT4).

On March 1st, 2008 a jury found Xuan Peng guilty of the second-degree murder of her daughter and she was sentenced to life in prison with no chance of parole for 10 years (Powell, 2008, p. A12). However, just over a year later, this sentence was overturned by the Ontario Court of Appeal on account that the original trial judge “effectively excluded” the jury from the possibility of reaching a lesser verdict of manslaughter. Faced with a new trial for manslaughter, Peng, who had, up until then, maintained her innocence, now pled guilty. The Star reports the story of the death of Scarlett Chen, agreed upon by prosecution and defense, as follows:

The 33-year-old mother was trying to put her daughter to sleep so she could do some chores – cleaning and soaking baskets and a shower curtain in the bathtub – but Scarlett wouldn't sit still, let alone lie down. Exhausted, Peng called her
husband - more than a dozen times - asking when he would be coming home to relieve her. It was the middle of July, and hot. Earlier in the day, a doctor told Peng and her husband there would be no "quick fix" for their daughter, who still wasn't speaking. Scarlett would need assistance for the rest of her life and would never function "normally." "Fascinated" by the water, Scarlett wanted to get in the bath. She took off her clothes and tried again and again to climb in the tub. Then, "at her wits end after a day of bad news and the extreme stress of taking care of her autistic child," Scarlett's mom "snapped." She pushed her daughter's head underwater and held it down until she stopped struggling. (Kennedy, 2010, p. GT7)

Following this version of events, counsel from the Crown and the defense reached a plea agreement on a five-year sentence that granted Peng two-for-one credit for the 18 months she had already spent behind bars (Kennedy, 2010, p. GT7). “Given her unique circumstances, especially given the stresses in her life and her mental state, a five-year prison sentence seemed the appropriate range,” said assistant Crown attorney Joshua Levy (Friday, 2010, p. A11). Peng was immediately released from custody to serve three years probation. Outside a Toronto courthouse, a newly freed Peng addressed reporters: “I miss my daughter every day” she said. “I still love my daughter. I hate autism” (Friday, 2010, p. A11).

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On the 13th of May 2006, 3-year-old Katherine “Katie” McCarron was suffocated in her grandmother’s home in Morton, Illinois, USA. Katie’s mother, Dr. Karen
McCarron, confessed that she suffocated Katie with a plastic garbage bag. Hours after Katie’s murder, McCarron attempted suicide. She survived. McCarron was arrested and charged with murder in the first degree, to which she pled not-guilty by reason of insanity.

The McCarron murder trial, which took place in Tazewell County in January of 2008, seemed to revolve around Katie’s autism. Peoria Journal Star reporter Kevin Sampier writes, “All of the witnesses who knew Karen McCarron, a former pathologist, said she was a woman obsessed with curing her daughter's autism and was a perfectionist who would not accept the fact her daughter wasn't "indistinguishable" from her peers” (Sampier, 2008b, p. B1). In a videotaped confession played at the trial, McCarron describes, according to the Journal Star, “the moment she learned Katie had autism and how it changed everything”. McCarron is quoted as saying: "I cried hard when she first got her (autism) diagnosis. Then I stopped crying. I was always trying to figure out how to cure it”. “I tried very hard to lessen the effects of autism," she continued "I sent her to a very good school" (Sampier, 2008c, p. A1).

Shortly after Katie’s diagnosis of autism, she and her father, Paul McCarron spent 18 months in Raleigh, North Carolina so that Katie could attend a clinic that specialized in treating autism. According to the Journal Star, the defendant’s husband took the stand to testify that Katie’s autism was “not severe” and that she “wasn't prone to kicking, screaming, biting or behavior sometimes associated with more severe autism cases”

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2 This is almost a direct quote from famed behaviourist Ole Lovaas, who developed what, is now referred to as the “best practice” therapeutic approach, Applied Behavioural Analysis. He said that intensive behavior therapy was necessary to ensure that autistic children became “indistinguishable from their normal friends” (Lovaas, 1987, p. 8). See page 52 in chapter 3.
"Katie was always a well-behaved little girl," he said, adding that she was developmentally behind for her age but [had] learned the alphabet, knew shapes and colors, and recognized various animals" (Sampier, 2008a, p. A1). While Katie’s father was pleased with the developmental progress she was making, McCarron was dissatisfied. “I didn't know what to do,” said McCarron in her videotaped confession, “she was not learning at a rate I would expect . . .” (McDonald, 2007, p. B1). "Everything I tried to do didn't help her" she said, "[Katie] was a tough nut to crack (McDonald, 2007, p. B1). Indeed, according the Journal Star, family members and friends who testified at the trial reported that “the progress Katie made was never good enough for McCarron, who was constantly critical of the girl” (Sampier, 2008c, p. A1). According to the Journal Star, “the topic of every conversation with her revolved around curing Katie's autism. Negativity and hatefulfulness were ceaseless when she discussed the child, who they say she never hugged, kissed or praised after she was diagnosed with autism” (Sampier, 2008b, B1). “It was never good enough”, testified family member Jennifer McCarron, “She looked at Katie as a problem, and she got rid of her problem. There's nothing more to it than that” (Sampier, 2008b, p. B1).

Yet, McCarron’s own testimony suggests there was something more going on than ‘merely’ understanding Katie as a problem. Most notably, in her videotaped confession, McCarron is seen to identify autism – and not Katie – as the source of her problem – the object, even, of a deep hatred. She said: "I loved Katie very much, but I hated the autism so, so much, ...I hated what it was doing to her. ... I just wanted autism out of my life" (Sampier, 2008c, p. A1). Of her decision to kill Katie, she said: "maybe I could fix her this way, and in heaven she would be complete" (Sampier, 2008c, p. A1).
In a most striking moment, defense lawyer Marc Wolfe questioned McCarron on the stand about her daughter’s murder. The exchange was reported in the *Journal Star* as follows:

(Defense lawyer) Wolfe: When you were suffocating your daughter, did you think you were killing her?

McCarron: No.

Wolfe: Who did you think you were killing?

McCarron: Autism.

(Sampier, 2008c, p. A1).

On January 17th, 2008, Dr. McCarron was convicted of the murder of her daughter in the first degree and was given a life sentence of 36 years in prison.

**Making Sense of Murder**

My interest in the re/telling of these stories of violence, is not, at least strictly speaking, a search for quick or easy origins. I do not, in other words, attempt to empirically decipher who or what is responsible for the violence enacted against these three children. My critique – an interpretive one – resists the (persistent, seductive, collective) desire for moral clarity in favour of an analysis of the ways violence is functioning in our culture – how this violence is made possible and even how it is framed as necessary. Rather than attempting to isolate an underlying cause, these instances of violence against autistic people must be read as an immediate cause for concern, an observation that demands that we – all of us ‘living with autism’ and so all of us who
belong to and participate in the making of this culture – look again to the cultural meanings we are making of autism and non-autism and the relationship between the two.

I suggested, earlier, that the conceptualization of autism as some pathological ‘thing’ that is not ‘lived’ but ‘lived with’ – where this ‘living with’ is understood, implicitly, as something done by both individuals and collectives – is animating dominant enactments of autism advocacy in this contemporary moment. I suggested, too, that this animus is generating significant ideological and material consequences. Let us examine this further and in relation to the stories of violence detailed above.

In the media coverage of the Dawes, Peng and McCarron trials, respectively, autism was never considered as a life. To the contrary, it was narrated – in the newspaper headlines and in the articles that followed them, from the defense strategies to those of the prosecution, from the perpetrators confessions to witness testimonials to the judges final pronouncements – as nothing more than life’s unfortunate and undesirable condition, a condition, moreover, that, discursively, served the purpose of rendering thinkable the seemingly unthinkable: the act of murdering one’s own child. Indeed, autism, conceived of as life’s unfortunate and undesirable condition, became a central way of understanding and, indeed, making sense of the seemingly non-sensical act of infanticide. The murders of Jason Dawes, Scarlett Cheng and Katie McCarron were transformed by the media and by the courts into nothing more than unfortunate and undesirable outcomes of the unfortunate and undesirable condition of “living with autism”.

Let us note, for example, how – and to what end – these three stories seem to revolve around the biomedical ‘fact’ that all victims had been diagnosed with autism.
Autism anchored these stories and became a kind of *leitmotif* tying together and making sense of a narrative of violence. Newspaper headlines announcing the murders and, later, those that charted the trial and the convictions almost always made mention of Jason, Scarlett and Katie’s autism – “Mom killed autistic girl...”; “Mom jailed for killing autistic daughter”; “Boy’s death vents despair over autism”; “Daughter's murder puts focus on toll of autism” and so on – and the articles that followed them place autism at the center of the act of violence. According to the *Herald*, Dawes was a mother who looked at her autistic son’s future with “despair”. The *Star* framed Peng as “a mother increasingly frustrated with caring for her autistic daughter” (Small, 2007, p. A8). Likewise, the *Journal Star* describes McCarron as “a woman obsessed with curing her daughter’s autism” (Sampier, 2008c, p. A1). Desperation. Frustration. Obsession. The very motives of murder are understood as revolving around and contingent upon the shared ‘fact’ that both victim and perpetrator were stuck living ‘with’ autism.

And, yet, most astonishingly (or perhaps, given our cultural orientation to autism, not astonishing at all), the relentless referencing of Jason, Scarlett and Katie’s autism was seldom – if ever – evoked, at least in the mainstream media, to argue that these three children were, in fact, victims of systemic oppression or targets of disability hate crimes. In order for their deaths to be conceived of as such, Jason, Scarlett and Katie’s autism must have first been conceived of as integrally bound up with who these children were and how they lived. It was not. Instead, autism was understood in these stories of violence, along the dominant lines of our culture, a culture that commits itself, over and over again, to the belief that autism is some pathological condition of life, some ‘thing’
that is, somehow, fundamentally separate from life and some ‘thing’ that, in the name of life, must be fixed, cured, eliminated, lessened.

**Autism as the Origin of Pathology**

In chapter 3, I touched, briefly, upon the normative structures surrounding the role of the ‘good’ mother. As many feminist scholars have argued, the ‘mother’ most often appears against a naturalized moral backdrop that figures ‘motherhood’ as the “supreme calling” of the woman – a “happy achievement, a heavenly blessing, a womanly profession, the consummate feminine achievement” (Barnett, 2006, p. 411). And, it is against this normative background of the good mother who loves, protects, nurtures and cares for her children that narratives of the ‘bad’ (and sometimes the ‘mad’) mother appears. Rebecca Hyman writes: “cases of maternal infanticide are gripping because they seem to violate an inherent natural law, calling into question the essentialist notion that women are endowed with a nurturing maternal instinct” (Hyman, 2004, p. 192). When we come face to face with a (seeming) departure from (mothering) nature – when we are forced to confront a defiance of the presumed natural state where mothers would and could not harm their children – it grips us, and we require further explanation. The unnatural abomination of infanticide, in other words, requires an etiological origin story. For example, when Andrea Yates drowned her 5 small children in their family bathtub in 2001, many (etiological) explanations were offered, ranging from stories of her ‘bad’ moral character (she was often characterized as ‘evil’ or as a ‘monster’), to stories of her religious fanaticism (she was described as a ‘fervent Christian’ who believed ‘god told her to kill her children’) to stories of her biomedical status and history of madness (she
was described as ‘mentally ill’ exhibiting acute ‘psychosis’ brought on by ‘postpartum depression’) (Hyman, 2004).

With respect to the McCarron, Peng and Dawes murders, autism was cast as the primary explanatory origin story. Indeed, media coverage of the three murders, and the trials that followed, frequently treated the (pathological condition of) autism as the only ‘backstory’ of the murders that seemed to matter. A great many news stories reporting on the murders and their trials referenced autism’s ‘red flag’ signs and symptoms, its genetic predispositions, the numbers it has ‘claimed’ and the frequency of its ‘hits’. Reporting on the Jason Dawes case, Leonie Lamont, of the *Sydney Morning Herald*, writes: “The Autism Council of Australia estimates there are 43,000 people in [New South Wales] with the disorder, including 11000 children and teenagers. Worldwide there [is] an epidemic in the numbers of children born with autism spectrum disorder” (Lamont, 2004a, para. 18). “Classic symptoms include lack of eye contact, trouble with social interactions, repetitive behavior and a rigid reliance on routines” states an article from the *Chicago Tribune* reporting on the Katie McCarron murder, “in more severe cases, children are extremely difficult to manage, sometimes causing injury to themselves and others” (Breslin, 2006, para. 10).

Indeed, in all three stories, the moment the children were first diagnosed ‘with autism’ was implicitly put forward as a marker of the beginning of the events that ended in their murder. If Peng’s motive for killing Scarlett was “frustration”, for example, it was a frustration that had its origins in Scarlett’s diagnosis of autism: “The same afternoon Scarlett was diagnosed” reports the *National Post*, “[...] frustrated by her daughter's disruptive behaviour, Peng pushed her daughter's head underwater in the
family bathtub” (Friday, 2010, p. A11). Similarly, if McCarron’s motive for killing Katie was an ‘obsession’ with ‘curing her autism’, it was an obsession that began with Katies’ diagnosis. In the words of McCarron herself: "I cried hard when she first got her (autism) diagnosis. Then I stopped crying. I was always trying to figure out how to cure it" (Sampier, 2008c, p.A1). Autism was implicitly understood, in other words, as the beginning of the end of the lives of the three children: the impetus for violence and the underlying reason for the trials.

It might be argued that autism was only one of many origin stories evoked to explain the murders of Jason, Scarlett and Katie. In some sense, this is true. Dawes, Peng and McCarron were each, for example, differentially positioned in terms of their social class, and, so, in terms of the resources they had at their disposal. While Dawes, for example, was described as working tirelessly to care for her son and to secure him resources, McCarron was framed as having all the resources and access to all the therapies. Additionally, each of the defendants was described as experiencing “severe depression” leading up to the murders. Neither dismissing the material distinctions of Dawes, Peng and McCarron’s differential experiences of social class and/or mental disability, nor forgetting the ways in which these distinctions are, invariably, structured in inequitable and oppressive ways, we must also note, however, how such differences only came to matter as secondary characteristics flowing from and exacerbated by an underlying condition of living with autism. This is evident, for example, in empirical studies such as Piven et al.’s (1991), “Psychiatric disorders in the parents of autistic individuals,” – which postulates a higher prevalence of affective disorders in parents of autistic children, a prevalence that is attributed, in part, to “the stress of raising a handicapped child” (p. 477) – but also in more commonsensical speculations. Such
commonsense understandings of autism as ‘naturally’ and self-evidently depressing is evident in the following statement from a local Australian newspaper covering the Dawes murder: “Frustration, stress and depression can become the norm for both autistic people and their carers” (Walker, 2004, p. 21). In some sense, autism came to be understood as the singular and underlying pathology that Dawes, Peng and McCarron were ‘living with’. The sole salient detail of the defendant’s ‘backstory’ and the only pertinent beginning point of the murder timeline, was the biomedical diagnosis of autism, a diagnosis that was narrated in all cases as the (tragic) confirmation that what were once “just lives” – just kids, just parents, just families – had become “lives with” autism’s pathology.

Autism as a Waning Spectrum of Life

The murder trial, at least in some sense, is charged with the task of reckoning with fatal acts of violence. It is, in other words, charged with piecing together, and, ultimately, (re)telling the story of violence so as to appraise this story in relation to the normative rules of conduct – both written and unwritten – in a given social order. In this (neo/liberal) social order, as I have argued in earlier chapters, the normative rule that rules all others, is the rule of life. And, it is this transcendent and vital(izing) rule that is functioning to govern the possibilities for collectively reckoning with the (autistic) lives and deaths of, among others, Jason Dawes, Scarlett Cheng and Katie McCarron. In the news reports of the murders and the ensuing murder trials, the meaning of “life with autism” – conceived of as a condition of the life of the individual and of the collective – was at once made conditional to (and so obscured by) questions of autism’s “severity” and of the subsequent “potential” of (all) life living ‘with’ it. This is evident in the three,
respective, trials where the biomedical status of the victim – and his or her subsequent ‘potential’ – became a materially salient detail that was evoked, substantiated, contested and debated over and again. Let us consider further this preoccupation not only with the victim’s status as autistic but also with the collective fixation on the relative degree of ‘severity’ of the autism that the victims (and the parents) were understood to have ‘had’ to ‘live with’.

Ten-year-old Jason Dawes was described, time and again, in the papers and in the courts as having had “severe autism”. His mother, Daniela Dawes, in the words of the judge presiding over her sentencing hearing, “was required to educate, feed, toilet, bathe, entertain and love” him (Lamont, 2004b, para. 10). Four-year-old Scarlett Cheng, although diagnosed as “mildly autistic”, was, nonetheless, framed as exhibiting some of autism’s “severe” symptoms. In the words of the Judge presiding over Peng’s re-trial, Scarlett “still wasn’t speaking” and would have “require(d) assistance for the rest of her life and would never function ‘normally’” (Kennedy, 2010, p. GT7). Three-year-old Katie McCarron’s autism, by contrast, was described over and again as “not severe”. In Paul McCarron’s words, "Katie was always a well-behaved little girl" and, according to the Journal Star, she “wasn't prone to kicking, screaming, biting or behavior sometimes associated with more severe autism cases” (Sampier, 2008a, p. A1).

Recalling the historical genealogy from Chapter 3, autism was re-articulated in 1994, in the DSM-IV, not only as a disorder afflicting the individual but as a spectrum of disorders of greater or lesser ‘severity’. To this day, then, autism is not so much biomedically (and so dominantly) recognized as a coherent and/or consistent group of pathological ‘signs’ and ‘symptoms’ but is recognized, rather, as encompassing a
‘spectral’ range of many different pathological referents anchored by oppositional (and correspondingly moral) poles of severity. Individuals ‘living with’ a so-called “mild” “case” of autism, then, are (hierarchically) coded, as living in a state of “high functioning” (i.e., can function ‘well’ in normative terms, can ‘fit into’ normative culture and are positioned as close to and can even ‘pass’ as non-autistic). Meanwhile, on the other end of the spectrum, individuals “living with” a “severe” “case” of autism are understood to be living in a state of “low functioning” (i.e., cannot function ‘well’ in normative terms, cannot ‘fit into’ normative culture, cannot or do not ‘pass’).

If autism is not a life but is – as per the dominant refrain of our culture – that which must be lived with…if autism is not, in other words, conceived of as (integral to) a living person, but is, instead, understood as a pathology that has become attached to a living person, it follows that a person ‘living with’ autism is a person whose relative ‘amount’ or ‘quality’ of life is and can be determined through a calculus of autism’s severity. The implicit logic goes something like this: if a “mild” autism (as pathology) becomes attached to life, this (inherently normative) life is mostly unafflicted and unaffected. In other words, normative life – unquestionably naturalized as inherently healthy and apolitically understood as at once good and desirable – is (at least mostly) unencumbered, permitted to thrive. However, as the “severity” of autism’s pathology increases, and as it increases its hold on life, (normative) life is understood to be ever more compromised: weakened, siphoned, lessened. Under such a logic, the relationship between autism and non-autism is split into a simple binary, with neither complexity nor nuance. Non-autism is hope where autism is hopelessness. Non-autism is life, where autism is a life-draining pathology. What is more, as non-autism is understood to be life
and autism representative of a negative spectrum of biopolitical death, the non-autistic
life 'living with' autism – whether this is the life of the individual with autism or the
individual or collective living with an individual living with autism – is re-framed not
only as a life tied to death, as we all invariably are, but as a life affixed to and with death.
A life, in other words, without the possibility of moving toward life.

In the three cases detailed above, as each individual instance of autism was
unquestionably evoked and defined – in both medical and moral terms – as a pathological
threat to life of greater or lesser severity, the lives and deaths of the three children were
understood and reckoned with – in the courts and in the media – in particular and
contingent ways. While Katie’s ‘case’ of autism, was repeatedly narrated as “mild”, and
as minimally affecting her own (normative) life and the (normative) lives of those around
her, Jason and Scarlett’s ‘cases’ of autism, were narrated in invasive and ‘profound’
terms. Jason and Scarlett’s autism was understood as inhibiting them (and their
respective parents, who ‘lived with’ them and their autism) from fitting in to the
normative order of life: a vital and vitalizing order where parents ought not be required to
bathe and toilet (and love!) their 10-year-olds and where children ought to be endowed
with the promise of growing up to become “fully” independent adults. In other words,
Jason and Scarlett’s autism was framed and so understood as inhibiting and even draining
their (otherwise normative) lives and the (otherwise normative) lives of their parents,
families and communities. Their lives “with autism”, in other words, were understood as
transgressing the liberal rule of life.

Yet, just as we are confronted with this rather bleak image of autism wasting
away (normative) life – an image that represents a violation of the liberal demand for life
– the spectral quality of this post DSM-IV version of autism, not as a static pathology but as a fluid range of pathologies, together with the mechanistic moral hierarchy of ‘higher’ or ‘lower’ ‘functionality’, offers a hopeful narrative of the possibility for an incremental recovery of (normative) life. As mechanistic paradigms of (higher or lower) functionality promise the possibility for ‘improvement’ (read: normalization), the moral hierarchy of the spectrum itself leads us to the understanding that ‘life with autism’ always can and ought to be actively moving along the gradations of difference toward the most vital pole of ‘life without it’. Under a rule of life, then, the only way for autism and non-autism to live together is if the pathology of autism is demonstrably moving (along the spectrum) toward the vital life of non-autism. This story of pathology and potentiality was crucial to the enactments of violence against Jason, Scarlett and Katie and to the ways such violence was subsequently reckoned with and normalized.

Fixing Autism

Let us return, once again, to the stories of violence pieced together above. Even as Jason Dawes was narrated as “severely autistic”, his life was not, interestingly enough, understood to be, by virtue of the “severity” of his autism, ipso facto without potential (Lamont, 2004a, para. 1). Rather, the narrative of his life and death tells the story of a life that had, gradually, lost its vital potential. Daniela Dawes was called a “crusader for her son”, having “battled doggedly for years to get the educational, behavioural and medical support her son needed”, moving the family around to secure the best treatments and services – treatments and services they “didn’t get” (Lamont, 2004a, para. 24, 8). Jason was narrated as entering puberty at the time he was killed and, at this time, time was understood to have run out. According to the Herald, “when Jason was diagnosed with
autism at 18 months, doctors had recommended he get 20 hours of early intervention help a week. All his parents could secure for him was three hours a week” (Lamont, 2004a, para. 16). By ten years old, Jason had outgrown the crucial ‘window’ of opportunity where his “severe autism” might have been lessened by early intervention therapies. And so, the child was, in words of defense lawyer, Roland Bonnici, “doomed” (Lamont, 2004a, para. 16). Jason’s ‘life with’ autism had, in other words, become understood as fixed on the wrong end of the vital spectrum and his mother was understood as having to ‘live with’ the fixity of this ostensibly non-vital state. Said Judge Roy Ellis: “[Daniela Dawes] constantly lived with the fact that her son had lost his best chance of acquiring greater life skills because of the failure of authorities to provide appropriate intervention during his early formative years” (Lamont, 2004b, para. 10). And so Daniela Dawes, whose life and the life of her son came to be understood as being, “with autism” in a permanent way, was subsequently interpreted as having been “driven” to commit a “tragic” but, nonetheless, vital (life saving) act of murdering her 10-year-old child – an act that, under a liberal rule of life, was coded as both reasonable and, even, as necessary (Lamont, 2004a, para. 1, 19).

Scarlett Cheng’s life, too, was framed as “fixed” to and on the autism spectrum, although the narrative of this fixity differs in some ways from Jason’s story above. Unlike Jason’s autism, Scarlett’s autism was described as “mild” and, what is more, at only four-years-old, she was still young (Vincent, 2009, p. GT4). She was still in her ‘formative’ years. She had not, according to dominant biomedical discourse, (entirely) missed that crucial “window” for early intervention where therapies might optimize life by lessening autism. According to the Star, “while Scarlett would never function
normally, she was only mildly autistic and there was potential for major improvement” (Vincent, 2009, p. GT4). Yet, even with a promise of life without autism – a unfulfillable promise that, as we shall see is, in and of itself, a damaging and dangerous one – Scarlett’s mother, Xuan Peng, was said to want a “quick fix”, a rapid return to normalcy that Scarlett’s doctor told her would never happen entirely (Small, 2008a, p. A16). On the day Scarlett was killed, Dr. Leung told the family “there was nothing to be done for the girl surgically” and that, while “there are all kinds of programs” that might help move Scarlett toward the vital end of the spectrum, the “reality” was, he said, Scarlett would “always be developmentally delayed” (Small, 2008a, p. A16). According to the Star, “Scarlett would need assistance for the rest of her life and would never function "normally" (Kennedy, 2010, p. GT7).

For Xuan Peng, the “reality” that her daughter could not be “fixed” – and quickly – served to affix both Scarlett and her mother to a ‘life with’ autism, a shared life that was not understood to be moving forward along the moral and medical gradients of the spectrum (or, at least, was not understood as moving fast enough) toward the vital life of non-autism. Stuck with autism, Scarlett and her mother’s shared life was framed as wasting and this version of ‘life with’ autism – combined with the “constant” non-normative demands made by Scarlett (and compounded, according to the judge, by the ‘hot’ July weather!) – was too much to ‘live with’. "At her wits end after a day of bad news [that there would be no “quick fix”] and the extreme stress of taking care of her autistic child”, Xuan Peng, in the words of the Justice Ian Nordheimer, “simply” and “tragically” “snapped” pushing her daughter’s head under the water and holding her there until she died (Friday, 2010, p. A11; Kennedy, 2010, p. GT7). This act of violence was,
moreover, made sensical (normalized) as a “tragic” but vital act that – reasonably and even necessarily – severed the tie between (normative) life and (a life draining) autism.

The story of the life and death of Katie McCarron presents us with still another permutation of the dangerous story of what happens when autism and non-autism are understood as “fixed” together. Like Scarlett’s autism, Katie’s autism was described as “not severe” (Sampier, 2008a, p. A1). Katie was “always a well-behaved little girl”. Compliant with the demands of normative conduct, she would never kick or scream or bite, according to her father, as is sometimes the case with more “severe” cases of autism. And on top of already being understood as being at the “good” or vital end of the autism spectrum, Katie’s parents had the means to send a two-year-old, very ‘formative’, Katie to a top-notch out of state school where she received the latest therapeutic ‘interventions’. Said Karen McCarron, “I tried very hard to lessen the effects of autism,” she said "I sent her to a very good school" (Sampier, 2008c, p. A1).

According to her father and her extended family, Katie had been making great (normative) progress, hurriedly catching up to her developmental milestones. Paul McCarron did note that while Katie was still “developmentally behind for her age”, at the age of three she had already “learned the alphabet, knew shapes and colors, and recognized various animals” (Sampier, 2008a, p. A1). Yet, despite Katie’s purported proximity to the markers and milestones of normativity, her mother saw a (normative or non-autistic) child that was ‘unfixable’ insofar as she was ‘fixed’ with and to her autism. And, so, Katie, too, was killed.

Most interestingly, unlike the ways in which the Dawes and Peng cases were received and reckoned with, the murder of Katie McCarron was not represented by the
courts or in the newspapers as a condition of how severe or demanding or trying (her) autism was, Katie’s autism was understood to be “mild”, her behaviours were described as “good”, palatable, approximating the norm. Neither was Katie’s murder made to be a condition of the accessibility or availability of resources. Her family was privileged; they were white, wealthy, educated and otherwise well positioned to secure the earliest diagnoses and the best medical opinions. They had help in the home and access to the latest rehabilitation treatments. Early ‘warning signs’ were noticed in ‘good time’. An early diagnosis of “mild autism” was attained ‘on time’. Early interventions were procured before it was ‘too late’. The child was responding to these treatments and normative progress was being made. By all accounts, Katie was catching up to her milestones, moving toward normality.

Indeed, it was this portrait of a three-year-old child with autism who was rapidly moving in the right and vital direction of life without it that led many to conclude that – unlike, say, the violent acts of Xuan Peng and Daniela Dawes that were understood to be caused by autism – McCarron’s act of killing her daughter had little to do with autism at all (Luciano, 2006, p. A1). In a statement to reporters, Katie’s grandfather, Michael McCarron said:

I am positively revolted when I read quotes that would imply any degree of understanding or hint at condoning the taking of my granddaughter's life [...] [this is] a very straight-forward murder case. This was not about autism. [...] We're not dealing with desperation here. We're not dealing with 'we have to end this child's pain. (Luciano, 2006, p. A1)
Yet, vis-à-vis Karen McCarron’s confession that explicitly describes her hate of autism, as well as her intent to kill it, how could this murder not be “about autism”? It most certainly had everything to do with autism. As Michael McCarron moves to distance Katie’s murder from an ‘autism murder’, what is revealed is the implicit, taken-for-granted understanding that a murder motivated by autism is a murder that, at least in some sense, is understandable, condonable, necessary, even. I move now to further explore this conceptual – and materially salient – split between ‘necessary’ murders and ‘unnecessary’ or ‘murderous’ murders with respect to a negative (life-draining) spectrum of autism.

‘Almost living’, ‘mostly dead’

In his haunting chapter, “Coming face-to-face with suffering”, Michalko (2002) grapples with meanings made of the life and death of Tracy Latimer, the 12-year-old Canadian girl with Cerebral Palsy who was murdered by her father, Robert Latimer in October of 1993. Tracy was described, by the courts and the media, by her physicians and by her parents as having had to ‘live with’ a “severe disability”, a disability that caused her to experience “severe pain” (Michalko, 2002, p. 104). Because of the ‘severity’ of Tracy’s disability and pain, for Latimer himself, as well as for those who supported him, “killing Tracy was an ‘act of mercy’ and not a criminal act” (Michalko, 2002, p. 104).

Throughout his chapter, Michalko reckons with the ways in which Tracy’s death – her murder – were reckoned with by the parties involved and by the public at large and he reveals how modes of reckoning with murder reflect the conditions under which Tracy’s death became possible and, in the minds of many, acceptable. Michalko shows how Tracy’s murder was, in other words, widely understood as a ‘necessary’ murder and
not a ‘murderous’ one and he does this by revealing how our ways of making sense of death have everything to do with our ways of making sense of life.

The dominant sentiment surrounding the Latimer case was that this was a case about pain: “severe” suffering. Yet, Michalko’s analysis of the event of Tracy’s murder demonstrates otherwise. He writes:

Contrary to all opinion about the Latimer case – that of the media, of the courts and of Latimer himself – his problem is not born of suffering. Latimer ‘knows’ suffering all too well and he can recognize it when he ‘sees’ it. For him, no mistake, Tracy was suffering. Latimer was equally firm in his knowledge of what to do about it – eliminate it. For him, ‘do the right thing’, eliminate Tracy’s suffering through the only available means, eliminate Tracy. Latimer had resolved the question of suffering, and what to do about it, long before Tracy’s birth. (Michalko, 2002, p. 107)

The problem of Tracy’s life and death was, according to Michalko, rather, a problem of normalcy. “Severely” disabled, Tracy was also “severely” distanced from the vital and morally good pole of normality. He suggests that the lives of disabled people are governed and evaluated by a “rationality of opposites”. Michalko writes: “thought of as the opposite of able-bodiedness, disability, and the lives of its people, is judged second-rate at best and unworthy at worst” (Michalko, 2002, p. 108).

For Michalko, one portion of the trial transcript in particular, was highly instructive in this regard. What follows is an excerpt of trial testimony given by
Latimer’s wife – and Tracy’s mother – Laura Latimer as she was questioned by the defense:

Defense lawyer: As Tracy developed in her first year, was there any suggestion that Tracy would not live at home?

Laura Latimer: No. – when she was born? No.

Defense lawyer: What were your hopes for her at that stage?

Laura Latimer: When we very first took Tracy home we knew that she had brain damage but they said it might be very mild or it might be worse. We…had every hope that…she would be able to go to school but would just be maybe slow in school…We tried to treat her like a normal child…we tried to make her life as normal as we could.

Defense Lawyer: How did you feel after Tracy died?

Laura Latimer: When I found Tracy I was happy for her…I was happy because she didn’t have to deal with her pain anymore. After she died…I don’t even know if I cried. Tracy’s her birth was way, way sadder than her death…we lost Tracy when she was born and…that’s when I grieved for her…I did all my grieving for her when she was little. We lost her then.

(Quoted in Michalko, 2002, p. 105-106)
Tracy, according to her mother, was “lost” not at the moment of her death – the moment she was killed – but at the moment she was given birth, the moment she was given life. Tracy was born ‘with’ cerebral palsy: she was born ‘with’ a permanent and pathologized ‘brain damage’ and, so, in Michalko’s (2002) words, “she was born without the prerequisite condition of normalcy (nondamaged brain)” (p. 109). Born ‘with’ all of this, Tracy was also born into the understanding that her life was to be forever affixed to life’s absence. Her parents “tried” to “treat her like a normal child” and “tried to make her life as normal as [they] could”, but Tracy did not approximate normalcy. As per her mother’s testimony, her vital life was expelled from the world the moment it entered it. Michalko concludes his analysis with the chilling observation, “the loss of normalcy and personhood – the loss of Tracy – occurred at her birth and her actual death was inevitable and anticlimactic. Robert Latimer killed his already dead daughter. As he said, no crime was committed; he did the right thing” (Michalko, 2002, p. 110).

Returning to my analysis of the Dawes, Peng and McCarron cases, which I understand to be not individual and isolated cases, but related disability-motivated murders, it becomes clear that these cases are bound to the Latimer case by a continuous logic. Much like the case of Tracy Latimer, the murders of Jason Dawes, Scarlett Cheng and Katie McCarron were also “governed and evaluated by a rationality of opposites”. In the three cases detailed, as per my analysis above, non-autism was made synonymous with hope and possibility, while autism came to be understood as hopelessness and limit. Where non-autism was conceived of as life, autism was made a life-draining pathology. Yet, the vital/izing conceptual device of the ‘autism spectrum’, a device which both
allows and obliges us to think about autism\(^3\) as a vital range of abnormalities of differing severities, and that was very much at the center of the three autism murder trials, reveals something of the governing power of an oppositional rationality.

As we have already seen, insofar as it is anchored by (hierarchical) poles of a ‘non-vital’, abnormal autism and a ‘vital’, normal non-autism, the autism spectrum (of life), supports and sustains such a “rationality of opposites”. Yet, in examining the three cases of violence against autistic people detailed above, this ‘rationality of opposites’ is doing something other than setting up the strict ‘either/or’ way of knowing disabled life that Michalko, correctly, identifies was at work in the Latimer case (Michalko, 2002, p. 108). Tracy was born into the biomedical category of ‘severe’ (non-vital) disability and so was born into death. Jason, Scarlett, and Katie were ‘born’ into an autism spectrum of life where the non-vital limit of ‘severe’ disability was but one of many intermediary possibilities of living and dying. The spectral quality of the autism spectrum, as a conceptual device for thinking about a range of autism ‘severities’, in turn, gives birth to a whole range of vital possibilities and non-vital limits within the category of autism itself: it inaugurates many, small and incremental ways of ‘living’ and, also and necessarily, many and incremental ways of ‘dying’. In this way, the autism spectrum inaugurates an array of new kinds of living people: people who ‘live with’ a pathological (life-threatening) autism. ‘Not yet’ living people who – depending on the ‘severity’ of their (non-vital) signs of autism and the degree to which they (can) approximate the

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\(^3\) As well as a range of other impairments that have been transformed, in recent times, into ‘spectrum disorders’, ‘Fetal Alcohol Spectrum Disorder’, ‘Obsessive Compulsive Spectrum Disorder’ to name just two.
(vital) signs of non-autism or normalcy – become conceptually understood as ‘almost living’ or ‘mostly dead’.

This subtle logic structured the autism murder cases of Dawes, Peng and McCarron. Unlike the violent acts of Dawes or Peng which were discursively naturalized as ‘necessary’ murders for they performed the vital function of preventing autism from further laying waste to (normative) life – acts that were rendered permissible by the courts and by the media accordingly – McCarron’s act of violence was recognized as, unnaturally, and so unjustifiably, taking life. In accordance with a liberal logic of life and its calculus of pathological severity, the fatal violence inflicted on Katie was judged to be characteristic of a non-vital or ‘murderous’ violence. It was understood, in other words, as a violence that was enacted in name of death and not life. While Peng and Dawes were framed and so understood as performing the vital act of releasing themselves and their ‘almost-dead’ children from autism’s morbid grip, McCarron was framed, and so understood as taking the life of her ‘almost-living’ child. Peng and Dawes were freed to resume their lives. Karen McCarron was sentenced to life in prison.

Because Karen McCarron’s violent action (and Katie’s subsequent death) was not naturalized, normalized, and so obscured as a “tragic” though reasonable outcome of life with autism, as were the actions of Peng and Dawes, this third case permits us – if not compels us – to think more and think again about how acts of violence directed against autistic people – acts of violence that are, quite evidently, endemic to our contemporary culture – are supported by hegemonic understandings of the meaning of “life with autism”. Katie McCarron’s murder, Karen McCarron’s confession and the ensuing murder trial makes explicit the danger of dominant contemporary understandings of “life
with autism” and, in so doing, it better positions us to glean an underlying story that remains (nearly) obscured in the Dawes and the Cheng murders and in our contemporary cultural backdrop out of which these cases of violence emerge and against which they are, subsequently, reckoned with. More specifically, what the lives and deaths of all three kids show us – and what the case of Katie McCarron makes explicit – is the danger in the dominant if not near monolithic cultural practice of representing and, so, understanding autism as, simply, some (pathological) thing one ‘has’ and the related promise that individuals and collectives living with autism might, someday, live without it.

**Splitting Matter**

“I wanted a life without autism”. These were the words offered by Dr. Karen McCarron as she sat in her hospital room, as she recovered from her suicide attempt, as she confessed to the murder of her three-year-old girl. McCarron ‘lived with’ a daughter who ‘lived with’ autism. McCarron’s daughter and life were ‘with autism’, and she wanted a daughter and a life without it. “I tried very hard to get autism out of our lives”, she said. She tried all the best therapies and interventions, she sent her to all the right schools. Yet, even still, she ‘lived with’ a child, and so she lived a life, that was not “indistinguishable” from other children and normal lives. Even after the schools and the therapies and the early interventions, in McCarron’s eyes, her (normal, non-autistic) Katie was still ‘with’ autism: near normative in her behaviours, ‘almost living’ – yet not, quite. McCarron lived a ‘life with’ autism.

McCarron lived ‘with’ all of this, but she also ‘lived with’ more than this. She ‘lived with’ a conception of her child that was given to her by her culture: where ‘life with’ autism is, as a given, life under threat. A culture that expresses, time and again, its

Beloved children split in two. A child-with: part child, part autism. A part to love and a part to hate. A part to cultivate and a part to eliminate. In this, our, culture, it has become possible to have individual bodies (as well as whole populations), split cleanly in two – part ‘living’ people and part ‘life draining’ pathology. Such a cultural orientation did not force McCarron (or Peng’s or Dawes’) hand in killing her child, but it, nonetheless, provides the necessary conditions that continues to make this kind of violence possible and, even, usual. Born of our culture, the violence enacted against Katie, Scarlett and Jason (and all of the people, named and unnamed, who belong to the growing column of violence above) is a cultural problem, and so, to borrow, again, from Michalko, “a problem for all of us” (Michalko, 2002, p. 111).

And this, I believe, brings us back to the central question of this dissertation: the question of advocacy, for the contemporary discourse of autism advocacy has become the dominant way of making sense of autism and non-autism and the relationship between these entwined categories of being. As we have seen throughout this dissertation, discourses of advocacy are engaged in the making of the meaning of people. Through the practice of dominant, contemporary autism advocacy, we learn about what autism means and what it means to advocate. The dominant ways we have of engaging in autism
advocacy by fighting autism, battling it, hating it, waging a war against it, working to
eliminate it require us to think of autism, not as itself, a way of living, but as that which
must be ‘lived with’. Such versions of advocacy require us to think of ourselves –
collective and individually – as cleanly split into ‘autistic’ and ‘non-autistic’ parts.
Autism is here and not there, you and not me: it is some ‘thing’ and not some ‘one’, a (in-
valid) brain, and not an (invalidated) identity. Such a parsing up of life and non-life,
people and pathologies, promises that there can be life without autism, that if autism is
eliminated or cured, someone without autism remains. Of course, such a promise is both
a false one and a dangerous one. Returning to Sinclair’s words, cited back in Chapter 3,
autism is “a way of being. It is pervasive; it colors every experience, every sensation,
perception, thought, emotion, and encounter, every aspect of existence.” And from this,
he, crucially reminds us, “it is not possible to separate the autism from the person – and if
it were possible, the person you'd have left would not be the same person you started
with” (p.2). Katie, Scarlett and Jason were not ‘people living with autism’ but living
autistic people – fighting their autism was fighting them, hating their autism was hating
them, killing their autism killed them.

With this in mind, in writing this dissertation, I am writing an advocacy appeal of my
own. I am appealing to advocacy to become more aware of the power of the awarenesses
we already have of autism and non-autism, and of the danger of routine, taken-for-
granted practices of advocacy that are, as we have seen, complicit in creating and
sustaining a culture ‘against’ autism. In critically attending to dominant
conceptualizations of autism in the field of advocacy, it is my hope that we (autistic and
non-autistic) might open up a space to begin to imagine the relationship between autism and advocacy otherwise.
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THE WHITE HOUSE
Office of the Press Secretary

For Immediate Release September 30, 2009

REMARKS BY THE PRESIDENT
ON THE AMERICAN RECOVERY AND REINVESTMENT ACT

National Institutes of Health
Bethesda, Maryland

11:03 A.M. EDT

THE PRESIDENT: Thank you. Thank you so much. Francis, thank you for the extraordinary introduction. I want to echo what has just been said about my Secretary of HHS. She is, I just think, outstanding. She hit the ground running, and with all the burdens that she carries, she always has a sense of fun and energy, and is just good to be around. So please give Kathleen Sebelius a big round of applause. (Applause.)

I want to acknowledge that we are in Congressman Chris Van Hollen's district, a Democrat from Maryland, and Chris is here and a great supporter of NIH historically. We are very grateful for him. And we are so happy to have Senator Arlen Specter, who is directly responsible for so much of the funding for NIH research. He is a huge champion for your cause. And I know you already gave him a rousing round of applause, but I just want to echo what a great job he's been doing and what a great partner he's been.

Finally, somebody who's not here but deserves a little credit is my Vice President, Joe Biden, who is managing the stimulus process -- (microphone screeches) -- whoa! That's Joe trying to call in. (Laughter.) Joe is doing a great job, but he is pretty tough when it comes to tracking the money and so he's going to be paying attention -- Doc -- (laughter) -- to make sure that it's going where it's supposed to be going.

Before I begin my remarks about this extraordinary institution I want to say a word about the tragic events that took place yesterday in America Samoa. My deepest sympathies are with the families who've lost loved ones and the many people whose lives have been affected by the earthquake and the tsunami. To aid in the response I declared this a major disaster to speed the deployment of resources. And FEMA -- the Federal Emergency Management Agency -- is working closely with emergency responders on the ground, and the Coast Guard is helping to provide immediate help to those in need. We also stand ready to help our friends in neighboring Samoa and throughout the region, and we'll continue to monitor the situation closely as we keep the many people who've been touched by this tragedy in our thoughts and in our prayers.

Now, today I'm here to talk about our nation's commitment to research. I want to thank Dr. Collins and his team for showing me and Kathleen some of the extraordinary groundbreaking research being done at the National Institutes of Health.

Appendix A:

Transcript of President Obama’s remarks at the NIH (30/09/09)
The work you do is not easy. It takes a great deal of patience and persistence. But it holds incredible promise for the health of our people and the future of our nation and our world. That's why I'm here today. For decades, the NIH has been at the forefront of medical invention and innovation, helping to save countless lives and relieve untold suffering. And yet, if we're honest, in recent years we've seen our leadership slipping as scientific integrity was at times undermined and research funding failed to keep pace.

We know that the work you do would not get done if left solely to the private sector. Some research does not lend itself to quick profit. And that's why places like the NIH were founded. And that's why my administration is making a historic commitment to research and the pursuit of discovery. And that's why today we're announcing that we've awarded $5 billion -- that's with a "b" -- in grants through the Recovery Act to conduct cutting-edge research all across America, to unlock treatments to diseases that have long plagued humanity, to save and enrich the lives of people all over the world. This represents the single largest boost to biomedical research in history. (Applause.)

Now, one of the most exciting areas of research to move forward as a result of this investment will be in applying what scientists have learned through the Human Genome Project to help us understand, prevent, and treat various forms of cancer, heart disease, and autism. And having been a leader of the Human Genome Project, Dr. Collins knows this promise all too well. And it's a promise that we've only just begun to realize.

In cancer, we're beginning to see treatments based on our knowledge of genetic changes that cause the disease and the genetic predispositions that many of us carry that make us more susceptible to the disease. But we've only scratched the surface of these kinds of treatments, because we've only begun to understand the relationship between our environment and genetics in causing and promoting cancer.

So through the Recovery Act, the NIH is expanding the Cancer Genome Atlas, collecting more than 20,000 tissue samples to sequence the DNA of more than 20 types of cancer. And this has extraordinary potential to help us better understand and treat this disease. Cancer has touched the lives of all Americans, including my own family's; 1.5 million people will be diagnosed in the next year. Half a million people will lose their lives. We all know the terrible toll on families and the promise of treatments that will allow a mother to be there for her children as they grow up; that will make it possible for a child to reach adulthood; that will allow countless people to survive a disease that's claimed far too many lives.

Through these investments in research, we will also have the opportunity to make strides in the treatment and prevention of heart disease, the leading cause of death in the United States. Since 1948, for example, researchers have been following generations of residents in the town of Framingham, Massachusetts, to better understand the cause of cardiovascular illness. Now, we have a chance to study the DNA of these participants and connect what we know after decades of observation to what we'll soon know about their genetic makeup. And perhaps we can identify those who are likely get high blood pressure or high cholesterol and find ways to intervene before heart disease even develops.
And finally, we'll also provide the largest-ever infusion of funding into autism research. Across the country, grant recipients will have the opportunity to study genetic and environmental factors of a disease that now touches more than one in every 150 children. What we learn will hopefully lead to greater understanding, early interventions, more effective treatments and therapies to help these children live their lives and achieve their fullest potential, which is extraordinary. (Applause.)

Now, we know that these investments in research will improve and save countless lives for generations to come. And as I was taking a tour with Dr. Collins and Dr. Fauci and others, just listening to the possibility of a HIV/AIDS vaccine, or hearing the latest treatments of cancer that allow people who previously only had resort to the most violent types of radiation or chemotherapy, now being able to take pills and seeing extraordinary progress, it is something that is entirely inspiring. But we also know that these investments will save jobs, they'll create new jobs -- tens of thousands of jobs -- conducting research, and manufacturing and supplying medical equipment, and building and modernizing laboratories and research facilities all across America.

And that's also what the Recovery Act is all about. It's not just about creating make-work jobs; it's about creating jobs that will make a lasting difference for our future.

From the beginning, our goal has been to rescue the economy at the same time as we're laying a new foundation for lasting economic growth. And central to that foundation is a health care system that can deliver the treatments and cures you discover in an affordable way. After all, decades of research make no difference to the family that is dropped from an insurance policy when a child gets sick. And breakthroughs with the potential to save lives don't matter when your insurance doesn't cover a pre-existing condition. And as costs rise and rise, that leaves less and less for the kinds of investments in health care and in basic research that will actually improve our well-being. That's why we're working so hard to pass long-overdue reforms.

Now, I should point out there are some who have opposed the reforms we're suggesting, saying it would lead to a takeover by the government of the health care sector. But this concern about the involvement of government I should point out has been present whenever we have sought to improve our health care system.

Here's an interesting quote from FDR -- he addressed it nearly 70 years ago right here at the dedication of NIH. And he said -- and I quote -- "Neither the American people, nor their government, intends to socialize medical practice any more than they plan to socialize industry. In American life the family doctor, the general practitioner performs a service which we rely upon and which we trust as a nation, and there can be no substitute for the personal relationship between doctor and patient which is a source of strength of [our] medical practice in our land."

FDR was being accused of a government takeover of health care. (Laughter.) But he thought NIH was a pretty good idea. And think about everything that's happened and all the lives that have been saved and all the progress that's been made -- and all the commercial activity that's been generated as a consequence of that early investment.
These words are a reminder that while we’ve made great advances in medicine, our debates haven’t always kept pace. And these words remind us that there have always been those who argued against progress, but that at our best we’ve never allowed our fears to overwhelm our hopes for a brighter future.

That’s been at the heart of the work of the National Institutes of Health for decades. It was here that Dr. Roy Hertz would develop the first successful cure of metastatic cancer through chemotherapy -- as a group of women who would have surely died began actually to get better. It was here that Dr. Nina Braunwald -- the first woman ever to be board-certified in cardiothoracic [sic] surgery -- conducted some of the earliest operations to replace heart valves. It was here, in the years after President Roosevelt’s visit, that polio vaccines would be tested to end a scourge that affected millions, including obviously the President that helped make the research possible.

We can only imagine the new discoveries that will flow from the investments we make today.

Breakthroughs in medical research take far more than the occasional flash of brilliance, as important as that can be. Progress takes time; it takes hard work; it can be unpredictable; it can require a willingness to take risks and going down some blind alleys occasionally -- figuring out what doesn't work is sometimes as important as figuring out what does -- all of this needs the support of government. It holds promise like no other area of human endeavor, but we've got to make a commitment to it.

And here at the National Institutes of Health, and at universities and research institutions across this country, you are demonstrating our capacity not just as a nation but as human beings to harness our creativity and our ingenuity to save lives, to spare suffering -- to build a better world for ourselves, our children, and our grandchildren. That is our great promise. And it is one that we've once again begun to fulfill.

So thank you for your extraordinary work. And we are going to keep on providing the support that you need. The American people are looking forward to the next set of discoveries that all of you are working on today.

Thank you so much. (Applause.)

END

11:18 A.M. EDT
**Appendix B:**

Directed by: Alfonso Cuarón Written by: Billy Mann

<p>| Voice of “autism”: | I am autism. I’m visible in your children, but if I can help it, I am invisible to you until it’s too late. I know where you live, and guess what? I live there too. I hover around all of you. I know no colour barrier, no religion, no morality, no currency. I speak your language fluently, and with every voice I take away, I acquire yet another language. I work very quickly. I work faster than pediatric AIDS, cancer, and diabetes combined. And if you are happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain. I don’t sleep, so I make sure you don’t either. I will make it virtually impossible for your family to easily attend a temple, a birthday party, a public park, without a struggle, without embarrassment, without pain. You have no cure for me. Your scientists don’t have the resources, and I relish their desperation. Your neighbors are happier to pretend that I don’t exist, of course, until it’s their child. I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up, you will cry, wondering ‘who will take care of my child after I die?’ And the truth is, I am still winning, and you are scared, and you should be. I am autism. You ignored me. That was a mistake. |
| Individual voices of ‘advocacy’: | And to autism, I say… |
| | I am a father… |
| | A mother… |
| | A grandparent… |
| | A brother… |
| | A sister… |
| | We will spend every waking hour trying to weaken you. |
| | We don’t need sleep, because we will not rest until you do. |
| | Family can be much stronger than autism ever anticipated, and we will not be intimidated by you, nor will the love and strength of my community. I am a parent riding toward you, and you can push me off this horse time and time again, but I will get up, climb back on, and ride on with the message: |
| | Autism? You forget who we are. You forget who you are dealing with. You forget the spirit of mothers… |</p>
<table>
<thead>
<tr>
<th>Chorus of voices of ‘advocacy’:</th>
<th>…and daughters, and fathers, and sons…</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual voices of ‘advocacy’:</td>
<td>We are Quatar…</td>
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<td>We are the United Kingdom…</td>
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<td></td>
<td>We are the United States…</td>
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<td>We are China…</td>
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<td>We are Argentina…</td>
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<td>We are Russia…</td>
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<td>We are the European Union…</td>
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<tr>
<td>Chorus of voices of ‘advocacy’:</td>
<td>…We are the United Nations.</td>
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<tr>
<td>Individual voices of ‘advocacy’:</td>
<td>We are coming together in all climates.</td>
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<td></td>
<td>We call on all faiths.</td>
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<td>We search with technology…</td>
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<td>and voodoo…</td>
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<td>prayer and…</td>
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<td>herbs…</td>
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<td>genetic studies…</td>
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<td></td>
<td>and a growing awareness you never anticipated.</td>
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<td></td>
<td>We have had challenges, but we are the best when overcoming them.</td>
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<td></td>
<td>We speak the only language that matters:</td>
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<tr>
<td>Chorus of voices of ‘advocacy’:</td>
<td>Love for our children.</td>
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<tr>
<td>Individual voices of ‘advocacy’:</td>
<td>Our capacity to love is greater than your capacity to overwhelm. Autism is naive. You are alone. We are a community of warriors.</td>
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<tr>
<td><strong>Chorus of voices of ‘advocacy’:</strong></td>
<td>We have a voice.</td>
</tr>
<tr>
<td><strong>Individual voices of ‘advocacy’:</strong></td>
<td>You think that because some of our children cannot speak, we cannot hear them. That is autism’s weakness.</td>
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<tr>
<td><strong>Chorus of voices of ‘advocacy’:</strong></td>
<td>You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands.</td>
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<tr>
<td><strong>Individual voices of ‘advocacy’:</strong></td>
<td>You have not properly been introduced to this community…</td>
</tr>
<tr>
<td><strong>Chorus of voices of ‘advocacy’:</strong></td>
<td>…of parents and grandparents, of siblings and friends and schoolteachers, therapists, pediatricians, and scientists.</td>
</tr>
<tr>
<td><strong>Individual voices of ‘advocacy’:</strong></td>
<td>Autism, if you are not scared, you should be.</td>
</tr>
<tr>
<td><strong>Chorus of voices of ‘advocacy’:</strong></td>
<td>When you came for my child, you forgot:</td>
</tr>
<tr>
<td><strong>Individual voices of ‘advocacy’:</strong></td>
<td>You came for me.</td>
</tr>
<tr>
<td><strong>Individual voices of ‘advocacy’:</strong></td>
<td>Autism: Are you listening?</td>
</tr>
</tbody>
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Appendix C:

New York University’s Child Study Center’s “Ransom Notes”
Retraction

A Message Regarding the "Ransom Notes" Public Awareness Campaign

When we launched our "Ransom Notes" public awareness campaign two weeks ago, our goal was to call attention to the millions of children with untreated psychiatric and learning disorders. We wanted a campaign that would grab people’s attention, break through the clutter, and serve as a wake up call to what we believe is America’s last silent public health crisis. We felt something dramatic was needed to call attention to the dire outlook for children with untreated disorders: higher risk for academic failure, school dropout, substance abuse, suicide, unemployment, and imprisonment.

The campaign succeeded in getting people’s attention and sparking dialogue, but much of the debate centered on the ads instead of the issues. We’ve received thousands of calls and letters from parents, mental health professionals, educators, advocates, and concerned third parties, all of whom are passionate about helping children. While many people praised the campaign and urged us to stay the course, others were troubled by it.

Though we meant well, we've come to realize that we unintentionally hurt and offended some people. We've read all the emails, both pro and con, listened to phone calls, and have spoken with many parents who are working day and night to get their children the help they need. We have decided to conclude this phase of our campaign today because the debate over the ads is taking away from the pressing day-to-day work we need to do to help children and their families. They are and remain our first concern.

Our goal was to start a national dialogue. Now that we have the public’s attention, we need your help. We would like to move forward and harness the energy that this campaign has generated to work together so that we do not lose one more day in the lives of these children. We hope you will partner with us to bring the issues surrounding child and adolescent mental health to the top of America’s agenda. Work with us as we fight to give children and their families equal access to health insurance, remove the stigma that the term “psychiatric disorder” so clearly still elicits, and, most importantly, support the drive to make research and science-based treatment a national priority.

We invite all of you to continue this conversation online at a “town hall” meeting that we will hold early next year as we plan the next phase of our national public awareness campaign on child mental health. Look for details on our web site www.AboutOurKids.org.

Sincerely,

Harold S. Koplewicz, M.D.
Founder and Director, New York University Child Study Center
Appendix D

Image Credits

Fig. 1.1: Press release originally published on Autism Ontario’s website, 2009. Reprinted with permission from Autism Ontario.

Fig. 2.1: Organization logos reprinted with permission from Asociatia Nationala pentru Copii si Adulti cu Autism din Romania (Filiala Iasi), the Hungarian Autistic Society, Autismo e Realidad, Autism Association of Western Australia, Fundación Teletón México’s program “Programa Autismo Teletón”, Good Friend Inc., Autism Speaks, Action for Autism: National Center for Autism, Autism Care Nepal, Autism and Asperger’s Föreningen.

Fig. 2.2: Image rights belong to Autism Speaks, 2005-2011. Reprinted with organization’s permission.

Fig. 2.3: Photograph by Eduardo Trejos, 2011. Reprinted with artist’s permission.

Fig. 4.1: Poster originally published on Autism Ontario (Durham) website, 2007. Reprinted with permission from Autism Ontario.

Fig. 4.2: Poster available for sale on the National Autistic Society website, 2008 Reprinted with permission from the National Autistic Society.

Fig. 4.3: Above: Photograph by Eduardo Trejos, 2011. Reprinted with artist’s permission. Below: Posters reprinted with permission from (left to right) Action for Autism, Más Psicología, APEPA, Autism Pakistan.

Fig. 5.1: Photograph by Nate Peterson, 2008. Reprinted with artist’s permission.

Fig. 5.2: Image of UN Resolution 62/139, 2008. Retrieved from www.worldautismawarenessday.org

Fig. 5.3: Image rights belong to Autism Speaks, 2005-2011. Reprinted with organization’s permission.

Fig. 5.4: Images reprinted with permission from Autism Speaks, 2005-2011.

Fig. 6.1–6.3: Photographic details of Autism Society of America ‘Getting the Word Out’ campaign, 2005. Photographs by Eduardo Trejos, 2011. Reprinted with artist’s permission.
Fig. 6.4-6.5: Photographic details of New York University’s Child Study Center’s ‘Getting the Word Out’ campaign, 2007. Photographs by Eduardo Trejos, 2011. Reprinted with artist’s permission.

Fig. 6.6: Poster rights belong to American Academy of Pediatrics, 2008. Reprinted with organization’s permission.


Fig. 6.8: Digital collage by Eduardo Trejos. Reprinted with artist’s permission.