The Neoliberal Biopolitics of Disability:
Towards Emergent Intracorporeal Practices

Kelly Fritsch

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Abstract

In this dissertation I link the contemporary biopolitical production of disability to the neoliberalization of social, political, and economic practices, policies, and discourses that capacitate some disabled bodies while leaving others to wither. While ableism insidiously functions to exclude and marginalize individuals through rendering disabled bodies as abnormal, I argue that neoliberal capacitation does not always function to normalize disabled subjects. Instead, neoliberal modes of capacitation and debilitation work alongside and also cross ableist categories to include enhanced and capacitated abled-disabled bodies and subjects. As opposed to producing clear-cut lines by which to demarcate disability and disabled bodies, the relationship between capacitating and debilitating and ableism shift and slide in relation to each other.

I further explore the ways in which practices of neoliberalization economize all aspects of life and disability relations. I find that disability emerges through the neoliberalization of disability relations as an individual object and problem to be solved, whether by way of the future-oriented promises and enhancements of biocapitalist technoscience, through processes of self-care, or through the good feelings of inclusion. Neoliberalization does not just simply construct barriers and reproduce forms of ableist oppression for disabled people, but also informs the solutions proposed by disabled communities to these barriers. Mapping out the power relations of the neoliberal material-discursive practices surrounding disability moves us away from positioning disability solely as a problem of exclusion to interrogating how worthiness as the basis of inclusion itself is produced within neoliberal biocapitalism. Focusing on the problematics of

inclusion highlights the dangers that are interwoven with potential gains for disabled people becoming productive neoliberal disabled subjects.

To move away from a neoliberal approach that includes only worthy disabled persons while also disrupting other ableist representations of disability requires going beyond including more disabled people within the exploitative and individualized relations of neoliberalism. That is, challenging the contemporary biopolitics of disability requires more than individualized access to education, employment, or social lives, but rather requires changing the conditions, practices, and discourses that surround and produce disability. To that end, I mark disability as an *intracorporeal emergence of the world* whereby the relations of disability extend beyond the human and are contingently practiced, emphasizing a relational approach that decentres the economized disabled subject.

Dedication

In memory of
Edward Joseph Fritsch (1938- 2011)
who always wanted to know:
"What's your thesis statement today?"

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Chapter 1

Introduction

In July 2014, while Canadian pop star and singer Justin Bieber was on a trip with his family to Disneyland, he surprised many of his fans by using a wheelchair to get around the large theme park. Pictures of Bieber posing with fans while seated in a wheelchair circulated across social media sites, and left celebrity gossip bloggers, entertainment news sites, and journalists wondering if Bieber was "faking" a disability to cut the lines at Disneyland (Toronto Sun 2014). Representatives of Bieber were quick to report that he was "nursing a knee injury," sustained after playing a game of basketball. In fact, his representatives went further to comment that Bieber had "no need for such tactics [of faking a disability] seeing as he was already being escorted around the theme park by Disney staff in order to avoid waiting with the general public" (Daily Mail 2014).

Bieber's use of a wheelchair at Disneyland came on the heels of the Walt Disney Corporation changing its Guest Assistance Program at all its theme parks, a program that had previously allowed disabled people access to the front of the line of an attraction without waiting. The Guest Assistance Program was well known across disability communities, and was part of the way in which Disney marketed itself as a providing a "magical" and "special experience" for those who "have a loved one with a disability" (Smith 2013). Such marketing has been incredibly effective among disabled people and their families, so much so that, for example, Disney is involved in 50 percent of the wishes that the Make-A-Wish Foundation of America grants to terminally ill children (MWF

2014).

Nonetheless, on October 9, 2013, responding to the apparent "abuse and exploitation" of the Guest Assistance Program, Disney changed its policy and adopted a Disability Access Service Card (DASC), intended to provide disability access to "guests who *truly* need it" (Disney Parks 2013). With the new DASC, a disabled visitor to the theme park is issued an entrance time to an attraction based on the current wait time for that attraction. While the disabled patron does not have to physically wait in line for the attraction, the disabled visitor still must wait as long as everyone else waiting in line, and can only attain one wait time at a time, essentially putting an end to the ability of disabled patrons and their care providers to go quickly from one ride to the next.

While doing research for her book on the upper class elites of Park Avenue, New York City, social researcher Wednesday Martin documented the "abuse" of the previous Guest Assistance Program. Martin discovered that wealthy able-bodied New York families were hiring disabled people in Orlando, Florida to pose as their family members at Disney World. Paying up to $1040 per day to have these disabled people accompany their family around the theme park allowed these socially and economically elite families to qualify for the Guest Assistance Program (Palmeri 2013). First reported by the *New York Post* in May 2013, one anonymous source told the newspaper that her able-bodied daughter was able to board the "It's a Small World" ride within one minute of arriving at the ride with her hired disabled "family member" rather than wait in line for upwards of two and a half hours (Palmeri 2013).

Disney alleges it changed its policy due to "abuse that was, unfortunately, widespread and growing at an alarming rate" (Disney Parks 2013). Many disabled people

have spoken out against the new DASC, arguing that this approach limits the abilities of many disabled patrons to actually enjoy Disney's attractions as their disabilities do not allow them to wait hours to board a ride (McCoy 2014). While the DASC may indeed hinder the ability of disabled people to adequately enjoy Disney's attractions, it is not in Disney's financial interests to penalize its wealthier patrons for employing disabled "family members." Rather, to capitalize on the desire of their wealthier patrons to easily access the front of line, and at the same time to crack down on "abuse," Disney offers various VIP tours ranging from $315 - $500 per hour, that allow patrons a "carefree" and "fun-filled day" through unlimited access to their Fast Pass lines where the wait is generally no longer than ten minutes per ride (Disney Parks 2014).

The way in which the popular media frames disability as those either deserving of accommodations or those undeserving, or how Disney is invested in particular forms of disability accommodation, in addition to the ways by which Bieber's press releases work to legitimate his use of a wheelchair at Disneyland, mark just how entangled disability is in ontological and epistemological questions about the body, the role of prosthetic and enhancement technologies (such as the wheelchair), the ways in which the social, cultural, political, and economic influence conceptions of the normal and abnormal, the assumed stability of disability as something one is or is not, and the role that race, class, gender, ethnicity, age, sexual orientation, and so on, play in shaping the discourses and material practices of disability. This one small news event of Justin Bieber using a wheelchair in the Magic Kingdom sparks larger questions, anxieties, concerns, and desires revolving around not only what disability *is*, but also what we can and should do about *it.* In short, this media spectacle reveals disability to be biopolitical: disability is a political problem that is at once

scientific, biological, economic, social, and cultural. What Bieber's spin around Disneyland in a wheelchair further suggests is that disability is both materially and discursively practiced and legitimated within a contemporary biopolitics that is predominantly framed through neoliberalized biocapitalist relations.

That Disney changed its Guest Assistance Program to crack down on "abuse," and that Bieber was accused of "faking" a disability to cut lines, shows the force by which individuals and institutions are wrapped up in marking what counts as a legitimate and illegitimate disability, how disability should be accommodated, and how such conceptions of ill/legitimacy are entangled in the contemporary neoliberalization of disability relations. This neoliberalization of disability relations functions to create and legitimate individualized disabled bodies and subjects that can be both capacitated and enhanced through and within biocapitalism while at the same functioning to position other individualized bodies and subjects as illegitimately disabled or as debilitated disabled bodies rendered for what Lauren Berlant (2007) has termed "slow death." For Berlant, slow death "refers to the physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence" (774). In some cases, the slow death of particular disabled people leads to their literal death, whereas in other cases, slow death highlights the continuous processes of the withering of disabled people or the ways by which disabled people are an "exclude-able type" (Titchkosky 2003) that marks their lives as lives not worth living. Whether or not Bieber is truly disabled matters less than the fact that his affluence, alongside other forms of privilege, affords him a fast pass to the front of all lines. Bieber is very unlikely to ever face slow death.

Despite the fact that Bieber's use of a wheelchair at Disneyland came *after* Disney changed its policy so as to no longer allow disabled people immediate access to rides, the discourse of "disability perks" remains strong despite such "perks" having been completely eroded. While accessing Disneyland is a privileged activity in and of itself whether or not you can afford VIP status, the notions of disability ill/legitimacy that are raised by Bieber's trip connect to the experiences of others who are marked in this dissertation as facing slow death as a result of the neoliberalization of social relations or in becoming variously capacitated by these very same material-discursive relations. The biopolitics of disability, constituted within the contemporary neoliberalization of capitalist economies enables some disabled bodies to live while others are left to die. By being compelled to either work to become legitimate disabled subjects or risk being excluded altogether, the contemporary production of disability is deeply entrenched in neoliberalized disability relations.

In this dissertation, I link the contemporary production of disability to the neoliberalization of social, political, and economic practices, policies, and discourses that capacitate some disabled bodies while leaving others to wither. While ableism insidiously persists and continues to exclude and marginalize individuals through rendering disabled bodies as abnormal, I argue that neoliberal capacitation does not necessarily work to normalize disabled subjects. Instead, through the neoliberalization of disability relations, disabled bodies and disabled subjects become valued as what Tanya Titchkosky (2003) has referred to as "the abled-disabled": productive individualized disabled subjects; resources to be drawn on; and consumers to purchase goods. Neoliberal modes of capacitation and debilitation work alongside and also cross ableist categories to include enhanced and capacitated abled-disabled bodies and subjects. As opposed to producing clear-cut lines by

which to demarcate disability and disabled bodies, the relationship between capacitating and debilitating and ableism shift and slide in relation to each other.

Not limited to the abled-disabled, in this dissertation I explore the ways in which practices of neoliberalization economize all aspects of life and financialize disability relations through both capacitating and debilitating disability. I do so by charting the social, political, economic, and cultural value of the difference of disability across disparate – yet entangled – sites such as curb cuts, toxic fetuses, wheelchairs, the Make-A-Wish Foundation, couches, guide dogs, mothering, and genetic blood diagnoses, so as to mark the multiple, contradictory, and ambivalent ways by which disability both does and does not have value, and disabled lives become or do not become a "life worth living." In all cases, the economization and individualization of disability is produced through the neoliberalization of disability relations. In sum, disability emerges through the neoliberalization of disability relations as an individual object and problem to be solved through the future-oriented and speculative promises of biocapitalism, through self-support, or through the ways by which the enhancement and inclusion of the abled-disabled produces good feelings. These promises, processes, and feelings are explored in my dissertation specifically to mark the ways by which the social, material, cultural, political, and economic practices and discourses by which disability comes to function in these ways is often erased or elided.

Therefore, my dissertation traces the many and multiple ways in which disability and disabled bodies both discursively and materially manifest within and through neoliberal economies in the Global North, particularly focusing on Canada, the US and the UK. Departing from the Keynesian industrial-based "welfare state" capitalism that held sway

particularly after World War II in countries like Canada, the US, Britain, and other European countries, the material-discursive practices of neoliberalization are characterized through intensifying the privatization of public goods, the individualization of labour, risk, and so on, the increased emphasis on immaterial labour, and the rise to dominance of biocapital industries and financial institutions (through which speculation on "immaterial" transactions creates spectacular wealth) as the drivers of economic growth. While global forces produce productive, entrepreneurial, and consuming abled-disabled individuals, neoliberalization does not simply happen to disabled communities to make them helpless victims of political-economic change. Instead, my dissertation marks precisely how social movements and various disabled-led political projects and discourses (re)produce neoliberal disability relations. As such, processes of neoliberalization do not simply construct barriers and reproduce forms of ableist oppression for disabled people, but as I show, these processes inform the very solutions proposed by disabled communities to these barriers. The impact of neoliberalization remains largely underexplored in disability studies.

However, it is not enough to chart the neoliberalization of disability relations. In drawing on the work of feminist materialists such as Karen Barad (2007; 2008) and others, I chart alternatives to the neoliberalized relations of disability. In particular, I trace out different practices of disability through considering the many ways in which matter (and thus bodies and machines) organizes and reorganizes itself in "intra-action" (Barad 2007) with discursive formations. I name these alternative practices of disability as an *intracorporeal emergence of the world* to mark the way in which the relations of disability extend beyond the human and are contingently practiced.

In the following sections, I map out my characterization of the neoliberalization of global capitalism, outline the ways in which the neoliberalization of disability relations have remained underexplored in disability studies, and introduce how and why I am using feminist materialists to push against the ways in which disability and disabled bodies predominantly manifest through the neoliberalization of disability relations.

Tracing the Neoliberalization of Policies, Practices, and Discourses

Kean Birch and Vlad Mykhnenko note that neoliberalism is not a "single hegemonic system" (2010, 1) nor a "homogenizing process" (6) but rather has developed unevenly across the globe, with "varying levels of ideological and political adherence" (5) to different social, political, and economic policies, practices, and discourses that results in "different forms of neoliberalism alongside the differing impacts of neoliberalization" (6). And yet despite differing policies, practices, and discourses depending on the particularities of any given location, "the neoliberal turn" (Harvey 2005, 9) can be generally characterized as a "hegemonic political-economic project" (Birch and Mykhnenko 2010, 6) encapsulated by five core principles: privatization; liberalization of trade and capital investment; deregulation of labour and markets; monetarism; and the marketization of all aspect of society (Birch and Mykhnenko 2010, 5). As David Harvey remarks, neoliberalism "proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade" (2005, 2).

The proliferation of this hegemonic project has resulted in what Stuart Hall (2003, 10) terms a "neoliberal common-sense" that has "colonized" society, characterized by its

economic, political, and ideological-based "market-like rule" (Birch and Mykhnenko 2010, 2), that is "taken for granted and not open to question" (Harvey 2005, 5). Wendy Brown marks this common-sense as a kind of neoliberal rationality, "a peculiar form of reason that configures all aspects of existence in economic terms" (2015, 17). Although the production of this common-sense market rationality has emerged through complex entanglements of various material-discursive practices, in what follows, I chart the ways in which the neoliberalization of social, political, and economic relations have come to economize nearly all aspects of life over the past 40 years, particularly focusing on its emergence in the US, Canada, and the UK, and its attendant impact on the practices of disability.

The New Liberal Road to Freedom

French philosopher Louis Rougier first uttered the term "neoliberalism" at the Walter Lippman Colloquium, a conference of 26 intellectuals organized in Paris in August 1938 to study American journalist Walter Lippman's 1937 book, *An Enquiry into the Principles of the Good Society*. The Colloquium was organized after Rougier returned from visiting the Soviet Union on a French-government sponsored trip. On that trip, Rougier became convinced that planned economies do not function as well as market economies. The aim of the Lippman Colloquium, then, was to discuss and construct a new liberalism that would reject and supersede the collectivism of British Keynesianism or the American New Deal, the totalitarianism of National Socialism in Germany, and the planned economies of the Soviet Union. Alexander Rustow, a German sociologist and economist, later coined "neoliberalism" to name the idea of a social market economy (Mirowski 2013). Whereas classical liberalism under the schema of *laissez-faire* separated the state and the

market to restrict the state's role in order to open up space for the market, this new liberalism was thought to operate as a reorganisation of the state, superimposing the market over the state. Or as Foucault (2008, 116) later remarked, neoliberalism entails "a state under the supervision of the market rather than a market supervised by the state."

As opposed to being the birth of a fully realized ideology and economic system, the Lippman Colloqium was a converging point for a multitude of already existing social, political, and economic discourses that buttressed the slow process of neoliberalizing social, political, and economic relations on a global scale through particular material-discursive practices. As such, these practices have no definitive end state but rather are entangled in ongoing processes as a protean set of practices, policies, and discourses, "emanating from both everywhere and nowhere within diffused loci of power" (Springer 2012, 136).

Many important figures who went on to radically shape the development and deployment of neoliberal practices, policies, and discourses, were in attendance at that Colloquium in 1938, including Walter Lippman himself, German Ordoliberals[1] such as Wilhelm Ropke and Alexander Rustow, Austrian School theorists and economists such as Friedrich Hayek and Ludwig von Mises, and other luminaries such as Michael Polanyi. The Colloquium participants formed an organization named the *Comité international d'étude pour le renouveau du libéralisme* (CIERL) to develop and promote this new form of liberalism, and incorporate neoliberal ideas into state policy discussions, particularly in Germany, the US, and Britain. As the result of geo-politically disparate actors, Jamie Peck

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[1] Ordoliberals are a German variation of social liberalism and neoliberalism. The term "ordoliberal" arises out of the journal *Ordo*, started in 1948, where many German postwar liberals published (Lemke 2011).

(2008, 3-4) argues that neoliberalism has always been a "transnational, reactionary and messy hybrid right from the start" representing "an attempt to conceive and construct a market-(like) order, one that has since been perpetually reconstructed through practice."

For political economists like von Mises, Hayek, and Milton Friedman, neoliberalism aimed to re-create liberalism so that it could defend capitalism. Von Mises, known for his love of "liberal dictators," opposed Marxism and state intervention in markets. In fleeing Nazism, von Mises, along with Polanyi and other Austrian economists like Fritz Machlup, moved to the US anchoring neoliberal ideas on both sides of the Atlantic (Albo and Fanelli 2014; Birch and Mykhnenko 2010). In 1944, Hayek, working at the London School of Economics, published *The Road to Serfdom*, arguing that total market freedom is necessary for democracy as "only capitalism makes democracy possible" (1976, 69-70). Most interestingly, Hayek believed that to be effective, ideas must seep slowly into public consciousness and policy, and that incremental intellectual and policy changes, once taken together, could be systemically transformative (Albo and Fanelli 2014; Harvey 2005). Efforts to develop neoliberal political-economic systems that built on these authors have been in opposition to alternative forms of economic order apart from the free market of capital and have been unyielding in their defense of the institutions of private property (Albo and Fanelli 2014).

After World War II, neoliberal thought became increasingly institutionalized through the business sponsorship and establishment of societies, think-tanks, and organizations that built on Hayek's view that "ideas play an important role in determining the outcome of events as they circulate through government, universities, civil society and the media" (Birch and Mykhnenko 2010, 4). While CIERL became largely ineffective

during World War II, Hayek formed the Mont Pelerin Society (MPS) in 1947, bringing

together historians, philosophers, and economists associated with the Austrian School of

Economics, the Chicago School of Monetary Theory and the Virginia School of Public

Choice (Albo and Fanelli 2014; Stedman Jones 2012). The MPS, named after the Swiss spa

where the Society first met, had two aims: first, redefining the role of the state, and second,

creating an international order to ensure economic agreement (Plehwe and Walpen 2006;

Harvey 2005).

      Other think-tanks like the Institute of Economic Affairs in London (1955), the

Heritage Foundation in Washington (1973), the Fraser Institute in Vancouver (1974), all

began producing a "constant stream of policy papers and conferences" and worked to

influence the "development of university curricula and hiring practices" (Albo and Fanelli

2014, 6). These practices persuasively reshaped public policy, capturing the imagination of

the public and legitimating the neoliberalization of policies, discourse, and state practices

that led to a hegemonic common-sense (Albo and Fanelli 2014). For example, as early as

the 1950s, the US government funded the training of Chilean economists at the University

of Chicago under the tutelage of Milton Friedman. These economists became known as the

"Chicago Boys," and played a central role in neoliberalizing the Chilean state after Augusto

Pinochet's 1973 coup of the Salvador Allende government (Harvey 2005). These "idea

centers" were key in developing neoliberal political projects that opposed Keynesian policy

and government intervention in markets, and were sites where diverse theories and ideas

from across the spectrum of economics and political science were incorporated into

neoliberal literature (Birch and Mykhnenko 2010, 4). Through the influence of think-tanks,

societies, university programs and curriculum, and newly developed policies, "by the late

1960s neoliberalism had surfaced as both a recognizable set of ideas and [a] political movement" (Albo and Fanelli 2014, 8). Perhaps the clearest sign of the increasing prominence of this neoliberal common-sense gaining ground was the awarding of the Nobel Prize in economics to Hayek in 1974, followed by Friedman in 1976 (Harvey 2005, 22).

Even as many postwar Keynesian economies boomed, neoliberals remained "relentless in their critique of the state – and especially social – expenditures as excessive and unaffordable" (Albo and Fanelli 2014, 6). In response to what was deemed "irresponsible social spending," market freedoms were designated as the "necessary check on the centralized power of the state" (Albo and Fanelli 2014, 6). This view became canonized with the release of Friedman's 1962 book, *Capitalism and Freedom,* which suggested that "capitalism is a necessary condition for political freedom" because it is dependent on a free market and on private property (Friedman 2002, 17). As Greg Albo and Carlo Fanelli explain, "Markets, for Friedman and Hayek, inherently tend toward rebalancing and severe economic downturns are the result of government policy mistakes" (2014, 8). Government interference, such as providing healthcare, education, pensions, and so on, are "always an infringement on some individual's choices and freedoms" and as such, "states ought to be limited to securing the institutional preconditions for a competitive market and, once established, mould state practices to ensure market rule" (Albo and Fanelli 2014, 8-9). In this way, as Milonakis and Fine (2009) have noted, the neoliberal state should be limited to protecting private property, security, national defense, and the legal enforcement of contracts in order to allow for favourable market conditions.

By the 1970s, declining profit margins led to a rise in unemployment and a stark rise in inflation across the US and Europe. Shifting international politics contributed to

major destabilizations in the global economy and increased stagflation[2] across the US, Canada, and Western Europe. In 1971, the US abandoned the "gold standard" and President Richard Nixon unilaterally ended the Bretton Woods system of international monetary management that had fixed the exchange rate of the world's major industrial states to gold in 1944. Referred to as the Nixon Shock, gold could no longer be directly convertible into US dollars except on the open market, effectively creating a free-floating currency to encourage flexible rates for increased international flows of capital (Harvey 2005).

The American abandonment of the "gold standard" led to a depreciation of the dollar, and because international oil was priced in dollars, the real income of oil producers decreased. Mixed with increasing tensions in the Middle East,[3] in 1973 the Organization of Arab Petroleum Exporting Countries (OAPEC) placed an oil embargo on Canada, Japan, the Netherlands, Portugal, Rhodesia, South Africa, the UK, and the US, increasing the cost of oil from $3 a barrel in 1973 to nearly $12 a barrel by 1974, and incrementally cutting oil production levels. In between 1973-1974, as a result of inflation pressure, world stock markets dropped drastically, particularly affecting the New York Stock Exchange and the London Stock Exchange. Fiscal crises ensued around the globe, requiring, for example, that the International Monetary Fund (IMF) bail out Britain in 1975-1976 (Harvey 2005).

In response to the deepening economic crises, socialist and communist parties across Europe advanced programs for stronger state control and regulation. As Harvey notes, the "left assembled considerable popular power behind such programmes, coming

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[2] An economic portmanteau of stagnation and inflation, describing a situation in which inflation is high, economic growth is slow, and unemployment continues to rise.
[3] Tensions included the US involvement in the 1973 Yom Kippur War in which the US supplied Israel with arms during the Egyptian and Syrian military campaign against Israel.

close to power in Italy and actually acquiring state power in Portugal, France, Spain, and Britain, while retaining power in Scandinavia" (2005, 12-13). In the US, the Democratic Party was able to introduce a variety of regulatory reforms that pushed Republican President Nixon into implementing wage and price controls, capping prices on consumer items and labour in order to try to respond to increasing rates of inflation. Canada and the UK followed suit in 1975 with similar controls. These reforms, in addition to other protections such as environmental protections (see Chapter 3) and civil rights led Nixon to remark: "we are all Keynesians now" (Harvey 2005, 13).

As communist and socialist parties and left popular forces gained ground in the US, Canada, and parts of Europe, the economic elite began feeling both a political threat and an economic threat. As Harvey notes, "One condition of the post-war settlement in almost all countries was that the economic power of the upper classes be restrained and that labour be accorded a much larger share of the economic pie" (2005, 15). Indeed, the top 1 percent of income earners fell from having 16 percent of the economic pie before WWII to less than 8 percent following the war. During the 1970s growth collapse, that figure plummeted even further. Harvey concludes that it became increasingly obvious that the "upper classes had to move decisively if they were to protect themselves from political and economic annihilation" (2005, 15). As Gerard Dumenil and Dominique Levy (2005) argue, neoliberalization has been a project to restore class power.[4] With the increased

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[4] Class, according to Harvey, "is not a stable social configuration" noting that while "neoliberalization may have been about the restoration of class power, it has not necessarily meant the restoration of economic power to the same people" (2005, 31). Class is also internationally configured, with links to colonial and neocolonial activities and is not limited to nation state borders, as in the case, for example, of media mogul Rupert Murdoch, who has economic and political interests in Britain, the US, and Australia. The class interests of

neoliberalization of policies throughout the 1970s, by the end of the decade the top 1

percent earners in the US soared to control 15 percent of the national income. This

concentration of wealth similarly happened in Britain, Russia, China, Mexico, as neoliberal

policies and practices were adopted in these places in the 1980s and 1990s. Despite being a

political ideology and set of common-sense practices supporting the capital accumulation

of economic elites, accumulation is only one aspect of a diverse and protean set of material-

discursive practices of neoliberalization that will come to bear on disability relations.

The Ins and Outs of Neoliberalization

Jamie Peck and Adam Tikell (2002) argue that neoliberalism has generally been

marked by two contradictory mobilizations of the state towards the extension and

reproduction of marketization, creating what Albo and Fanelli term the "concerted policy

initiatives" that have led to "a new international governance matrix across the entire world

market" (2014, 10). Peck and Tikell call the first contradictory mobilization a "roll-back"

and the second, a "roll-out" (2002, 388-389). "Roll-back" neoliberalism marks the politics

during the 1980s when state power was mobilized behind marketization and deregulation

projects. This was followed by the "roll-out" of the early 1990s when the neoliberalisms of

"Thatcher and Reagan encountered their institutional and political limits" (388) leading to

"a reconstitution" of the neoliberal project "epitomized by the Third-Way contortions of the

Clinton and Blair administrations" (388-389) in which "new forms of institution-building

and governmental intervention" became concerned with "new modes of 'social' and penal

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someone like Murdoch, however, can at the same time, be said to "feed off and nurture specific state
apparatuses" while also exerting "class power in more than one state simultaneously" (Harvey 2005, 35-36).

policy-making, leading to the "aggressive reregulation, disciplining, and containment of those marginalized or dispossessed by the neoliberalization of the 1980s" (389).

In the 1980s, "neoliberalism offered an alternate policy kit to tackle stagflation and a political practice firmly set against emergent democratic and anti-capitalist demands," with neoliberal language bringing Margaret Thatcher to power in the UK and Ronald Reagan in the US (Albo and Fanelli 2014, 8). Thatcherism and Reaganomics both rolled-back regulation through cuts to welfare services and through the privatization of state ownership. This roll-back was motivated in part by the structural crisis of the 1970s and led to things like the Washington Consensus and globally imposed Structural Adjustment Programs through the 1980s and 1990s.

In practice, the neoliberal "alternative policy kit" has resulted in "reducing public services and assets in order to open-up the state sector to new profit-making opportunities; lowering wages, benefits and working condition for a more flexible and market-dependent workforce; and deploying the coercive capacities of the state to enforce these 'market measures'" (Albo and Fanelli 2014, 7). Neoliberal directives led to concrete economic policies such as keeping real wages below increases in productivity; applying monetarist shock therapy followed by inflation-targeting by the central bank; regressive tax reform; constraining the growth of social services; export-led growth strategies, lifting regulations on foreign direct investment and trade liberalization. Economic policies that focus on inflation control and supply-side incentives; privatize and commercialize public sector assets and services; liberalize trade in goods and capital movements; restructure labour and business regulations to reduce market impediments; and increase commodification of goods and services neoliberalize social relations as these policy practices "steadily transformed

the social form of the state into a set of institutions and policy mechanisms supporting

market disciplines" (Albo and Fanelli 2014, 9).

The Washington Consensus – ten policy reforms proposed by John Williamson in

1989 and supported by the US Congress, senior members of administration, technocrats of

international financial institutions, US economic agencies, the Federal Reserve Board, and

many think-tanks – included tight fiscal discipline with virtually no public deficits allowed,

an end to public subsidies and the re-direction of spending on health, education and

infrastructure, tax cuts, free-floating exchange rates, financial liberalization, low tariffs and

trade liberalization, deregulation and private property rights (Birch and Mykhnenko 2010,

9). The Washington Consensus sought to extend neoliberalism into Latin America, Eastern

Europe, and sub-Saharan Africa in order to promote structural reforms that offset debt

obligations through trade income, and worked to facilitate the transition of the East Bloc

zone and China, Vietnam, and others into capitalism (Birch and Mykhnenko 2010; Albo

and Fanelli 2014). Through the liberalization of trade and capital flows, and in reworking

Bretton Woods and GATT institutions, the Washington Consensus reorganized these

economies through Structural Adjustment Loans and Programs to "break [them] from

nationalist projects of import substitution industrialization" (Albo and Fanelli 2014, 10).

Aid loans, grants and other kinds of financial aid were conditioned on the elimination of

"market-inhibiting" policies and creating a neoliberal policy environment abroad (Van

Waeyenberge 2010).[5]

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[5] However, "contrary to popular expectations, and despite the most far-reaching programme of deregulation and privatization in the world's history, the 1990s and 2000s turned out to be lost decades for most developing and transition economies" (Birch and Mykhnenko 2010, 10).

These "roll-back" practices were followed by "roll-out" practices in the Global North throughout the 1990s "to contain the 'internal' contradictions inherent in the neoliberal project such as mass unemployment" (Birch and Mykhnenko 2010, 7). This involved, among other things, the "rescaling of governance as sub-national partnerships [that were] encouraged to deliver on nationally, or increasingly, supranationally set priorities and goals oriented around competitiveness" (Birch and Mykhnenko 2010, 7). As these economic policies were implemented, "an ethos of personal responsibility and individual culpability supplemented by private charity, philanthropy and volunteerism would be prioritized in the place of state-administered social programs" (Albo and Fanelli 2014, 9; Peck 2010).

Birch and Mykhnenko argue that roll-outs have led to "race-to-the-bottom" strategies, that increasingly download responsibilities onto individuals such that "societal rights and responsibilities transform personal 'deficiencies' (such as unemployment) into 'failures' of the individual rather than society" (2010, 7). This analysis is echoed by Albo and Fanelli as they note that "Across the 1990s, the employment relationship was re-worked to expose workers more forcefully to 'market forces'" (2014, 11), including what Guy Standing (1999, 42) notes as measures designed to "weaken protective regulations, restrict collective institutions and strengthen pro-individualistic regulations." Flexible labour and disciplinary practices characterized by increased shift work, variable schedules, short-term contracts, workplace speed-up, evening and overnight work, part-time labour, weekend work, split shifts, and casual and seasonal employment have led to precarious and stressful lives, increased the occurrence of work-life conflicts, and created an employment sector working long hours without control over conditions or working-time (Vosko 2006).

Individuals are "encouraged to compete in flexible labour markets that depend on entrepreneurship, life-long learning and transferable skills (that is, employability) – by shifting responsibility for social justice, well-being and health outcomes from the state to the individual" (Birch and Mykhnenko 2010, 8). As Birch and Mykhnenko note, one way in which this downloading has been made possible is through increasing access to consumer credit in Anglo-American countries that allows individuals to offset their inadequate wages and unemployment by going into debt (2010, 8). By encouraging competition between individuals for resources, "the market state, already enrolled as a facilitator in the 're-regulation' and extension of markets, fosters new individualistic subjects for market rule" (Birch and Mykhnenko 2010, 7). At the heart of neoliberalization, then, "is the systematic use of state power to impose (financial) market imperatives" so as to offer a "finance-friendly solution to the problems of capital accumulation at the end of a relatively long cycle of prosperity" (Saad-Filho and Johnston 2005, 4). According to Dumenil and Levy (2005, 10), this finance-friendly solution includes:

> a new discipline of labour and management to the benefit of lenders and shareholders; the diminished intervention of the state concerning development and welfare; the dramatic growth of financial institutions; the implementation of new relationships between the financial and non-financial sectors, to the benefit of the former; a new legal stand in favour of mergers and acquisitions; the strengthening of central banks and the targeting of their activity toward price stability…

The spread of neoliberalism has not been even across the globe, but has instead seen regions and countries implementing different political and economic policies. While neoliberalism represents a specific power configuration, it does not "preclude the continuation of long-term trends in the transformation of capitalism" (Dumenil and Levy

2005, 12). However, generally speaking, financial policies have become supranational in scope while social welfare is downloaded on subnational agencies with the state left responsible for policing and building infrastructure to support competition.

Neoliberalization has also led to the technological and organizational restructuring of manufacturing in North America and Central Europe (Harvey 2005; Panitch and Gindin 2012; Albo and Fanelli 2014). While this restructuring led to a transfer of capital from the Global North to emerging industrial regions as corporations sought out cheaper labour, it also led large corporations to think of themselves as financial institutions even when, for example, the corporation was engaging in material production, such as in the automobile sector. Harvey notes:

> Since 1980 or so it has not been uncommon for corporations to report losses in production offset by gains from financial operations (everything from credit and insurance operations to speculating in volatile currency and futures markets). Mergers across sectors conjoined production, merchanting, real estate, and financial interests in new ways to produce diversified conglomerates. When US Steel changed its name to USX (purchasing strong stakes in insurance) the chairman of the board, James Roderick, replied to the question 'What is X?' with the simple answer 'X stands for money.' (2005, 32)

Through this restructuring, neoliberalization became synonymous with "the financialization of everything," whereby financial relations gain a hold over not only all areas of the economy, but also over the state apparatus and daily life.

This neoliberalized financialization has been especially clear in the life sciences and biotechnology sectors. Melinda Cooper (2008), for example, argues that the project of US neoliberalism is wrapped up with the emergent possibilities of the life sciences (3), and is "intimately and essentially concerned with the limits of life on earth and the regeneration of living futures" (20). Cooper notes that the 1980s marked a turning point in US research and

development through the implementation of the Bayh-Dole Act[6] that gave rise to the

scientist-entrepreneur, and public-private alliances in research and development (27).

Particularly of interest for the life sciences and biotech industries has been the profitability

of patent protection, and innovation through genetic technologies that have led to things

like DNA patents and personalized medicine. It is not that industrial production is disposed

of with financialization, but rather that it has been displaced. In the life sciences, this has

meant that, for example, a handful of transnational companies (all US and EU based)

control every level of world food and pharmaceutical production (23).

Kaushik Sunder Rajan (2007) terms the systems of exchange and circulation

involved in the contemporary workings of the life sciences "biocapitalism" where

information itself has become a form of currency, susceptible to commodification and

decommodification (42). Biocapitalism as a biopolitical form of capitalism rests largely in

its speculative form: life becomes, as Sunder Rajan terms it, "a business plan" where, for

example, the focus shifts from "disease manifestation" toward "disease potential" (283).

The speculative promise of life entangles life in a biocapitalism that is future-oriented;

manipulating life processes to create new possibilities and potentialities. Cooper (2008), for

instance, traces out how the goal of technologies like stem cell science lies largely in the

biological promise of transformability that can overcome contemporary limits through the

promise of possible futures. As I will show, these speculative promises of possible futures

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[6] The Bayh-Dole Act allowed institutions and other investors who were the recipient of Federal research
funds to own the intellectual property rights to any results of that research instead of the Federal Government.
In essence, the Bayh-Dole Act created financial incentives for researchers to develop monetarily valuable
research, and allowed investors – especially corporate investors – to own any intellectual property produced
from research primarily supported by Federal funds.

come to both capacitate and debilitate material-discursive practices of disability (see in particular Chapter 3, 4, 5, 8).

The Financialization of Everyday Lives

In 2008, the future was not looking promising. What was thought to be an isolated series of mortgage defaults in various parts of the US in 2007 ended up leading to a major bank and financial market liquidity crisis. The US financial meltdown quickly mutated into a global economic crisis by 2009 when banks and hedge funds around the world discovered the American subprime mortgage-backed securities that triggered the crisis in their very own portfolios. As a result, many states "were soon exposed as being just as over-leveraged in their national banking systems with their own areas of 'systematic risk' revealed" (Albo and Fanelli 2014, 13).

As opposed to leading to a slow down or even dismantling of neoliberal policy frameworks as many predicted would happen, Albo and Fanelli contend that the economic crisis of 2008-2010 further implemented a "total privatization" of the public sector that "marginalizes, and even criminalizes, dissent in defense of austerity and market forces" (2014, 7). Indeed, economic activity and monetary policy remain 'finance-led' through "the expansion of credit markets, the role of finance in overall corporate structures and decision-making, the vast expansion of derivatives and other secondary markets and even the role of credit in meeting the needs of households" (Albo and Fanelli 2014,12). Financial institutions remain integral to, and prominent in, international political alliances, while their role in administering public debt has given these institutions an increasing amount of power

in determining the power structures at play in the state and government policy making (Albo and Fanelli 2014,12).

Across Europe and the US a series of bank-mergers, "quasi-nationalizations" and bailouts "resulted in 'troubled assets' being shifted into the state sector and onto central bank balance sheets" (Albo and Fanelli 2014,13). These policies were not a return to Keynesianism but rather a form of "emergency monetarism" that neoliberal economists like Friedman had "long formulated as part of their necessary policy arsenal in the case of severe demand shocks caused by instability in financial markets depleting the available means of exchange" (Albo and Fanelli 2014,13). At the same time, government sponsored stimulus measures like temporary public works programs were set in place to support demand and bolster the consumption of private goods. As a result, since 2012, states have been both reconstructing and deepening neoliberal policies where many capitalist countries have entered a period of "permanent austerity" and "total privatization" (Albo and Fanelli 2014,14). However, such competitiveness has not just been apparent on the national and supranational levels, but has also led to new forms of subjectivity marked by a common-sense market rationality that, as I will show, has deeply affected the material-discursive practices of disability.

The financialization of everyday lives creates what Wendy Brown (2015), following Foucault, calls a market-rationality within society. With market-rationality, material-discursive practices of neoliberalization become so thoroughly entrenched within society "that competitive mechanisms can play a regulatory role at every moment and every point in society and by intervening in this way its objective will become possible, that is to say, a general regulation of society by the market" (Foucault 2008, 145). As Brown remarks,

neoliberalism "casts the political and social spheres both as appropriately dominated by market concerns and as themselves organized by market rationality" (2006, 694). With neoliberal forms of governance, the state does not simply facilitate the economy, but rather also promulgates "a political culture that figures citizens exhaustively as rational economic actors in every sphere of life" (Brown 2006, 694)

In *The Birth of Biopolitics*, Foucault notes that "neoliberal government intervention is no less dense, frequent, active, and continuous than in any other system" (2008, 145). The difference of neoliberalism, however, is the *point* of application. Neoliberalization creates a new form of governmentality in which the state performs a different function: organizing society to subject it to the economic. Foucault highlights the ways in which within neoliberal practices, power is exercised as biopower, or power over life. With politics reframed as biopolitics, power is invested with the job of determining, maintaining and enhancing the conditions by which a life is deemed worth living. Operating as a positive force, neoliberal biopower organizes capitalist distributions of power and wealth to support a particular formation of *homo oeconomicus:* the entrepreneurial, individualized, competitive subject that promotes themselves as human capital (Lazzarato 2009). That is, Foucault argues that neoliberalism creates the conditions for the emergence of the entrepreneurial individual.

The emergence of entrepreneurial individual marks neoliberalization not only as a set of economic policies, practices, and discourses, but also as a social way of being. As Patricia Ventura (2012) argues, neoliberalism cultivates particular economies of feeling. Ventura charts this economy in her book *Neoliberal Culture: Living with American Neoliberalism* (2012). There she notes that neoliberalism can be understood as sets of

economic and political practices and ideologies as well as modes of governmentality – "the way subjects think about the collection of practices, techniques, and rationalities used to govern them and which they use to govern themselves" (2). Through neoliberal governmentality the wellbeing of a population is intimately tied to the ability of individuals to adopt market principles as the guiding tenet of their lives, and to see themselves as individually competitive products that they can create, sell, and optimize (2). Drawing on Raymond Williams, Ventura traces out how neoliberalism as a structure of feeling – as "meanings and values as they are actively lived and felt" (Williams 1978, 131) is "not merely an ideology, not merely an economic perspective, not merely a rationality, but is the concatenation of them" (Ventura 2012, 2). As a whole, they form a cultural common-sense impelling us to:

> extend the market, its technologies, approaches and mindsets into all spheres of human life, to move the ideology of consumer choice to the center of individual existence, and to look to ourselves rather than larger social-welfare structures or society as the source of our success or the blame for our failure – indeed, to define 'success' and 'failure' in market terms. (2)

Neoliberal governmentality works to elide the ways in which there is no such thing as society, working through dominant cultural sensibilities to produce only individuals and families. And yet, as Ventura traces, the common-sense sensibilities and assumptions of everyday life are *social* rather than *personal* "even as neoliberal culture undermines the validity of thinking and working on the level of society" (Ventura 2012, 3).

As the social and economic reorganization of capitalism and governance, neoliberal subjects are not simply mindless or passive consumers. Instead, neoliberalization creates the conditions for the emergence of an entrepreneurial individual. As neoliberalized

economic policies privatize and outsource previously public services like education,

prisons, the police, hydro, water, or garbage collection, neoliberal governmentality

represents and produces individual entrepreneurs (and their families[7]) who are governed

through "self-care" so as to be responsible for their own needs and ambitions (Brown

2006).

This language of self-care reflects the transformation of social responsibilities into

individual risks and personal deficiencies, marking the moral failure of individuals to abide

by neoliberalized common-sense. Cuts to social services, in addition to the downloading of

responsibilities onto local governments, community organizations, and individuals, as well

as the privatization of many social services have had grave effects for the individuals that

use those services. Further, invoking an individualistic entrepreneurial consumer that is

morally assessed according to their capacity for self-support has had huge implications for

disabled people who have historically been cast as dependents and "useless eaters" who

feed at public expense (Mostert 2002). Not the least of these implications is how

neoliberalism has come to inform disability rights politics. For even though disability rights

groups have protested and fought the cut backs to public disability services and supports

that have accompanied neoliberal austerity measures in order to secure resources, many

groups have cast disabled subjects as potential individualistic entrepreneurial consumers

capable of self-care. As such, disabled communities have a complex relationship to

neoliberalization: as neoliberal roll-backs and roll-outs leave disabled subjects to wither,

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[7] As Ventura remarks, "In the midst of neoliberalism's changes we see a patriarchal family-values orientation projected in policy such as with welfare reform… The family has become a key strategy for replacing commitments to multitudes and citizens. So neoliberalism as a governmentality works at the level of the population to promote the atomization of individuals" (2012, 14-15).

disabled subjects are also positioning themselves as potentially ideal neoliberal entrepreneurs.

On the one hand, any confluence of disability rights and neoliberalization should not come as a total surprise given that at the same time that the disability rights and independent living movements emerged in the US, Canada, and UK to demand more from the welfare state, neoliberal policies, practices, and discourses were hailed as a dynamic and viable alternative to that welfare state. As disabled activists and allies pushed for greater inclusion and political recognition, disability rights groups also began adopting entrepreneurial approaches to reach their political goals. Rather than disability being associated with notions of lack and pity, disability movements fought to be recognized as productive and independent workers, capable of self-care, and therefore morally autonomous and worthy citizens.

On the other hand, the lack of attention to this confluence between neoliberalization and disability rights is surprising given the great deal of work done by disability scholars to interrogate how disability is intimately tied to capitalism. Disability scholars and activists have long drawn connections between contemporary material-discursive practices of disability and the emergence of industrial capitalism, marking the many ways by which capitalist social relations have historically both produced disability and also excluded disability. Lennard Davis, for example, marks the social processes of disablement as arriving "with industrialization and with the set of practices and discourses that are linked to the late eighteenth and nineteenth century notions of nationality, race, gender, criminality, sexual orientation, and so on" (1995, 24). This is affirmed by Brendan Gleeson (1999), who charts the ways in which disability comes to be an important bodily difference

through the historical implementation of laws such as The Factory Acts and the Poor Laws in England. These laws in part served to discipline bodies that could not work, or could not work at an average acceptable rate. These disability studies scholars, among others, have marked the ways in which capitalist social relations that are entangled in practices of medicalization and eugenics have produced the contemporary material-discursive practices of disability.

In what follows, I chart the way in which disability has been understood in relation to capitalism by disability studies, and in turn, in relation to neoliberalism. I mark the ways in which disability scholars and activists have not fully explored the effects that the neoliberalization of disability has had on the practices and discourses of disability. I will then articulate my contribution to this conversation.

Industrialization, Capitalism, and Disability

For many disability studies scholars, disability is not simply a corporeal deficit but a material body entangled in a complex set of oppressive social structures that emerged in particular ways with the development of industrial capitalism, the homogenization and normalization of the labouring body, and the increasing prominence of medicalization (Abberley 1987; Davis 1995; Barnes 1997; Gleeson 1999; Russell and Malhotra 2002; Oliver 2009). These contributions can be broken down into two approaches: the first is the way in which industrial capitalism – through the factory and the standardization of labour – disables people in particular ways.[8] The second is the way by which processes of

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[8] In *The Condition of the Working Class in England*, Friedrich Engels writes: "A number of cripples gave evidence before the Commission, and it was obvious that their physical condition was due to their long hours

normalization, medicalization, and eugenics produce disabled subjects as abnormal bodies.

Together, these approaches elucidate how "disability is a socially-created category derived

from labour relations, a product of the exploitative economic structure of capitalist society:

one which creates (and then oppresses) the so-called 'disabled' body as one of the

conditions that allow the capitalist class to accumulate wealth" (Russell and Malhotra 2002,

212).

In *Capital Volume One* (1990), Karl Marx argues that capitalism cannot create itself

without labour power. For Marx, labour power is abstract meaning that it is not equal to the

actual number of hours laboured but an abstract time that determines the usefulness or the

worth of the hours one worked by dividing the actual time it took to produce a commodity

by the average labouring time it took to produce all the commodities of that type available

for exchange (129). As the particular material character of work is displaced by abstract

labour, labour becomes homogenized and equal to and exchangeable with all other forms of

labour (155).

This homogenized and commodified notion of abstract labour also allows for the

development of the conception of the "average" worker. This abstraction turns the average

worker into the norm, transforming and standardizing the particular working body into a

normative body by which all bodies must conform. Since abstract labour power is always

also embodied and material, the norm and standardization of the young male able-bodied

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of work. Deformity of this type generally affects the spine and legs" (1968, 171). Engels furthers that "it is
easy to identify such cripples at a glance, because their deformities are all exactly the same. They are knock-
kneed and deformed and the spinal column is bent either forwards or side-ways" (173). Furthermore he
describes miners as "either bandy-legged or knock-kneed" suffering from "splayed feet, spinal deformities
and other physical defects. This is due to the fact that their constitutions have been weakened and they are
nearly always forced to work in a cramped position" (280). Capital consumes labour-power and the life
energies of labour-power (Marx 1990, 342).

worker informs not only how much the rate of production can be increased, but also the

architecture of buildings, urban planning, modes of transportation, the length of the

working day and what is required for labour power to reproduce itself through sufficient

subsistence required for the "normal state as a working individual" (Marx 1990, 275).

While the disciplinary regime of the factory shaped and transformed this normative

able-bodied subject, against this normative able-bodied labouring subject, a disabled body

becomes construed as a body that cannot produce, or cannot produce at an average

acceptable rate. Paul Abberley (1987, 16) notes how disability is a primary concern for

capitalism:

> …the 'problem' of disability is why these people aren't productive, how to return
> them to productivity, and, if this is not seen as economically viable, how to handle
> their non-productivity in a manner which causes as little disruption as possible to
> the overriding imperative of capital accumulation and the maximisation of profits.

The categories of disabled, impaired, crippled, handicapped, or retarded emerged

historically as "products of a society invested in denying the variability of the body" (Davis

1995, xv) so as to invest in the standardized productivity of the normative able-bodied

worker.[9]

As Marx points out, industrialization and urbanization necessarily produce an

"incapable" social stratum that could not sell its labour-power at the average rate of

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[9] While it may appear that disability is an effect of the norm, the relationship between normal and abnormal is
far more reciprocal. Davis (1995) argues that disability is integral to the very assertion of normativity. Davis
states: "Just as the conceptualization of race, class, and gender shapes the lives of those who are not black,
poor, or female, so the concept of disability regulates the bodies of those who are 'normal.' ... normalcy and
disability are part of the same system" (24). The ways by which disability and normalcy are entangled are
noted by Tanya Titchkosky and Rod Michalko who comment, "Disability brings normalcy into view and
allows for the possibility of wondering how normalcy came about or how it was constructed in the first place"
(2009, 6).

production and could not adapt their bodies to the new modes of production that resulted from the change in the division of labour (1990, 797). Thus, they suffered from the consequences of being excluded from the market: poverty, ill-health, brevity of life, social marginalization, and dependence upon the informal economy. This group includes not only the "sickly" but also the "mutilated," the elderly and "victims of industry" (Marx 1990, 797). These people form what Marx calls "the dead weight of the industrial reserve army" (1990, 797). Not wanting to take on the burden of caring for this dead weight, capital externalizes this cost. By the late nineteenth century, many of those deemed "incapable" were incarcerated in workhouses, hospitals, asylums and "crippleages" (Gleeson 1999, 108). Disabled people "came to be regarded as a social problem," and as a social problem, "justification emerged for segregating them out of mainstream life and into a variety of institutions" (Russell and Malhotra 2002, 213).

The 1834 Poor Law in England distinguished between the able-bodied poor who should be compelled to labour and the disabled poor, who were considered objects of charity (Gleeson 1999). As objects of charity, disabled persons were placed in the new national system of workhouses. As Emile Durkheim remarks, "The insane and the sick of certain types, who were heretofore dispersed, [were] banded together from every province and every department into a single enclosure" (1964, 188). Higgins (1982) furthers that the workhouse was a "pen of inutility":

> The workhouse, the true shrine of the work ethic, was a sort of concentration camp in which were incarcerated, and held up as an example, those who admitted their inutility to capital - the sick, the mad, the handicapped, the unemployed - and in conditions which were even more monstrous than in the factories. (202)

While the enclosure of the disabled in workhouses was never universal – with some localities resisting the new law, and others operating in a variety of different ways – the "later establishment of hospitals and purpose-built institutions for disabled people by both the public and charitable bodies would considerably extend the landscape of social dependency" (Gleeson 1999, 105). That is, while changing the way disability was determined, the medicalization of bodies – able and disabled – intensified the enclosure of disabled bodies.

Abberley (1987) notes that the specific category of "disabled people" emerged and was constituted as a product of the development of capitalism and through the compulsion to work. Until the late 19th century, this categorization was produced largely through legal means. However, in the UK, shortly after the passing of the Poor Law, the state began compiling statistics and placing its subjects into identifiable categories (Gleeson 1999). Medicine, in relation with the emergent discipline of statistics, worked to explain that the inability to labour was a natural consequence of physical deviancy, ultimately devaluing the impaired body at the same time as it naturalized the causes of impairment. This is to say, through processes of medicalization, disability was reduced to individual, natural biological impairments in ways that hide the social nature of disability as well as the social, political, and economic causes of disability.

With the rise of medicine and the increasing popularity of Social Darwinists and eugenics, disability increasingly became categorized and regulated through medicalized practices. Much of the social authority that medicine gained throughout the 19th and 20th centuries was a result of normalizing discourses of the body that were entangled in notions that some bodies were genetically and racially inferior. In many jurisdictions, including the

US, Canada, and the UK, this led to the involuntary sterilization of disabled people as it was thought that "the birth of disabled children should be regarded as a threat to racial purity" (Russell and Malhotra 2002, 213).

Therefore, with the rise of industrialization, new forms of labour changed the social body and what was considered to be a desirable make-up of that social body. More specifically, the political and economic shift lessened the ability of disabled people to make meaningful contributions to their households as their bodies and minds were considered inferior. As households became more and more dependent on the competitive sale of labour-power, their ability to support and accommodate "slow" or "dependent" members became untenable (Gleeson 1999). As a result, many disabled people were institutionally segregated, transformed into "natural" dependents, and excluded from paid employment. Many disability activists and scholars argue that "the primary oppression of disabled people" is "their exclusion from exploitation as wage labourers" (Russell and Malhotra 2002, 212) and the rendering of disabled people as the "deserving poor" (216). It is of little surprise, then, that the fight for disability rights is caught up in returning disabled subjects to the working world and having the world recognize disabled subjects as valuable labourers.

From Marx to the Movements

Disability activism across the US, Canada, and the UK, came about through recognizing the social aspect of disability, marking disability as the product of oppressive power relations. In this way, industrialization and the historical development of capitalism have undoubtedly shaped disability. Connecting the oppression of disabled people to the

social relations of capitalism sparked the very beginnings of the disability rights and independent living movements, marking the problem of disability not a problem of any individual body but rather in the interaction between bodies and the social and material environments in which they are situated. Disability as a social oppression emphasizes the social origins of impairment, recognizes the social, financial, environmental, and psychological disadvantages placed on impaired people as historical products, and asserts the value of disabled modes of living while condemning the social, political, and economic forces that produce impairments, aiming to transform the material lives of disabled people and organize "together into a coherent conceptual whole" (Abberley 1987, 17).

In the US, the disability rights and the independent living movements formed over many years of organizing. This history of organizing includes the 1935 protests held by the League of the Physically Handicapped in New York City, whereby disabled people spent several weeks occupying the city's Emergency Relief Bureau to express their anger at city and federal policies that automatically reject disabled people from work programs. This automatic rejection marked disabled people as "unemployable." Slogans employed during these protests included: "We Don't Want Tin Cups. We Want Jobs," and "We Are Lame But We Can Work" (Nielsen 2012, 132). The group handed out fliers demanding that the government "recognize its obligation to make adequate provisions for handicapped people in the Works Relief Program" (Nielsen 2012, 133). Upon their success in New York City, 35 League members traveled to Washington DC in 1936 to press President Roosevelt for a permanent jobs program for physically disabled people. Many of the League leaders ended up with jobs in the civil service and the group disbanded in 1938 (Zames Fleischer and Zames 2011, 7).

In the US after World War II, many returning veterans "expected assistance and acceptance from the nation they had served" (Pelka 2012, 21), and desired to attend colleges, obtain degrees, and find full employment. As such, many veterans became involved in activist associations and groups that focused on political advocacy, remedial training, and played an influential role in technological innovations such as curb cuts, wheelchairs (see Chapter 2), lift-equipped buses, and so on (Pelka 2012).

While various disability groups and charities existed throughout the 19th and 20th centuries, it was not until the 1970s that a significant number of organizations run by disabled people began to emerge (Oliver 2009). In the US, a national disability rights movement solidified around Section 504 of the 1973 Rehabilitation Act, which prohibited discrimination on the basis of disability by any public employer or private entity receiving federal funding. President Richard Nixon vetoed the first two versions of the Act, and when it finally passed, Section 504 was not enforced. By 1977, a national cross-disability movement emerged, identifying the need to enforce 504 as its main campaign. The newly formed American Coalition of Citizens with Disabilities (ACCD) called for a national day of action to put pressure on the newly elected Carter administration. On April 5, 1977, disabled persons protested across the US. In San Francisco, over 150 activists and allies (including union activists, members of the Butterfly Brigade, Chicano activists, and the Black Panthers who supplied a daily hot meal) occupied a floor of the regional federal office building for 25 days until Joseph Califano, US Secretary of Heath, Education and Welfare signed the enforcement regulations (Pelka 2012; Nielsen 2012). While Ronald Reagan's administration tried to weaken Section 504 through the early 1980s, suggesting that the federal government should not be used to advance or enforce civil rights as he also

worked toward ending Social Security benefits for hundreds of thousands of disabled

recipients, grassroots disability organizing eventually led to the writing and passing of the

1990 Americans with Disability Act (ADA). The success of much of this organizing came

as a result of "the vitality of the women's movement, the Black civil rights movement, the

gay and lesbian movement, the Chicano movement and other new social justice

movements" that created "an opening in which the case for eradicating disability

oppression could also get a hearing" (Russell and Maholtra 2002, 217-218).

In Britain, the disability rights and independent living movements took shape out of

organizing done in 1966 by The Disablement Income Group (DIG), which in 1976

transformed into the Union of Physically Impaired Against Segregation (UPIAS). UPIAS

had its activist start when Paul Hunt, a resident of Le Court Cheshire Home, wrote a letter

to *The Guardian* newspaper on September 20, 1972 calling for the formation of a consumer

group to represent those living in institutions. Hunt had researched independent living,

inclusive education and welfare benefits that already existed in the US and Nordic

countries. According to the UPIAS founding policy statement, the aim was to replace

segregated facilities with opportunities for people with impairments to participate in

society, living independently and undertaking work to have full control over their lives. The

policy statement defined disabled people as an oppressed group.

In 1975, UPIAS and the Disability Alliance (a coalition of existing disability groups

formed in 1974), published *The Fundamental Principles of Disability*, which defined

disability as being a situation caused by social conditions, specifically noting that it is

"society which disabled physically impaired people. Disability is something imposed on

top of our impairments, by the way we are unnecessarily isolated and excluded from full

participation in society" (UPIAS 1976, 3). The distinction UPIAS made between impairment as physiological and disability as social oppression on top of physiological difference became a core distinction within disability rights ideology (Shakespeare 2006). In other words, while people might be impaired, disability was a social distinction that required political contestation. This distinction proved to be productive. For while many disabled people were unable to support themselves, and often ended up institutionalized up to and through the 1960s, by the 1980s, a number of disabled people's organizations flourished in Britain working towards independent living, promoting disability rights, and challenging the position of charities, leading to the 1995 Disability Discrimination Act (Oliver 2009, 136).

In Canada, disability activism grew out of the many disability advocacy organizations that flourished in the 1960s and 1970s (Barnartt 2008). For example, Rob Kitchin and Robert Wilton (2003) note that as early as 1967, disability advocates in Hamilton, Ontario petitioned city council to demand that City Hall and polling places be made accessible. However, the first major disability rights protests did not occur until 1975 when activists sought to include disability in the Quebec Charter of Rights and Freedoms (Boucher, Fougeyrollas and Gaucher 2003; Barnartt 2008). In 1976, disabled people across Canada formed the Coalition of Provincial Organizations of the Handicapped (COPOH). COPOH demanded disability rights such as self-determination and equality for disabled peoples.

In 1977, some gains were made with the passing of the Canadian Human Rights Act, which included disability as a prohibited ground of discrimination. These gains were concretized through further activism and protest, including the November 4, 1980

demonstration on Parliament Hill to demand that equality rights on the grounds of disability be included in the newly proposed Charter of Rights and Freedoms (Peters 2003). This protest "was the first time that people with a variety of disabilities from across the country gathered together to publicly express their frustration and dissatisfaction with government" (Peters 2003, 121), leading to what activist Yvonne Peters describes as the "emergence of people with disabilities as a political force in Canadian democracy" (2003, 122).

Throughout the 1970s, the political scope of this force in Canada was largely limited to fighting for disability to be enshrined as a civil and legal issue. Alongside fights for Charter inclusion, at its annual conference in Vancouver, British Columbia in 1980, members of COPOH presented on the Independent Living philosophy, fuelling participants to hold a workshop in 1981 in Winnipeg to examine the possibilities for independent living in Canada (Phillips 2003). The first independent living center was established in Kitchener, Ontario in 1981, and by 1985 many more were popping up across the country. Nonetheless, despite the collective action of disabled activists, the disability rights and independent living movements in Canada were very focused on "individual and self advocacy rather than collective advocacy," focusing on the needs of individuals rather than "social or political change" (Phillips 2003, 205). This history of disability rights in Canada has led Barnartt (2008) to conclude that in "Canada there were few early protest successes, although there were major policy successes." That is, many of these "policy successes" were geared toward benefiting particular individuals (through, for example, individual access to independent living) rather than dismantling systems of oppression that affect disabled people as a whole.

Even if the focus on disability rights has been individualistic in scope, framing disability as a social oppression has been crucial to the disability movements in the US, Canada, and Britain and to the development of their political strategy, namely that of barrier removal. By focusing on the ways in which people with impairments are disabled by society, the removal of barriers is prioritized in order to promote the inclusion of people with impairments. An important shift is made away from individualized rehabilitation and medicalization towards pursuing social transformation that has resulted in the implementation of anti-discrimination legislation and the encoding of civil rights for disabled people in many different countries. The social oppression model of disability has enabled activists and researchers to challenge the discrimination and oppression of disabled people, interrogate the inequitable relationship between disability and capitalism, and to critique various ableist cultural representations.

However, with the shift in capitalist relations towards the neoliberalization of economic, political, and social policies, practices, and discourses, it is important to account for the ways in which disability has been hailed and mobilized by practices neoliberalization. Specifically, the social oppression model of disability cannot account for the ways that capitalism benefits from the incorporation of disabled people as it rubs against the ways by which disabled people are oppressed by earlier capitalist relations. This is to say, neoliberal capitalist relations are interested in disability in so far as it provides new ways to integrate and include disability in society so as to profit from it. This has important consequences for disability rights movements and has informed the development of critical frameworks of disability justice. As I will mark below, the neoliberalization and economization of disability relations remain underexplored in disability studies.

Neoliberalizing Disability: Relations of Capacitation and Debilitation

Key shifts taking place in the practices of disability as a result of the neoliberalization and economization of disability relations have been notably traced by scholars such as Marta Russell and Ravi Malhotra (2002), Matthew Sothern (2007), David Mitchell and Sharon Snyder (2010), Jasbir Puar (2011), and David Mitchell (2014). In addition to these chartings, Mad, Queer, Indigenous, and People of Colour disability communities have been actively shaping new critical frameworks of disability justice that contest the neoliberalization and economization of disability relations, and challenge the white, middle-class, heteronormativity of disability movements and disability studies (Abdelhadi 2013; L. Brown 2015; Gorman 2013; Mingus 2010b; Mingus and Macdougall 2013; Mingus and Talley 2013; Erevelles 2014; Bell 2006, 2011; Lamm 2015).

Russell and Maholtra argue that disability has been commodified in such a way as to be "big business," whereby "social policies get created or rejected according to their market value" (2002, 215). In the US, for example, both the institutionalization of disabled people in nursing and care homes and the deinstitutionalization of disabled people through independent living and in-home services have been organized through the logic of capital and in the interest of maximizing profit (215-216). However, in many instances, neoliberal cuts have led to the "widespread closures of the institutions that warehoused disabled people, but without an allocation of adequate resources and services to enable them to live independently" (216). Thus, the independent living and disability rights movements that have long fought for the deinstitutionalization and increased rights and independence of disabled people are confronted with the neoliberal and "Third Way" political language that

"rights entail responsibilities," and the argument for downloading the responsibility of caring for disabled people onto disabled individuals and their families by emphasizing the need to end dependency and increase productivity (220).

As opposed to seeing this confrontation as being an opposition between neoliberalism and disability movements that exists outside market rationality, as Russell and Maholtra chart, independent living, in its promotion of autonomy and self-determination "implicitly accepts the foundations of free market ideology by framing the debate in terms of the right of disabled people as consumers to receive equal treatment from the market" (2002, 218). In this way, independent living remains a strategy that is helpful for only a "tiny fraction of the most privileged disabled people" (218), leading to an intensification of the exclusion of the remainder of disabled people. Russell and Maholtra conclude that the liberation of disabled people is only possible through questioning "the very basis of the rules of the market" (2002, 218) and contesting "productivism" and the ability to labour as "a requirement for full membership in society" (2002, 223). US disability activist Sunny Taylor reaches a similar conclusion in her 2004 article, "The Right not to Work: Power and Disability." Such a questioning of capitalism and labour requires disabled people to forge links "with other marginalized members of society" (Russell and Maholtra 2002, 219), a point that is taken up by disability justice activists.[10]

Adding to this understanding of the neoliberalization of disability relations, Sothern (2007) marks disability as "the category that neoliberal figurations of biomedicine promise to eliminate even while neoliberalism invests in the proliferation of categories of disability"

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[10] Taylor (2004) notes, however, that many disabled movements have "tried to join forces with other identity groups in the struggle for change" but have been "ignored and in fact shunned."

(146). That is, while the policies of neoliberalism promise that our active, self-cared-for-selves will avoid illness and disability through the wonders of technoscience, "there is the simultaneous pharmaceutical-industrial production of increasingly complex and expanding categories of disability that can be medicated or otherwise manipulated for profit" (2007, 146). Sothern's research points to sharp tensions within the neoliberalization of policies, practices, and discourses, particularly to emphasize the way in which neoliberal biocapitalism wants to both prevent and overcome disability while also expanding categories of disability through practices like changing definitions of conditions in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) so as to enable more and varied modes of existence to be increasingly medicalized and therefore open to potentially profitable treatment regimes.

The attention paid to disability by neoliberal thinking is remarked on Mitchell and Snyder (2010, 180) who argue that "disabled people have become objects of care in which enormous sectors of post-capitalist service economies are invested." For Mitchell, these investments have largely been a way for disability to "integrate based on the ability to approximate values of normalcy" (2014, 1) and to become "normative versions of less threatening differences" (2014, 5).

While processes of normalization have not disappeared, following the work of Jasbir Puar (2009; 2011), I contend that given biopolitical developments in neoliberal biocapitalism, a shift has occurred such that the focus is more on the *differential* capacitation of bodies rather than their normalization. That is, through capacitating processes like genetic therapies, surgeries, supplements, prosthetic enhancements, and healthism, bodies are to be capacitated and enhanced beyond what is thought of as the able-

body. And yet, bodies are neither entirely capacitated nor debilitated: there are gradations of debility and capacity. This tension between debilitation and capacitation is what motivates Puar (2011) to argue that *all* bodies, not just disabled bodies, within neoliberalized relations are "being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, [and] enhanced capacity" (155). According to Puar, neoliberalism mobilizes the tension between capacity and debility in order to profit from both the debilitation of certain bodies and also from the ways in which people recover or overcome debility through processes of capacitation. An economics of both debility and capacity serve the interests of neoliberal capitalism and reshapes formations of disability.

Using these conceptual tools, disability cannot be reduced to a uniformly oppressed identity category or form of embodiment defined by lack or equated with being abnormal. Although oppression remains part of the story, disability is caught up in processes of both debility and capacity. Thus, through neoliberalization, those who are "upwardly mobile" become not only the abled-disabled, but also entrepreneurs, employers of attendants, and consumers of therapies, supplements, and enhancements. Neoliberalization orients and capacitates those disabled who can afford to be included. The capacitating and debilitating economics of disability are entangled in processes of privatization, individualization, and deregulation, and profoundly affected by austerity measures (Goodley 2014). It is for this reason that Sothern argues: "the space of the disabled body must also be thought of as a space of the contradictions of neoliberalism – it is at once privileged as a site of inclusion, but that inclusion is also the promise of its exclusion" (2007, 146).

These interventions are uncomfortable for disability studies insofar as they challenge the ways in which the field and some forms of disability activism reproduce disability as an oppressed identity and an aggrieved subject enacted through what Brown (1993) terms "wounded attachments." In focusing on normal/abnormal, or abled/disabled rather than on gradations of debility and capacity, disabled people hang on to an understanding of themselves as being excluded in a way that is not productive for fighting the neoliberal conditions in which disabled people are situated.

At the forefront of contesting the goals of including disabled people as capacitated and enhanced neoliberal subjects are Mad, Queer, Indigenous, and People of Colour disabled communities who have developed critical frameworks of disability justice. In an interview with Greg Macdougall, disability justice activist Mia Mingus comments: "a lot of disabled people come to Disability Justice because they didn't see themselves reflected, or don't see themselves reflected, in the more mainstream disability rights movement" (2013). Disability justice seeks to "build multi-issue politics," mobilizing intersectional critiques of race, class, gender, citizenship, colonialism, and so on, that mark "different systems of oppression and different forms of violence" (Mingus and Macdougall 2013). Disability justice critically examines how ableism, as a system of oppression, "gets leveraged in service of white supremacy, it gets used as a tool to help maintain and perpetuate patriarchy and male supremacy, [and] transphobia" (Mingus and Macdougall 2013). As such, disability justice is fundamentally about going "beyond access" for the sake of "assimilation" and rather seeks to create "the world that we actually want – access for the sake of justice and liberation, access for the sake of deeper connection and breaking isolation" (Mingus and Macdougall 2013). Mingus notes: "it is so rare for movement

spaces to ever consider disability and access in ways that go beyond logistics; in ways that

challenge the ableist culture of our work" (2010b). As such, disability justice is also

concerned with implementing practices of interdependence and moving away from rights-

based equality models that simply expand "the ranks of the privileged" (Mingus and

Macdougall 2013). For Mingus,

> To pretend like ableist oppression and privilege do not manifest themselves
> differently among disabled people would be such a disservice to cross-disability
> community building. For example, to pretend as though those of us who pass as
> able bodied or "don't look like we're disabled," don't receive a totally different
> reality than those of us who are undeniably and obviously marked as disabled by
> everyone they meet, would be ridiculous and does not do justice to what we are up
> against nor how powerful a system ableism is. (Mingus and Talley 2013)

Examining ableist oppression and privilege also means understanding disability justice as a

framework that informs social justice on a whole. Mingus comments that disability justice

is "liberation for my disabled communities that I'm a part of, but also for the queer and

trans people of color communities that I'm a part of, also the Korean communities that I'm

a part of, also the radical women of color communities that I'm a part of" (Mingus and

Macdougall 2013).

Disability justice builds on the intersectional frameworks of Indigenous feminist

scholars such as Andrea Smith by extending this intersectional understanding of feminism

to ableism and disability (Abdelhadi 2013). For example, disability justice activist Abla

Abdelahdi writes: "I cannot separate being Palestinian, from being disabled, from being a

womyn," noting that by "centring the experiences" of disabled queer, trans, and Indigenous,

People of Colour (IPOC), "disability justice allows us to understand violence against and

criminalization of disabled people in more critical ways" (2013). For example, a disability

justice framework "centres the experiences of missing and murdered Indigenous womyn, girls and two-spirit people and their families and communities across Canada/USA, families and communities living with the trauma of racist misogynist colonial violence" (Abdelhadi 2013). Further, as Abdelhadi remarks, "Disability justice also allows us to complicate discussions about the Medical Industrial Complex (MIC) and how closely the MIC works with the Academic Industrial Complex in paving the way to criminalize queer trans disabled IPOC." For:

> There can be no critical discussions of disability or mental health without centring the experiences of queer trans IPOC in these institutions. A very brief look at the historic roots of asylums in Canada and the USA shows how these institutions not only have a history of oppressing IPOC, but have in fact been founded on the principles and legacies of colonial and anti-black racism and violence. (Abdelhadi 2013)

Disability justice activist and scholar Lydia Brown (2015) affirms this approach, remarking: "It's long past time that our movements, our organizations, our activists in the disability community start addressing our replication of white-centric structures and start challenging racism – and anti-blackness in particular." Brown (2015) furthers:

> This is what intersectionality means: to practice social justice in ways that grapple with the complex impacts of multiple systems of structural oppression (or systemic injustice, if you will). For those of us who are non-Black autistic activists, that means recognizing that behavioral compliance, indistinguishability, and conditionally passing as neurotypical can be tools of survival for Black autistic people. Resistance to arbitrary norms of abled and neurotypical existence can take multiple forms. Survival and resilience can mean navigating complicated tensions between out and proud autistic existence and safety from racialized violence. Intersectionality demands complexity without easy answers or simple slogans, because the real lives of everyone in the movement are infinitely more complicated than single-issue politics can recognize. Intersectionality requires thoughtful organizing and intense labor if we truly seek to build more just and equitable communities.

It is for these reasons that Mingus concludes: "We cannot move toward disability justice without the lived experiences of the people who get marked and oppressed as disabled and any work to challenge, reimagine and transform what disability is or could be cannot forget this" (Mingus and Talley 2013).

These principles, practices, and critiques are echoed by members of California-based Sins Invalid, a grassroots performance project that creates space for queer, gender nonconforming, disabled people of color to engage in art and activism (Sins Invalid 2015). On their website they note: "Sins Invalid is committed to social and economic justice for all people with disabilities – in lockdowns, in shelters, on the streets, visibly disabled, invisibly disabled, sensory minority, environmentally injured, psychiatric survivors – moving beyond individual legal rights to collective human rights." Member Nomy Lamm (2015) writes that disability organizing:

> was single-issue focused. It was dominated by whiteness, straightness, and maleness. And it was concerned primarily with mobility impairments. Meanwhile, the radical spaces I had felt more drawn to – anti-capitalist, feminist, anarchist spaces, for example – had little awareness of disability, and often relied on high levels of physical and mental exertion without acknowledging limitations or access needs, inevitably leading to burnout and alienation.

Lamm further remarks that disability justice was born out of conversations disabled activist Patty Berne had in 2004 with other queer disabled women of color, trying to find language for a framework that would center disabled queers of color in order to challenge "the idea that our worth as individuals has to do with our ability to perform as productive members of society" (Lamm 2015). Rather, disability justice insists: "our worth is inherent and tied to the liberation of all beings. Like transformative justice, reproductive justice, and environmental justice, it implies a movement-building strategy and an anti-capitalist

critique" (Lamm 2015). Disability justice is "a growing movement, and we are just developing the practice right now. We make the road by walking, rolling, prancing, crawling, limping along it" (Lamm 2015).

My dissertation makes a contribution to this area of study by considering the ways in which neoliberalism continues the oppression of disabled people. I also consider the ways in which disabled people are capacitated by, and entrenched in, neoliberalism. At the same time, however, I argue that ableism continues to be an important category to interrogate and operates alongside gradations of capacity and debility, and thus I argue that forms of compulsory-able-bodiedness work alongside material-discursive practices of enhancement that produce better-than-able-bodies (see Chapter 3). In exploring this relationship in each of my chapters, I come to suggest that in order to further disability justice it is imperative to expose and expand upon the ways in which disability is not a thing to be capacitated or debilitated, but rather is an intracorporeal emergence of the world that extends beyond the human. I now turn to what I mean by intracorporeal emergence and its implications.

Intracorporeal Entanglements: A Turn to Feminist Materialism

In constellating the work explored thus far, an important insight emerges: while disability scholars and activists continue to predominantly reject the medicalization of disability on the grounds of wanting "Ramps not Cures," the medical-industrial-complex has largely shifted its focus away from cures and towards a proliferation of ways of capacitating and enhancing bodies. At the same time, much of the science at the heart of what has influenced this proliferation has also profoundly affected social theory,

particularly in what is now known as feminist materialism, which draws upon insights developed in science and technology studies[11] and poststructuralist theory. This has resulted in theories of the body, embodiment, and corporeality that can account for "how the discursive and the material interact in the constitution of bodies" (Alaimo and Heckman 2008, 7), where the material-discursive interaction is human and nonhuman, and an interaction of culture, history, technology, biology, and the environment, without privileging any of these elements.

Karen Barad's (2007; 2008) work in particular moves towards performative alternatives to representationalism. Representationalism is the belief that there is an ontological distinction between representations and the objects that they purport to represent (Barad 2007, 46). That is, it is the belief that what is represented is independent of the practices of representing such that representationalism assumes that there are external objects that exist independently of any attempts to depict them. Further, representationalism privileges the human knower as distinctly able to create meaning through representations, words, images, and so on. Representationalism seeks to produce objective and correct correspondences between reality and how it is described. Both scientific realism and social constructivists approaches participate in representationalism to greater or lesser degrees. According to Barad, both approaches believe that "scientific knowledge mediates our access to the material world" (2007, 48). However, an important difference between these approaches lies in how each identifies the 'real' to which the representations refer. That is, the difference between scientific realism and social constructivist approaches differ on the

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[11] According to Kim TallBear, science and technology studies "explain how social, political, and cultural values affect science-and-technology (technoscientific) research and innovation and, in turn, how technosciences affect our politics, cultures, and social institutions" (2013, 11).

point as to "whether scientific knowledge represents things in the world as they really are (i.e., nature) or objects that are a product of social activities (i.e., culture)" (2007, 48).

In contrast to representationalism, Barad develops a theory of "agential realism" which marks how "practices of knowing," such as those of science or social science, "are specific material engagements that participate in (re)configuring the world" (2007, 91). Agential realism is predicated on quantum mechanical theories that address the entanglement of matter and meaning, shifting the focus to how practices stabilize and destabilize differential boundaries (2008, 126). Agential realism asserts that "we are a part of the nature we seek to understand" (2007, 67). For Barad, matter is a doing, not a thing, and the point is not that there are material factors in addition to discursive ones but that the material-discursive is conjoined in all practices, conditions, and constraints of nature. Discourse is not what is said, it is what constrains and enables what can be said (2008, 137): discursive practices produce rather than describe subjects or objects. As such, Barad argues that "existence is not an individual affair" (2007, ix) as there is no independent, self-contained existence. Rather, she argues, "individuals emerge through and as part of their entangled intra-relating" (2007, ix).

Barad's performative approach is not concerned with assessing the truth of a representation, nor with assessing whether a representation is a product of nature or culture. Rather, Barad bypasses questions of correspondence by inquiring into the ways in which practices or performances themselves make meaning through direct material engagement with the world, as well as inquiring into how those practices produce effects and the conditions of their efficacy (2007, 49). Importantly, for Barad matter is not passive and "humans are not the only ones engaged in performative enactments" (2007, 49). As such

Barad contends that: "What is needed is a robust account of the materialization of *all* bodies – 'human' and 'nonhuman'– and the material-discursive practices by which their differential constitutions are marked" (2008,128).

Barad posits a posthumanist performativity that builds on the work of both Michel Foucault (1977; 1978) and Judith Butler (1990; 1993). In *Gender Trouble* (1990), Butler collapses the sex/gender distinction, arguing that there is no natural body that pre-exists its cultural inscription: sex is always already gender. That is, "sex itself is a gendered category" (1990, 11) and the gendered body is inseparable from the acts that constitute it. For Butler materiality is "a certain effect of power" (1993, 34) and performativity "must be understood not as a singular or deliberate 'act,' but, rather, as the reiterative and citational practice by which discourse produces the effects that it names" (1993, 2). That is, "there is no reference to a pure body which is not at the same time a further formation of that body" (1993, 10). Drawing on Foucault's notion of regulatory power, Butler argues that the repetition of regulatory practices materializes bodies and produces "*the effect of boundary, fixity, and surface we call matter*" (1993, 9).

While in some ways Barad echoes Butler's theory of performativity, for Barad, both Foucault and Butler ultimately fail to account for "*how the body's materiality* (including, for example, its anatomy and physiology) *and other material forces as well* (including nonhuman ones) *actively matter to the processes of materialization*" (2007, 65). Barad suggests that "To restrict power's productivity to the limited domain of the social, for example, or to figure matter as merely an end product rather than an active factor in further materializations is to cheat matter out of the fullness of its capacity" (2007, 66). As such, Barad's agential realism seeks to account "for the materialization of all bodies" so as to

understand "the nature of the relationship between discursive practices and material phenomena; an accounting of 'nonhuman' as well as 'human' forms of agency; and an understanding of the precise causal nature of productive practices that take account of the fullness of matter's implication in its ongoing historicity" (2007, 66).

Barad's work is compelling for disability scholars at this particular social and political juncture precisely because it provides an opening to materially and discursively produce alternatives to the neoliberalized relations of biocapitalism. A theory of matter as a dynamic and shifting entanglement of relations, rather than a property of things (2008, 35), works against the insidiously individualizing logic of neoliberalism, but also pushes against the ways in which disability is often assumed to be a discrete object in the world. That is, disability is frequently cast as discretely knowable – a wheelchair, a mutated gene, a woman with a cane, or a ramp that circumnavigates a flight of stairs, even as it is often mobilized as an abnormal form of individual human embodiment that can be contained, accommodated, or overcome.

In contrast to these approaches, I build on Barad's work to mark disability as an intracorporeal emergence: relational intra-active practices of the human and nonhuman that have the potential to disrupt the individualization and economization of disability relations. Positioning disability as an intracorporeal emergence is not to place disability outside of neoliberal relations, but it is to re-situate the intensive individualizing forms of neoliberal governance that repeatedly locate disability within a particular bounded body that can be capacitated or debilitated.

I follow Barad (2007; 2008) to argue that disability is not a property of a thing and is not bounded within a singular body. In other words, the "essence" of disability is neither

a genetic mutation nor a wheelchair blocked by a flight of stairs. Rather, disability emerges as an historically-specific onto-epistemological materialization of intra-active bodies. "Onto-epistemology" highlights knowing as a material practice of engagement that is of the world in its differential becoming (Barad 2007, 89). Epistemology and ontology cannot be separated because practices of knowing are material in ways that are saturated in power relations that constitute how a subject or object emerges, though they do not fully determine its emergence. In this way, impairment is not a biological condition of an individual body but rather is a shifting material-discursive practice that provides an opening to imagine and practice disability in new ways (see Chapter 6 and 8).

While a number of disability scholars have been active in pursuing alternative practices of disability through mobilizing assemblage theory (Gibson 2006; Shildrick 2009; Goodley and Runswick-Cole 2014), or relational approaches (Kafer 2013; Hoogsteyns and Horst 2013) many of these approaches either mark the relations of disability as primarily human relations, or when they do approach disability as an assemblage of the human and nonhuman, they do not adequately address the ways by which neoliberalism constrains the practices of disability, or they already assume multiply formed bodies coming into interaction (i.e., human and ventilator) rather than a body being formed within an intra-action (i.e., humanventilator). In contrast to these approaches, while also being in dialogue with them, I constellate the logics of neoliberalism alongside the politics of disability justice and the material-discursive practices of disability as an intracorporeal emergence. In doing so, I work towards Puar's convivial call for a "cyborgian goddess" (2012, 63) that can account for the ways in which disability is produced and functions through processes of signification, identity, affective capacities, intensities, tendencies, and habituations. I work

to chart the relations of disability through multiple senses of composition, whether through the circulation of affects and feelings (Chapter 2, 7), or through nonlinear temporalities (Chapter 4, 5, 8) and nonhuman agencies (Chapter 3, 4, 6), in addition to examining representations, legal and medical categories, and other "events, actions and encounters between bodies" (Puar 2012, 58).

Finally, Barad's attention to be accountable to "what matters and what is excluded from mattering" (2007, 184) marks each moment as "alive with different possibilities for the world's becoming and different reconfigurings of what may yet be possible" (Barad 2007, 182). For as Barad notes: "We are not outside observers of the world. Neither are we simply located at particular places *in* the world; rather we are part *of* the world in its ongoing intra-activity" (2007, 184). This "ethico-onto-epistem-ology" (2007, 185) – an "intertwining of ethics, knowing, and being" (2007, 185) – requires a political commitment to reconfiguration that changes what may yet be possible. In Barad's commitment to both the scientific and the social, the material and the discursive, an opening is made to push back against neoliberal biocapitalism and to assert that disability too, is *of* the world. It is our ethico-onto-epistemological responsibility to reconfigure what disability *of* the world renders possible.

Emergent Methods and Entangled Methodologies

This work is necessarily interdisciplinary, informed by a critical engagement with the fields of disability studies, feminist science and technology studies, political economy, and feminist philosophies of bodies and embodiments. I read the emergence and proliferation of the disability rights movement in Canada, the US, and the UK, and the

implementation of neoliberalized policies and practices of deregulation, privatization, and individual entrepreneurship together, charting the changing practices and discourses of disability as a marker of the various human and nonhuman intra-actions involved in the contemporary constitution of disability. I find these practices and discourses across disparate sites: I read newspaper articles, scientific studies, theoretical articulations, legal and institutional policies and regulations, historical materials, genetic diagnoses, memoirs, social movement blog postings, city bylaws, annual reports of nongovernmental organizations, government statistics, pamphlets, posters. I also listened to radio documentaries and watched news broadcasts. These productions of disability are varied and have been collected over many years. Some of these materials I actively sought out. In other instances, colleagues alerted me to materials at various academic and social movement-based conferences. Some materials I simply happened upon by chance. Aside from my reading materials, I also collected my own personal stories of disability, taken from my experiences of diagnosis, of altered prognosis and abilities, of becoming a mother, of being variously and contradictorily included and excluded, and of being both capacitated and debilitated. What began with bookmarking an online newspaper article or reading a press release about new technologies or enhancement-drugs, in time developed into a database brimming with stories, representations, and materialities that while seemingly fragmented and incongruent actually form a compelling constellation that marks the relationship between disability, biopolitics, neoliberalism, and agential realism.

My approach mirrors the methods employed by scholars such as Sara Ahmed (2010) and Lauren Berlant (2011). This approach to data collection and analysis has allowed me to attend to, account for, and begin in the middle of the ongoing and shifting

production of disability. In doing so, I glean the particularities of their singular resonances so as to trace out their continuities. Ultimately, through varied discourses and practices I expose a dominant approach to the production of disability relations that not only works to individualize disability but also to delimit the multiple, complex, and meaningful ways in which disability intracorporeally emerges. This individualized dominant approach that obfuscates the multiplicity of disability has ongoing and alarming consequences for the pursuit of disability justice.

This dissertation is divided into nine chapters, each of which provides a different take on the constellation of neoliberalism, biopolitics, and intracorporeal enactments of disability. While this chapter serves to introduce the major frameworks I utilize, in Chapter 2 I explore how the wheelchair has come to be a marker of disability, so much so that it appears ubiquitously in our everyday lives as the universal symbol of disability access: the blue and white wheelchair symbol, otherwise known as the International Symbol of Access (ISA). The correlation between disability and wheelchair is no accident and is tied to the emergence of neoliberalism. While much disability activism in North America predates the emergence of neoliberalism, it was not until the 1960s and 1970s that disability rights became a prominent political issue. In the United States, Canada, and Britain, this increasing prominence was partly due to the growing demands of war veterans after both the Second World War and the Vietnam War, improvements in technologies that enabled individuals to leave their homes to work or to attend college and university, the prominence of unions and labour-related groups fighting for safer and healthier working conditions and workplace accident compensation, the success of a number of lawsuits related to disability access and accommodation, and the growth of impairment specific organizations and

associations that lobbied various levels of government for increased research funding, access to services, and to pass legislation in recognition of civil rights. The gains made by the disability rights movement for disabled people and the political organization of disabled people are both valuable. However, what is of interest in this chapter is the way in which disability inclusion, as tied to the wheelchair, has had lasting consequences for the ways in which disability is mobilized in contemporary neoliberal social relations.

Chapter 3 dives into the politics of neoliberal biocapitalism and its implications for disability. Disabled people have called for "Ramps not Cures," but neoliberal biocapitalism does not offer one or the other: the technologies that bring ramps, lighter wheelchairs, more advanced batteries, pacemakers, better prosthetics, or better drugs with less side effects, are part and parcel of the socioeconomic and political context that brings cures, promulgates international war, and creates the very kinds of global inequalities that produce ever growing numbers of disabled people. Chapter 3 begins to parse out the way in which the emergence of neoliberalism, the boom in the life sciences, and the beginnings of the disability rights movement in North America form a constellation that have had lasting impacts on how disability comes to appear in the world both discursively and materially.

I build on the politics of biocapitalism in Chapter 4, which examines the discourses surrounding Philippe Grandjean and Phillip Landrigan's 2006 and 2014 studies that highlight the dangers of exposing fetuses in utero to toxic chemicals that are commonly present in our everyday environments. In unpacking their analysis of "neurodevelopmental toxicity" and the effects of such toxicity on the economy, I argue that the production of disability is intimately linked to forms of neoliberal biocapitalism that have consequences for how we think toxicity and disability together. Grandjean and Landrigan's studies draw

attention to the sorely lacking standards and laws regulating chemical production and distribution in the US and how everyday environmental exposure to particular toxic chemicals can debilitate certain populations more than others. However, the emphasis of their studies and the resulting media attention has focused not solely on lax regulations but rather also on the economic impact toxic chemicals have on the developing fetal brain. The production of disability as economically unviable in their studies is comprehensible precisely because of the ways in which disability is entrenched in neoliberal biocapital and speculative futures. The question of human capital is a question of how individualized entrepreneurs can be capacitated or debilitated, or made to overcome their debilitations so as to contribute to the present and future profitability of neoliberal biocapital. Using Grandjean and Landrigan's studies as a starting point, and building on the work of Mel Chen (2011), this chapter develops a critical disability studies response to toxic, disabling environments by placing disability studies in conversation with feminist science studies. As such, this chapter seeks to critique the relationship between toxic environments and neoliberal biocapitalism to attend to its forms of producing particular speculative futures of disability. In doing so, I emphasize the importance of reproducing disabled lives – future lives – worth living while still critiquing neoliberal economies that produce disability.

In Chapter 5, I turn my attention to the future to explore how the withering of some disabled lives and the capacitation of others are a result of material and discursive processes that imagine the suffering disabled child as a life without a future. In other words, this chapter takes up what can be called neoliberal futurity and how it organizes disability and makes it intelligible through the suffering disabled child that is never imagined to grow up. Usually figured as the negation of the future, or having no future, neoliberal futurity also

speaks to the difference of the futures imagined for disabled children: disabled futures. Building on Lee Edelman's (2004) critique of what he calls "reproductive futurity" that privileges the Child as the image of the future, I show how neoliberal futurity underwrites the medical procedures that prevent the suffering child from being born; infanticide and filicide; the Make-A-Wish Foundation that aids the suffering disabled child; and the Jerry Lewis Muscular Dystrophy telethon that works to cure the suffering child. By looking at these disparate discursive and material sites, I show that as opposed to homogenizing actions and desires, neoliberal futurity is productive in that it informs economies that prevent life, end life, capacitate infantilized bodies, and re-invest a caring public in biocapitalism.

At the same time, even as neoliberal futurity diversifies, I also show that the suffering disabled child nonetheless re-inscribes the hope for a future without disability or, at least, a future in which disability no longer seems to be difference that matters. That is, I show that it is at the confluence of this double lack-of-futurity – disabled children without futures and a future without disability – that some disabled adults become unanticipated lives left to wither by the state while others become capacitated as an inspirational, hopeful, and progressive success story of neoliberal inclusion. Building on my argument from the previous chapters that the capacitation and withering of disabled people within neoliberal economies are linked, I show that some disabled people flourish in the future precisely because their futures gain traction in neoliberal society; these tractable futures demand that others have no future.

In Chapter 6 I build on the importance of "wounded attachments" as explored in Chapter 3, to question why it "is still not fashionable to be disabled" (Goodley, Hughes,

and Davis 2012, 1). I argue that this undesirability of disability stems in part from what disability theorist Alison Kafer calls "an ableist failure of imagination" (2013, 4). This ableist failure of imagination exposes how it is the case that disabled people are increasingly included and integrated into western neoliberal economies and social life and, yet, disability simultaneously remains a deeply and profoundly undesirable category of being. I mark the ways in which challenging the undesirability of disability is a shared responsibility that goes beyond the inclusion of disabled people within the exploitative and individualized relations of neoliberal capitalism. Challenging the undesirability of disability requires that disability be imagined differently, that is, imagined in ways that ensure that disability can be collectively practiced and experienced differently. Throughout this chapter, I argue that in order to practice disability differently, we must begin with marginal, heterotopic imaginations whereby disabled lives are not only worth living, but worth flourishing. Building on Michel Foucault's concept of heterotopia (1998), a concept that marks "outside places" by their discontinuity and multiplicity, and drawing on the work of Mel Chen (2012) and Rod Michalko (1999), I argue that the heterotopic imagination reconfigures how disability emerges, with whom it emerges, and where. When disability is viewed through the lens of the heterotopic imagination, it becomes an intracorporeal, non-anthropocentric, multiplicity that exceeds the individualized human body inscribed by neoliberal biocapitalism.

In Chapter 7, I address the ways in which dominant cultural discourses of disabled parenting, with a particular focus on disabled mothering, re-enforce disability as located in an individual body. I begin by mapping out the extensive social barriers faced by disabled parents (Frederick 2014; Track 2014; Malacrida 2007, 2009; Blackford 1993; Grue and

Laerum 2002; Evans and de Souza 2008; Asch and Fine 1992; Asch, Rousso and Jefferies 2001; Kent 2002; Prilleltensky 2003). Then, in tracing out the narrative accounts of disabled mothers appearing in popular media (Erdreich 2015; Peachman 2014), I show how neoliberal processes of capacitating disabled people as parents sustain and celebrate disability as an individual problem that can be overcome by an inclusive society. Building on the good feelings of inclusion presented in Chapter 2, I show how disabled people are hailed to feel good about being capacitated into ideal normative mothers through neoliberal forms of care. The problem then, is that disabled mothers, by coming to feel good about themselves, or in being hailed to feel good by others in order to to feel like good mothers, re-inscribe normative forms of parenting that support neoliberal forms of care that capacitate some as the successful abled-disabled, while leaving others to wither. In contrast to these individualizing cultural discourses of mothering, in the last section of this article I take into account the capacitating and debilitating logic of neoliberalism by showing how disabled mothering emerges intracorporeally within and between bodies. Such an approach to disability, I argue, contests the affective neoliberal forms of good feelings that re-enforce individualizing uptakes of disabled parenting, and can be mobilized to interrupt the ongoing apprehension by the state of disabled mothers' children.

In Chapter 8, I build on the work of Ellen Samuels (2014) to examine how blood has historically functioned through modes of biocertification to co-produce race and disability in the US as a stable, biological property of an individual so as to be able to know and govern such social identities. I trace how with the rise of genomic research, this biologically-based stable-identification has become a form of "biosociality" (Rabinow 1996), pointing to the novel alliances between patients, scientists, politicians, doctors and

biotech companies that give rise to new kinds of disability socialities. And, while new

forms of disabled biosociality have had the potential to break down the way in which

biology has been inscribed in a nature-culture divide that locates impairments in individual

bodies, I follow the work of Thomas Lemke (2002; 2015a) to argue that disability studies

has largely left biology untouched as an active agent in the social production of disability.

Building on the work of feminist materialists like Aryn Martin (2008; 2010), Annemarie

Mol (2002), and Karen Barad (2007), I note the ways in which disability as an

intracorporeal emergence is both materially and socially "natureculture" all the way down

to the molecules of the body. I end by summing up what I perceive to be the consequences

for thinking the biological facts of the body as shifting entanglements of the human-

nonhuman.

In my conclusion I mark the complexity and importance of desiring disability

differently through new practices and intracorporeal emergences.

Chapter 2

The Neoliberal Circulation of Affects:
Happiness, Accessibility, and the Capacitation of Disability as Wheelchair

In this chapter I argue that the International Symbol of Access (ISA) produces, capacitates, and debilitates disability in particular ways. This production of disability is grounded in a happy affective economy that is embedded within neoliberal capitalism and runs counter to the dismantling of ableism and compulsory able-bodiedness. Ableism, as outlined by Fiona Kumari Campbell (2009, 5) is "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human." Further, as Robert McRuer argues, compulsory able-bodiedness masquerades able-bodiedness as "a nonidentity, as the natural order of things" (2006, 1). Together, ableism and compulsory able-bodiedness cast disability as "a diminished state of being human" (Campbell 2009, 5).

The ISA is the most ubiquitous and prototypical representation of accessibility in Western societies: a white graphic depiction of a wheelchair user, faced to the right, presented on a blue background. In charting the development of the modern wheelchair, the rise of disability rights in North America, and the emergence of the ISA as a universally acceptable representation of access for disabled people, I argue that the ISA produces disability through a neoliberal, ableist logic, capacitating disability as an individualized problem that can be known and solved. To serve such a capacitating function, the ISA engages particular forms of impairment and disability that can be captured through a

neoliberal economy of inclusion. By coming to know disability as an individualized problem and by having the ISA adorn a bus or a building, the uncomfortable problem and unease of the difference of disability appears to be taken care of. That is, the ISA as a symbol of inclusion and accommodation allows disability to appear in order to disappear.

By appearing and appearing to have been taken care of, the difference and uncomfortableness of disability disappears. In this way, the ISA produces happy feelings (Ahmed 2010) and such happy feelings circulate with ease, reproducing the capacitation of particular productions of disability and leading to the limited inclusion of capacitated forms of disability within neoliberal economies. Thus, this chapter explores the ways in which the ISA produces an exclusionary form of inclusion, allowing for the production of the "abled-disabled" (Titchkosky 2003) while other debilitated disabled people face "slow death" (Berlant 2007). In this way, through the ISA, disability both appears so as to be included in neoliberal economies and disappears by way of slow death. I conclude by critically approaching the happy affects of the ISA, including the way in which the symbol creates a sense of "cruel optimism" (Berlant 2010) for disabled people. In engaging the investment of happy feelings disabled people have towards the ISA, I trouble the ease by which certain forms of disability are capacitated. In this way, my chapter not only critically approaches how the ISA produces disability through ableism and compulsory able-bodiedness, but also draws attention to the ways in which disabled people are invested in the neoliberal economy of happy affects that can impede disability justice.

The Appearance of Disability as Wheelchair

Two experiences I had with accessible transit situate my concerns. In 2011, I attempted to take a bus operated by a regional public transportation company to a small town outside of Toronto. This transportation company offers accessible service to disabled people on both its trains and buses. I have used its trains many times but I had never used its bus service. There was a bus that ran semi-frequently to the town I wanted to get to. But, as I discovered upon arriving at the bus station, the bus *is* accessible but *only* for wheelchair users, and, I should add, probably only *some* wheelchair users.

At the time I was not a wheelchair user, although my status as a "walkie" (Clare 2001, 359) has fluctuated over the past few years. My predicament was that I could not climb the steep steps of the bus, but the lift that the bus was equipped with could only be used if I was seated and secured in a wheelchair. As a result of the policy surrounding how the bus lift may and may not be used, I was unable to board this *accessible* bus. I found myself in a position of being both disabled and not disabled enough, or not disabled in the right way. When I pointed out this contradiction to the bus driver, he shrugged his shoulders and commented: "Why don't you just get a wheelchair if you can't climb stairs?" Feeling defeated, I went home.

Later that same year, my partner and I wanted to take a trip out of town with our tandem bike by way of the train operated by the same regional public transportation company. I consider the tandem bike to be a mobility device in that it allows me to travel far distances without too much effort (since, as my partner often likes to remind me, he does most of the peddling). The train has one accessible car that you can walk or roll right

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onto while the other cars are accessed by raised stairs. However, what we didn't know is that bikes are not allowed on this accessible car. We were thus left with the predicament of what to do since I needed to get on the accessible car, but my mobility device, as it were, was not allowed on. "Wheelchairs!" the train worker shouted at me. "This train car is for wheelchairs!" What he didn't say was that able-bodied people frequently use the "wheelchair car" when travelling with strollers, luggage, or other cumbersome items that make it difficult to get on and navigate the other train cars. It also didn't seem to matter to the worker that it was a Sunday afternoon and that the accessible train car was empty. "No bikes allowed," he said, pointing to the blue and white icon of the wheelchair mounted on the train walls. A bike is not a wheelchair, and thus a bike is not an acceptable form of mobility device, even when used by a disabled person. In the end, I rode in the accessible car while my partner and bike rode in another car. These events, along with other stories,[12] have pushed me to consider the ways in which the wheelchair, as the symbol of accessibility, came to produce and capacitate certain forms disability, while at the same time, debilitating and curtailing other forms of disability.

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[12] After giving a version of this paper in June 2013 at the *Society for Disability Studies* conference, a number of people told me about the ways in which their disabled bodies were compelled to "become wheelchair" or alternatively were expelled from disability accommodations because they did not fit the register of being disabled. Included in these stories were ways in which wheelchair users themselves denied other disabled people access to elevators or washroom stalls because "they did not look disabled." In all these stories, disability and accessibility were intimately tied to the wheelchair. In another story, an able-bodied professor was expelled from an academic lecture because he attempted to place a standard chair in the open space designated for a wheelchair user. The lecture hall was at full capacity and there were no wheelchair users in attendance. In terms of room capacity, his body counted as the body of a wheelchair user but as he was not using a wheelchair, there was nowhere to sit. When security escorted him out of the lecture hall, he was told that another chair could not be placed in the designed wheelchair spot, even if there were no wheelchair users in the room. What would have happened if a disabled person with crutches, a cane, or some form of a visible or invisible impairment tried to sit in the wheelchair spot using a chair from another classroom?

The ISA, as one of the most ubiquitous and prototypical representations of disability in Western societies appears everywhere from doors, elevators, and parking spots to placards, t-shirts, and pamphlets. Approved and promoted globally in 1969 at the 11th World Congress of Rehabilitation International, an international non-governmental organization, the ISA is recognized and used internationally as the official symbol to identify facilities accessible to disabled people (Groce 2002). In 1984, the International Organization of Symbols (ISO) registered the ISA as ISO Standard 7001 for public information symbols, and thus, protected the copyright, style, shape, and proportion of the symbol. According to Rehabilitation International, through its widespread use, the ISA has enabled disabled people to locate, identify, and use accessible facilities and has also "created a more general awareness of the problems of accessibility faced by disabled persons" (Rehabilitation International 1978). The ISA, in other words, directs individuals to accessible locations, informs people about the availability of an accessible facility or service, and raises general awareness about disability and accessibility by symbolizing disability (Fritsch 2013).

When opening their design competition for what was to become the ISA, Rehabilitation International asserted that the designed symbol must be self-descriptive, simple and aesthetic, practical, identifiable from a reasonable distance, and have no secondary meaning (Groce 2002; Powell and Ben-Moshe 2009). Remarkably, all submitted entries to the international competition were graphic representations of wheelchairs or wheelchair users (Groce 2002), which as Justin Powell and Liat Ben-Moshe (2009, 91-92) note, indicates the power that wheelchair users had in shaping conceptions of access. Susanne Koefoed, a Danish graphic design student, won the competition with her design of

a white outline of a wheelchair within a black square (Groce 2002). After further discussion, Rehabilitation International's committee changed the design by adding a head to the wheelchair icon and placing it on a blue background (Groce 2002).

The ISA as a ubiquitous and prototypical symbol produces both individual and institutional understandings of disability. Focusing on whether or not the ISA is an accurate representation of disability – and thus inquiring into the truth of this symbol – is to focus on what disability is and is not, and thus reifies disability and able-bodiedness. I am not interested in whether or not the wheelchair adequately represents disability. Instead, building on the work of Tanya Titchkosky (2011), I am more interested in how the ISA functions to produce, capacitate, and debilitate certain forms of disability within contemporary neoliberalized conditions. That is, I am interested in both what the ISA *does* and *how* this symbol does it in relation to both capitalism and through the circulation of happy affects. To get to this point, however, I turn briefly to the history of the modern wheelchair and the rise of disability rights in North America.

Doing Disability as Wheelchair

In the history of disability in the 20th century, the modern, self-propelled wheelchair is entangled with the development of post-war capitalism. The first semi-portable folding wheelchair, developed in 1933 by Everest and Jennings, was made out of lightweight metal aircraft tubing, and weighed fifty pounds (Shapiro 1993; Tremblay 1996). Canadian Lieutenant John Counsell, a combat-injured paraplegic from an upper class family, used his personal resources to acquire an Everest and Jennings chair so that he could independently navigate the streets of Toronto (Gerber 2003). Shortly after acquiring this chair, Counsell

used both his social connections and the support of several influential doctors involved in spinal cord injury-care in Toronto to lobby the Canadian Department of Veteran Affairs to provide Everest and Jennings chairs to all paralyzed veterans (Gerber 2003). While sales were poor during World War II for Everest and Jennings, in 1945 the Canadian government made the first large order purchase of over 200 wheelchairs to provide to war veterans (Tremblay 1996; Gerber 2003). While at once a feel-good story of a concerned government looking out for its veterans, the arrangement was also cost effective. The Canadian government agreed to purchase these newly designed wheelchairs for veterans so as to enable the veterans to get out of hospitals and long-term care institutions and enter the labour force. As Canadian historian Mary Tremblay remarks, the veterans "demonstrated that once educated appropriately they could compete successfully in professions, business, specialized trades, and live in their own homes. Thus, they demonstrated that as tax payers they more than returned to government coffers the costs of outlay for rehabilitation" (1996, 164). Access to wheelchairs led to a dramatic increase in the everyday presence of disabled veterans in public, thus making disability – at least for those disabled by war – more publically visible (Sapey, Stewart, and Donaldson 2005). This shift in government policy to get veterans out of hospitals and long-term care institutions by providing personal wheelchairs led to a noticeable increase in the development and production of wheelchairs and related accessories, bolstering the post-war economy in Canada and the US.

Such a growth in the public presence of disabled veterans restoring their independent lives through rehabilitative practices and new technology was a crucial component of post-war national projects of rebuilding hope and happiness, and a way of overcoming, if not forgetting, the suffering and catastrophes of war (Stiker 1999; James

2011; Fritsch 2013). Disabled veterans were profoundly valorized (Gerber 2003, 899) and emphasis was placed on "individual men pursuing the existing opportunities for entering the mainstream" in order "to compete with able-bodied workers on the majority's terms" (909). As such, the wheelchair was a tool of aggressive normalization even as it simultaneously marked the individual as different. Henri-Jacques Stiker, in his *A History of Disability* (1999), notes the ways in which the practice of rehabilitation arose as a way to turn the injured body into an "object of repair" (124), a body that could be restored, redeemed and normalized, "making alterity disappear" (131). The use of the wheelchair by veterans to access mainstream employment opportunities "on the majority's terms" integrated and normalized disability. However, this normalization was only made possible by "making alterity disappear," that is, both by marking the individual as different, and by ensuring that the difference of disability appeared only in order to disappear.

It was not just Canadian veterans who were given wheelchairs. In both the US and Europe there was considerable positive political will "to find technical solutions to the problems of impairment generated by the violence of World War II" (Woods and Watson 2003a, 166). While the impaired veterans of the Vietnam War in the 1960s and 1970s prompted that continued research into technical solutions, the polio epidemics of the late 1940s and early 1950s, and the impairments caused by thalidomide in the 1960s all further "generated engineering research and development into assistive devices" (Woods and Watson 2003a, 166). As welfare state economies boomed, equipment for the disabled began to be provided for all citizens rather than just to veterans. The Paralyzed Veterans of America and the Invalid Tricycle Association in Britain struggled to gain access to employment for its members, create accessible public transportation systems, and modify

public buildings for increased accessibility. These efforts impacted innovations to wheelchair design and use. In the 1950s, the Canadian Department of Veteran Affairs worked with the National Research Council to develop an electric drive that would fit the standard Everest and Jennings wheelchair. The result was the 1953 Klein Chair, the technology of which Veteran Affairs made freely available in 1955. While the gesture was promoted as "a symbolic gesture of sharing technology for the greater good" (Woods and Watson 2003a, 167), Canadian firms were not interested in mass-producing the Klein chair because they deemed the demand too low (Woods and Watson 2003a, 167). Nonetheless, in 1956, Everest and Jennings and the American Wheel Chair Co. each introduced electric wheelchairs to the general public.

In utilizing wartime technology and providing for the rehabilitation and integration of disabled veterans into the labour force, the development, availability, and visibility of the wheelchair was directly tied to welfare state capitalism. Additionally, the emphasis placed on hope, of overcoming the ravages of war, and of reintegrating into society those visibly different, shows the ways in which the wheelchair is intimately tied to war and a part of a politics of happiness caught up in a capitalist economy of rehabilitation.

The connection between wheelchair development, war veterans, and the welfare state is not the usual story of the wheelchair told within disability circles. Rather, the more common story leaves out this history of the manual wheelchair and starts with the electric wheelchair and how it led directly to the rise of disability rights. Brian Woods and Nick Watson (2003a; 2003b) argue that the electric wheelchair was central to the rise of the disability rights movement and key to the emergence of the 1970 Physically Disabled Student's Program (PDSP) in Berkeley, California, the precursor to the Independent Living

Movement. With the advent of electric wheelchairs, disabled students who were unable to push themselves in a manual chair were able to leave their homes and institutions. This independence changed the way that these students viewed themselves but also changed their interaction with the outside world (Woods and Watson 2003b). For example, the Rolling Quads, a group of radical disabled students, used their electric wheelchairs to occupy space and demonstrate against the lack of services provided by the California State Department of Vocational Rehabilitation. The success of these demonstrations eventually led to the founding of PDSP, an organization run for and by disabled people that provided personal assistants, repaired wheelchairs, and aided disabled students in accessing funding.

In doing wheelchair repairs, members of the PDSP became specialists in understanding the design limitations of wheelchairs available on the market. Alongside veteran associations, members of the PDSP became actively involved in advocating for better wheelchair technology (Watson and Woods 2003b, 7-9). In 1972, the Independent Living Movement grew out of the PDSP when community members started requesting assistance with accessing funding, acquiring personal assistants and accessing wheelchair repairs. At the same time, between the growing use of powered wheelchairs and the rise of the PDSP, the social meaning of wheelchairs also shifted away from rehabilitative and medical modes that provided disabled bodies "opportunities for entering the mainstream" (Gerber 2003, 909). Rather, the wheelchair became a political instrument in the fight for independent living, the development of disability rights, and a means by which to change the mainstream. Thus, the electric wheelchair both shaped, and was shaped by, the social conditions in which it arose.

Despite the development of the electric wheelchair and its attachment to notions of independence, the manual wheelchair was hardly obsolete. In the early 1980s, the lightweight Quickie replaced the standard manual Everest and Jennings as the chair of choice for wheelchair users. In 1978, Marilyn Hamilton, who became paraplegic after a hang gliding accident, invented the Quickie wheelchair out of aluminum tubing used for hang gliders with the help of her fellow glider pilots, Don Helman and Jim Okamoto (Shapiro 1993). Their design weighed 26 pounds, half as much as an Everest and Jennings chair. As Joseph Shapiro writes, Hamilton "took a piece of medical equipment and made it fun and sporty. She took the universal symbol of sickness and turned it into the symbol of disability self-pride" (1993, 213). After a folding version hit the market in 1984, Sunrise Medical bought out Quickie. By 1994, Quickie was a $40-million-a-year business (1993, 214). Everest and Jennings failed to anticipate the demand for such a sporty and portable wheelchair, and as result they "missed the rise of a newly independent generation of wheelchair users who, with new jobs and less dependent on welfare, were emerging as a powerful consumer group" (1993, 216).

With the visibility of wheelchair-using veterans, students, and others who "were emerging as a powerful consumer group," it is not surprising, then, that the wheelchair came to mind for those entering Rehabilitation International's design competition, nor that Rehabilitation International chose the wheelchair as the winning submission. As Titchkosky (2011, 55) remarks, "Imagining disability is, more often than not, imagining wheelchair use." Wheelchair users had managed to make themselves publicly visible and politically important in ways that other forms of disability had not. However, while the modern wheelchair made veterans visible within the auspices of the welfare state, the

electric wheelchair at the heart of disability rights and the independent living movement emerged alongside the neoliberal challenge to, and dismantling of, the welfare state. While veterans called for the state to intervene, discourses of independence and disability rights arose alongside broader political policies of deregulation, privatization, individualization, and, as Brown (2005, 40) notes, the dissemination of market values and market rationality to all institutions and social actions. That is, the independent living movement gained momentum as the state abdicated responsibility for funding unionized positions in nursing homes and other institutions while it trumpeted the cost-effectiveness of using flexible labourers as personal attendants. The deregulation of the workplace brought significant changes to care providers' safety and rights while the state and businesses promoted public-private partnerships in mental health, rehabilitative services, and various forms of outpatient community-based services. As a result of these measures, state responsibilities have been downloaded onto local municipalities, non-governmental organizations, grassroots organizations and charities, or individual families, as disabled people become entrepreneurs and employers. The ISA appears on the front doors of multinational banks and homeless shelters alike. Along with disability rights and the independent living movement, the ISA was created and continues to work within the neoliberalization of the economy. This has implications for how the ISA functions to produce, capacitate, and debilitate disability, and leaves disability politics vulnerable to being captured by neoliberalized capitalist social relations.

The ISA *Does* Disability

In depicting the wheelchair as the symbol of access, a mobility-impaired person who uses a wheelchair comes to symbolize all other forms of disability. Conceptualized in this way, disability pertains only to a "young man in a wheelchair who is fit, never ill, and whose only need is a physically accessible environment" (Morris 2001, 9). This internationally-recognized, allegedly universal symbol, in other words, comes to produce disability as a physical impairment that requires a wheelchair, while sidelining and erasing other forms of impairment and disability, and the various needs of a disabled person (Fritsch 2013). Drawing on Butler's (1993) theory of performativity of language, the ISA can be considered as enacting or producing what accessibility and inaccessibility are. The ISA also constitutes disability such that it is impossible to conceive of disability without thinking of someone needing special access. In this sense, the ISA produces that which it names (Butler 1993). If accessibility and disability are to be denoted by a figuration of the wheelchair, then the ISA produces disability as requiring wheelchair things like ramps, elevators, and large bathroom stalls. Further, the ISA produces a palatable form of disability. The figuration of the wheelchair user is not unsettling for non-disabled viewers as it does not evoke any ideas of pain or mess. The disabled body of the ISA is contained and orderly. For disability as produced by the ISA, there are no leaky bodies or boundaries (Shildrick 1997).

Because the ISA is considered "self descriptive" with "no secondary meaning," (Rehabilitation International 2013) it constitutes disability in such a way that allows for taken-for-granted conceptions of who has an access issue and what access means to prevail,

and these prevailing conceptions influence how people perceive these issues and act upon them (Titchkosky 2011). As Ben-Moshe and Powell (2007) argue, the ISA attempts to create clear boundaries between who is considered disabled and who is considered able-bodied in which some bodies are just disabled and others are not. This constructed binary "belies the relational context-dependent aspect of disablement" (495). The ISA, as a static image, does not show the fluid, context-dependent nature of disability and impairment that changes over the course of one's life. Nor can the static character of the symbol account for the ways that developments in cybernetics, pharmaceutical therapies, prosthetic enhancements, and other medical or technological interventions have already radically altered what bodies can do and will continue to do in years ahead (Fritsch 2013; see also Chapter 3).

By designating spaces that are accessible in contrast to inaccessible spaces, the ISA positions disability as something apart from normative embodiment. Such a division of space flies in the face of universal design or notions of collective access (Hamraie 2013; Mingus 2010a), and reinforces the divide between non-disabled and disabled that again reinforces a static, reified understanding of disability. In creating separate spaces, the ISA naturalizes able-bodies as not requiring "access," and ignores the ways in which most people may only ever be "momentarily able-bodied" (Zola 1982, 242) and thus have bodies that are always moving between varying modes of capacity and debility. By naturalizing disability as an inherent and static mode of being, the ISA also obfuscates the ways in which disability appears through the construction of space (Gleeson 1998; Freund 2001; Dolmage 2012; Himraie 2013). The ISA relies upon creating an exclusionary space. As Titchkosky (2011, 61) argues: "Every universal access sign suggests that access is available

only in particular locations. If access were widely available, signs of access would not be necessary." Furthermore, she contends:

> Disability is a key way of constitutively perceiving non-normalcy; it is a way of referring to and dealing with that which is regarded as anomalous and is almost always devalued. This means that the concept of disability gives us access to certain people, places, and events, but it does so while shoring up a belief in a naturalized version of access: one either has access or does not; one personally needs access or does not. Through unexamined relations to both disability and non-disability, the idea that the world is 'naturally' for some and not for others is reproduced. A failure to attend to the ways the world is naturalized, and thus to appear 'naturally' there only for some, is the basic premise of the social processes of able-ism, patriarchy, and colonialism. (6)

The ISA naturalizes access as being needed for some and not others. Thus, the ISA naturalizes disability as an individualized access problem, separate from normative embodiment.

In addition, the ISA produces disability through directing and orienting bodies in certain ways. Titchkosky comments, "We typically read signs as indicators, as giving information, as directing us to the required and the expected. Signs, in other words, are a form of orientation" (2011, 65). In *Queer Phenomenology*, Sara Ahmed (2007) argues that bodies get directed in some ways more than others. The ISA orients some bodies to be turned toward certain wheelchair objects - ramps, elevators, larger bathroom stalls, and so on, and in doing so orients other bodies away from these objects. Ahmed remarks: "The direction we take excludes things for us, before we even get there" (15). Again, through directing us towards accessible spaces, the ISA produces disability as being about some bodies and not others. Hence, the ISA creates disability as an individualized problem that needs solving rather than disability being a welcomed and diverse form of embodied difference. The ISA sets up disability as turned toward certain objects that reaffirm those

objects as "disability-things" (Smit 2013). Reaffirming that some directions and objects are "disability things" gestures toward a whole network of "taken-for-granted background expectations" (Titchkosky 2011, 65) that produce disability in particular ways.

The ISA also produces disability through its appearance after a retrofit has been done. For Jay Dolmage (2012; 2013), the retrofit, an addition or alteration to something that has already been built, is part of the logic of neoliberalism. Disability is accommodated by adding ramps onto the side of a building or around the back, instead of at the main entrance, relegating disability as a form of difference "supplemental to society" (Dolmage 2013, 1). Disability is included as an afterthought; welcome, but only by way of the side entrance, and often, only grudgingly conceded to as a point of law. The ISA often appears after a retrofit has been done, allowing disability to appear only to orient disability to disappear through the side entrance. The retrofit offers a quick and temporary fix through cheap additions or alterations rather than designing with disability as a routine part of spatial organization. While capitalism has produced inaccessible geographies (Gleeson 1999) and thus excluded disabled people, the retrofit acts as a bandage solution, a charitable form of inclusion without changing too much. The retrofit shows the ineffectiveness of capitalism to contend with crises of its own making, even as capitalism constantly adapts (Dolmage 2013). Further, the retrofit fosters happy affects (Ahmed 2010) among the retrofitters for having done something visible in the name of inclusion.

At the same time, the ISA produces disability by disguising the way disability is capacitated and debilitated within neoliberalized capitalist social relations. Much like the overcoming and forgetting of suffering associated with rehabilitating war veterans (Stiker 1999; Fritsch 2013), the ISA covers over the ways in which disability is incurred by

capitalist social relations whether by way of poverty, war, austerity measures, environmental destruction, workplace conditions and injury, or other debilitating processes (Sothern 2007; Erevelles 2011; McRuer 2012; Chandler 2013; Murphy 2006). By making disability appear to be an individualized problem, or as Alison Kafer puts it, "casting disability as a monolithic fact of the body" (2013, 3), the ISA makes its innocuous appearance on buildings, buses, and bathroom stalls without so much of a hint of the ways in which disability often only comes to appear by way of a lack of access to adequate health care, an exploding land mine, a revoking of social benefits, a lack of labour rights, or dirty water.

In sum, the ISA produces disability as a static thing rather than marking disability as a fluid, contextual, social relation. As a thing, disability can be known, contained, marketed, consumed, profited from, and solutions can be found. Inclusion can be celebrated, as if accessibility were simply about arriving at the side entrance. In thing form, disability can be capacitated by neoliberal practices of inclusion: that is, one can be included if one can be captured by market rationality, or market values. Bodies that are profitable, that can be marketed to, can be enhanced, or incorporated into the labour force, are bodies that neoliberalism deems worthy. These "abled-disabled" (Titchkosky 2003) bodies are included because they can be predictably productive under neoliberalism and as such are rewarded and trumpeted as evidence of an inclusive society. These bodies are entrepreneurs and have the capacity for "self-care" or "the ability to provide for their own needs and service their own ambitions" (Brown 2005, 42). Those bodies that do not fit within the static thingness of disability as produced by the ISA, or cannot be capacitated in such a way as to participate in the labour force, are debilitated or rendered for "slow death"

(Berlant 2007, 776). This rendering does not place these people outside of capitalism because "slow death" is, as Jasbir Puar (2011) points out, also profitable (see Chapter 3).

Even recent "progressive" attempts to redesign the ISA cannot fully escape the capturing of disability as an individualized problem within neoliberalism. For example, the US-based Accessible Icon Project (2013) has redesigned the ISA to be a more active symbol, emphasizing an independent wheelchair user in motion. Their redesign focuses on the mobility of the person using the wheelchair, in contrast to the immobile, static, and passive wheelchair user of the traditional ISA. By focusing on the abilities of the wheelchair user, by emphasizing the motion of the individual, by situating the person as the "'driver' or decision maker," the redesign seeks to "suggest the dynamic mobility of a chair user" and represent the user's "active status of navigating the world" (Accessible Icon Project 2013). Through this symbol, the wheelchair user is re-capacitated as an active agent. The redesign of the ISA re-inscribes person-first politics that individualize disability in that they seek to make the person, not the chair, important and visible. The person-first approach posits that people are more than their disabilities and it is important to see the person, emphasizing the human beyond the (presumed inhuman) disability. However, separating the person from disability places disability as a medical or biological problem existing in addition to the individual, rather than conceiving of both disability and impairment as being produced historically through social relations (see Chapter 6 and 8). The Accessible Icon Project has flourished throughout the United States, and the new mobile icon has replaced the ISA in cities like Austin, El Paso, New York City and Boston. The Project has paired up with corporate sponsors such as Clarke's and The Talbots Inc., in addition a slew of other partners like The Bronx Zoo (Accessible Icon Project 2013).

Corporate partners like these know the financial potential both of disability as "fun and sporty" and of disability in motion. Their new mobile wheelchair user does not need the welfare state to push her wheelchair. Rather, this upwardly mobile subject wheels herself to wherever neoliberal capitalism will take her.

The ISA opens up possibilities to pay attention to and capacitate disability in particular ways, while excluding others. Titchkosky asks if we might come to know disability differently by critically addressing how it is we have come to know disability with certainty (2011, 16). To this, I wonder if we might come to know disability differently by confronting the happy, affective feelings that circulate around the inclusion and capacitation of disability by the ISA.

The Happy Disappearance of Disability

Indebted to the work of Henri- Bergson, Baruch Spinoza, and Gilles Deleuze and Felix Guarttari, affect can be conceptualized as pre-individual forces that augment or diminish a body's capacity to act, engage, or connect. For Ahmed (2010), happiness involves affects in order for the objects of happiness to become social goods. That is, she argues that feelings do not reside within individual subjects and then move outwards towards particular objects but rather, she contends, objects create impressions through feelings (14). To feel happiness "is to recognize that happiness starts from somewhere other than the subject who may use the word to describe a situation" (21). And, as Ahmed continues, "If happiness creates its objects, then such objects are passed around, accumulating positive affective value as social goods" (21). Through the production of

happiness, objects become social goods that have positive affective qualities. "To be affected 'in a good way' thus involves an orientation to something as being good" (24). Happiness is an affective economy that allows us to have contact with good objects. Since "we move toward and away from objects through how we are affected by them" (24), happiness orients what objects we come into contact with. That objects are considered happy or are considered the cause of happiness "means they already circulate as social goods before we 'happen' upon them, which is why we might happen upon them in the first place" (28). That is to say, the objects we encounter are never neutral. In order to happen upon an object, its affective value is already in place; the object is already invested with positive and negative value (34). As happiness is a shared social orientation toward what is good (56), going along "with happiness scripts" is a way of getting along; "to get along is to be willing and able to express happiness in proximity to the right things" (59).

The ISA is, I argue, a site of affective happiness within neoliberalism and functions in such a way as to hamper the conditions necessary to dismantle ableism and compulsory able-bodiedness. In what follows, I trace the ways in which the production of disability has been built upon positive affects, and in turn, how the ISA is imbued with happy affects that capacitate certain forms of disability inclusion. I conclude by considering where the "cruel optimism" (Berlant 2010) of the ISA leaves disability scholars and activists who seek disability justice.

The contemporary production of disability has been built on positive affects. The circulation of positive affects in the production of disability does not replace other modes of producing disability, but rather is layered within them. This is to say, the ways in which disability is produced through tragedy, pity, or disgust, are all tangled up with positive

affects; all these forms of producing disability work together and re-enforce one another. From the demand to overcome shame and embody pride (Kolarova 2012), to the medically driven imperative to overcome suffering and embody an expression of hope (Fritsch 2013), the disabled have been positioned as the inspiring and courageous crip, the ones who will be cured through positive thinking, and as an individualized problem that is solvable. Disability is caught up in the ableist turn towards healthism and the imperative for everyone to have intensively enhanced bodies (see Chapter 3). From the oft-cited "Jerry's Kids" (see Chapter 5), to the culturally ubiquitous inspirational quotes that mark disability as something to conquer and fight, happy affects of cure, overcoming, and progress are embedded in dominant conceptions of disability. Happy affects drive what McRuer (2006) has termed "compulsory able-bodiedness," not only because people are invested in the "happiness scripts" of biological cures, narratives of overcoming, and the allure of technological advances, but because compulsory able-bodiedness is always, already, a social good in neoliberal capitalism. As such, the happy affects circulating by way of pride, hope, cure, or progress, end up retrofitting disability as "a vector of neoliberal governance" (Kolarova 2012, 268).

Disability as thing, or disability as contained by the International Symbol of Access is not only knowable and profitable, but it is also the site of happy affects. By having the wheelchair symbol adorn a bus or a building, the problem and uncomfortableness of the difference of disability appears to be taken care of. With the appearance of the ISA, happy affects of having "done our duty for the disabled" circulate, even in the face of contested understandings of disability or accessibility.

For example, Titchkosky (2011) writes of her struggle to make her university workplace more accessible. She observes that in July 2006, the twelve-story university building in which she worked at the University of Toronto had no washrooms that met provincial minimal disability accessibility standards. She notes how the ISA appeared on five bathroom doors that were entirely inaccessible. Titchkosky found from her colleagues and staff working in the building that the signs were posted "some twenty years ago" when the building was retrofitted to include a ramp to the front entrance of the building. When Titchkosky pointed out the inappropriate posting of the ISA signs on places like inaccessible washroom doors, users of the building commented, "How were we to know any better?" (75). Others questioned Titchkosky's interest in the inappropriate signs, remarking "Isn't something better than nothing?" And further stated, "If they can't use the washrooms *what are they doing* here anyway?" (75). Here, the positive circulation of affects happens through the disavowal of ableism and compulsory able-bodiedness. That is, the comment "something is better than nothing" suggests that disabled people should be happy with what they have, even if it is entirely inappropriate. The ISA is a marker of accessibility and inclusion, even when it fails. For good feelings to continue with ease, it is important for no one to get upset by the inappropriate signs. If someone does get upset, the response is to question why disabled people are appearing in these inaccessible spaces. Clearly, this space is not intended for them and was never intended to be for them, even if the sign of inclusion promises otherwise. To suggest that "something is better than nothing" or to be baffled that a disabled person would appear in a space that has no accessible bathrooms exemplifies the retrofitted nature of neoliberal approaches to disability. It is also

representative of the ways in which disability is located in particular bodies and is not considered to be a difference we are all implicated in (re)producing.

When Titchkosky began making inquiries into the possibilities for renovating washrooms to make them accessible, administrators concluded that there was no reason to renovate, as accessible washrooms already existed in the building. Incredulously they asked her if she had not seen the wheelchair symbol adorning the doors to the washrooms? Of this struggle, Titchkosky comments: "it was difficult for people to know that they were living without an accessible washroom because there were signs that said otherwise" (84). And yet, Titchkosky observes: "People who worked and were educated in this building witnessed wheelchair users getting stuck while attempting to enter the main-floor washrooms since there was a wall that immediately confronted whoever pushed open the door" (84). That disability appears to be taken care of is a good feeling and such good feelings circulate with ease, even when someone is confronted with a contradictory reality.

With the ISA, disability appears in order to disappear, is included to be excluded. The deployment of the ISA solves the problem of disability without ever needing to include disabled people or without ever needing to confront the contradictions of accessibility as it reduces "the lived complexity" of disabled embodiment "into a caricature – literally, disability-diversity becomes a stick figure" (Titchkosky 2011, 81). Disability becomes a thing that is contained and known; a stick figure in a blue box. In being known, disability can be taken care of by building ramps or, more importantly, simply by posting the ISA. That disability is taken care of is a good feeling. In this good feeling, ableism and compulsory able-bodiedness are covered over by happy affects. It is only when someone gets upset that these happy affects are disrupted. In these moments disability becomes a

problem again. However, the problem is not ableism but the uncomfortable presence of the debilitated individual disabled person. As a problem, the upset debilitated disabled individual becomes the individual killjoy that disturbs "the very fantasy that happiness can be found in certain places" (Ahmed 2010, 66) by interrupting the ease by which happy affects circulate.

For the ISA to be posted, disability must already be depoliticized and desocialized in particular ways. The inclusion of disability is done through a conditional embrace of difference: through accommodating the wheelchair, through compliance with neoliberal forms of capacitation, and through discrediting the killjoy as the debilitated "benefit scrounging scum" (McRuer 2012). By capacitating certain forms of disability and inclusion, this conditional embrace of difference separates out who can have a liveable life and who is marked for social death. Caught up in happy affects of disability, this economy of inclusion works toward particular forms of normalization (Kolarova 2011; Titchkosky 2003), and also, as Puar (2011) and Sothern (2007) suggest, through a neoliberal ableist project of continuous bodily enhancement (see Chapter 3).

Disabled people themselves also participate in the happy affects of the ISA. If the ISA offers able-bodied people the good feelings of being part of the solution, the ISA also contains within it the promise of an accessible path, an accessible future, a place and space for disabled people. This hope and happiness contained within and expressed through the ISA is "cruel optimism" (Berlant 2010). For Berlant, a "relation of cruel optimism is a double-bind in which your attachment to an object sustains you in life at the same time as that object is actually a threat to your flourishing" (Berlant and Seitz 2013).

Cruel optimism is a politics of deferral for disability. By making hope and happiness that which the ISA can deliver, disabled people hold back from forcing the contradictions of the ISA that confront them in their lives. Through the hope and happiness invested in the ISA, any future disabled utopia is always already deferred. This is to say, the problem is not simply ableism. Rather, disabled people themselves are invested in the ISA as a beacon of accessibility, as tied to the history of disability rights, and as a symbol of pride. That the ISA has persisted over 40 years after its original design is not due to a lack of alternative symbols, but rather because the sign *does* something for disabled people. Disabled people have a vital investment in the ISA as evidenced by the excitement of disabled communities surrounding the newly designed ISA by the Accessible Icon Project. Disabled people want accessibility to work, and to work better. Participating in the affective happiness of wanting the ISA to work is a way of reinvesting in the neoliberal individual who ensures their own self-care through market relations. Simply put, the ISA is an affectively happy object, and an object of cruel optimism.

Showing up to ride an accessible bus and being told that I should just get a wheelchair if I can't climb stairs is a moment of cruel optimism. I am invested in the ISA, but I, individually, do not fit its production of disability or accessibility. While this anecdote ends with me returning home without taking the bus where I wanted to go, this moment also reveals what I have elsewhere (Fritsch 2013) called the importance of utilizing the suffering for rethinking disability.

While many important stories of disability are ones of exclusion, poverty, and erasure, this chapters marks out important forms of inclusion. Such inclusion, however, comes at the cost of being integrated into capital by constituting a group of workers and

consumers through the object of the wheelchair. The wheelchair then becomes the symbol of inclusion and accessibility for disabled people, and forms of inclusion and accessibility circulate happy affects. The ISA sets up the possibility of knowing disability, capacitating certain forms of disability and solving the problem of disability so that we can all collectively feel better. The collective ease of good feelings comes at the expense of the killjoy, at the expense of the benefit scrounging scum and at the expense of all those who leak outside of the boundaries produced by the ISA. Clearly, accessibility is important and the rights disabled people have fought for and won have often been necessary for mere survival, much less for flourishing. But at the same time, the debilitation and capacitation of disabled people happen within the context of neoliberalism, in the offloading of social issues onto the shoulders of individuals, enabling corporations to make a profit off of debility and capacity, and of shifting public concerns into the private realm. It is within such a context that this symbol functions to both include and capacitate disability and to exclude and debilitate disability in particular ways, all the while making us feel good about consuming accessibility and feel like once the ISA appears, we've taken care of the problem.

In the next chapter, I explore more good feelings of inclusion through developments in biotechnological enhancement and the ways in which disabled bodies come to be individually capacitated and debilitated within what Kaushik Sunder Rajan (2007) terms "biocapitalism."

Chapter 3

Gradations of Debility and Capacity: Biocapitalism and the Neoliberalization of Disability Relations

In 1972, the Club of Rome, an international think-tank, released their report entitled "The Limits to Growth." The report, commissioned by a group of scientists at the Massachusetts Institute of Technology, problematized unlimited and unrestricted market growth in a world of finite resources, marking the irreversible decline of Fordist production, and the ways in which mass production and mass consumption were leading to increasing economic and ecological problems (Cooper 2008). The report sold more than 12 million copies in over 30 languages and stressed the "choices open to society to reconcile sustainable progress within environmental constraints" (Club of Rome 2015). In response to this analysis, right-wing "futurologists" advocated for a radical restructuring of the US economy, arguing for a post-industrial economy organized around scientific research and innovation. These futurologists argued that this post-industrial economy would increase economic growth and overcome any ecological and biospheric limits predicted by the Club of Rome. The neoliberalization of the economy and social relations, alongside developments in the life sciences and biotechnology, became the future promise of biocapitalism – a new and healthier future – that would overcome the limits to growth and regenerate the earth (Cooper 2008).

1972 was the same year in which disability activist Ed Roberts cofounded the Center for Independent Living and the year in which the first curb cut was installed at the

corner of Bancroft Way and Telegraph Avenue in Berkeley, California, inaugurating the world's first "wheelchair route" – a continuous set of curb cuts made through a pedestrian district in Berkeley (Pelka 2012; Williamson 2012). Throughout the 1960s, 70s, and 80s, disabled activists united across the United States to secure civil and political rights, to advocate for the deinstitutionalization of disabled persons, and to push for advances in technologies such as electric wheelchairs (see Chapter 2) and accessible house design (Serlin 2015). For many disabled individuals involved in activism across the United States, as well as other countries like Canada and the United Kingdom where similar changes were occurring, the future promise of increased access, independence, and inclusion was the basis for a better future.

At first glance, the speculative promises of neoliberal biocapitalism and the freedom to independently wheel along a newly designed curb-cut route have little to do with each other. However, I argue in this chapter that the material-discursive practices of disability were transformed by the ways in which the disability rights and independent living movements in North America emerged and developed alongside the boom in American biotechnological industries and the life sciences that has been termed neoliberal "biocapitalism." This has had lasting consequences for the material-discursive practices of disability, including how disability has come to be differentially included through modes of debility and capacity that are not clearly defined along traditionally normalizing abled/disabled binaries (Puar 2011). Debility and capacity are not absolute categories pertaining to individual bodies, but rather draw attention to what bodies do, their capacity to act, including their affective processes. Bodies are neither solely capacitated nor debilitated: there are graduations of debility and capacity. Building on this conceptual

framework as set out by Jasbir Puar (2009; 2011), I consider disability not as a predominantly oppressed identity category or form of embodiment that lacks or is abnormal. Rather, I examine what it means for disability to be caught up in processes of both debility and capacity.

The effects of the co-emergence of the disability rights and independent living movements and developments in neoliberal biocapitalism have been left largely unaccounted for within disability studies. This chapter, then, explores how disability is entangled in contemporary neoliberal biocapitalism, and through this entanglement, caught up in processes of debility and capacity so as to trouble the assumption that disability is not a uniformly oppressed category of being. As such, in considering the differential inclusion of disability in neoliberal biocapitalism, and aligned with the push for disability justice, I draw attention to who gets to have grievances about particular forms of disabled oppression and structural ableism. I further question how to forge a disability politics that is able to traverse the complexities of the contemporary social and economic landscape. In what follows, I trace the emergence of neoliberal biocapitalism and mark the possibilities that manifest out of this context for the material-discursive practices of disability.

The Birth of Biocapitalism

In *Biocapital: The Constitution of Postgenomic Life* (2007), Kaushik Sunder Rajan builds on the work of Donna Haraway (1991; 1997), Sheila Jasanoff (2004), and Jenny Reardon (2001; 2005), to argue that science and society are not two separate systems, but rather are mutually constitutive. In particular, Sunder Rajan marks the ways by which scientific knowledge is co-produced materially and discursively alongside the political and

economic practices of capitalism. That is, rather than a relation in which either society or science is the cause or effect of the other, science and social relations, such as the social relations of capitalism, are "mutually implicated and emergent epistemologies and systems concerning life and value" (Sunder Rajan 2012, 8). This co-production has resulted in what Sunder Rajan terms "biocapitalism," a new phase of capitalism whereby the development of biotechnology and the life sciences are made comprehensible through shifts in global capitalist production and consumption. Linking Foucault's (2008) concept of biopolitics, "whereby life becomes the explicit center of political calculation" (Sunder Rajan 2007, 79) to a Marxist critique of political economy, Sunder Rajan ethnographically analyzes the constitution of biocapitalism in the US and India by provocatively asking: "…what forms of alienation, exploitation, and divestiture are necessary for a 'culture of biotechnology innovation' to take root? On the other hand, how are individual and collective subjectivities and citizenships both shaped and conscripted by these technologies that concern 'life itself'?" (2007, 78).

The notion of biocapitalism extends Foucault's concept of biopolitics as a practice of governance that brings "life and its mechanisms into the realm of explicit calculations" (1978, 143) to organize not only "state, national, or colonial governance," but also to increasingly structure economic enterprises that take life as its object in the pursuit of the creation of value, markets, wealth, and profit (Helmreich 2008, 464). In this way, as Stefan Helmreich notes, the biological entities that inhabit this landscape are "no longer only individuals and populations – the twin poles of Foucault's biopower – but also cells, molecules, genomes, and genes" (Helmreich 2008, 464). The contemporary biopolitics of

biocapitalism, therefore, engages not just with individuals or populations, but all aspects of life itself.

For Sunder Rajan, capitalism is "a political economic system whose contours are not unitary or rigid[;]" rather, "capitalism is mutable and multiple; it is always capitalisms" (2007, 7). This mutable and multiple character of capitalism is made apparent across Sunder Rajan's reading of the three volumes of *Capital*, in which Karl Marx analyzes both industrial and mercantile capitalism. Sunder Rajan notes that for Marx, while mercantile capitalism is a continuation of industrial capital, it emerges as a distinct formation of capital in so far as it emphasizes a commercial form rather than a commodity form. That is, the function of merchant's capital "is not just the production and exchange of commodities as a means to an end (that end being the generation of surplus value) but is commercial activity as an end in itself" (2007, 8). Thus, "the merchant is to commercial capital what the producer is to commodity capital" (2007, 9).

Capitalists that are most interested in commercial activity as an end in itself are speculative capitalists such as venture capitalists and investment bankers "who are central to sustaining the dynamics of contemporary capitalism" (2007, 9). For Sunder Rajan, drawing on Marx, merchant's capital "does not create surplus value in and of itself but does so indirectly by constantly perpetuating the circulation of capital, and by providing it with its own self-perpetuating, self-sustaining logic" (2007, 9). The contemporary emphasis on commercial activity "as an end in itself" has emerged for Sunder Rajan as "biocapital." For Sunder Rajan, biocapital emerges in the economic shift from Keynesianism to neoliberalism, emphasizing the role that the development of the life sciences and

biotechnologies in the US has played in the financialization of the American neoliberalized economy.

The height of the Keynesian influence on American, Canadian, and British economies – the period between the end of the Second World War and the 1970s – were marked by the rapid expansion of industrial production, leading to "large growth rates, sustained technological change, an increase in purchasing power and the development of a welfare system (concerning, in particular, health and retirement) and low unemployment rates" (Dumenil and Levy 2005, 9). However, by the late 1960s and early the 1970s, the profits from the postwar reconstruction boom waned, growth rates diminished, and unemployment and inflation rates grew. As opposed to this downturn being just an inevitable part of the cycles of capitalism, US analysts, international think-tanks, and others argued that given the earth's finite non-renewable resources, continued industrial growth was not only unsustainable economically, but also a possible threat to life on earth (Cooper 2008). In response to this analysis, Right-wing "futurologists" advocated for a radical restructuring of the US economy, particularly pushing for the development of a post-industrial economy that could be organized around scientific research and innovation that would both increase economic growth and overcome ecological limits (Cooper 2008). Biotechnology, in particular, became the future promise that could overcome the limits to growth and regenerate the earth's resources.

The most interested in these predictions and the promise of biotechnology were the petrochemical and pharmaceutical industries who, in part, turned to the life sciences and emerging biotechnologies to overcome the limits of industrial capitalism and the rising cost of manufacturing due to the oil prices shocks of 1972 and 1979 (Cooper 2008). Indeed,

throughout the 1980s, these industries "embarked on a dramatic self-imposed make-over, reinventing themselves – at least prospectively – as purveyors of the new, clean life science technologies" (Cooper 2008, 22). One aspect of the relationship between the life sciences and neoliberal financialization has been through speculation. While Keynesian economic approaches attempt to "safeguard the productive economy against the fluctuations of financial capital, neoliberalism installs speculation at the very core of production" (Cooper 2008, 10). Speculation and investing in future possibilities itself came to shape the way biotechnological research was done. As Stephen Hilgartner (2007, 382) comments: "The production and use of anticipatory knowledge, such as predictions, scenarios, forecasts and narratives about possible futures, has become a salient feature of the action at the interface of the life sciences and society." Efforts to anticipate the future simultaneously shape biotechnological research and investment in the life sciences to advance the potentials of biocapitalism as both "a concept and as a set of technological and economic activities" (Hilgartner 2007, 382). By investing heavily in biotechnologies in the early 1980s, major chemical and pharmaceutical companies were able to dominate from the beginning such that just a few multinational corporations now "effectively control every level of world food and pharmaceutical production" (Cooper 2008, 23).

The neoliberal policies of deregulation, privatization, individualization, and, as Wendy Brown (2005, 40) notes, the dissemination of market values and market rationality to all institutions and social actions eroded the welfare state throughout the 1970s and 80s, deeply affecting the development of biocapitalism. As Melinda Cooper charts in the her 2008 book, *Life as Surplus: Biotechnology and Capitalism in the Neoliberal Era,* the 1970s American deregulation of banking and financial markets, along with a highly liquid stock

market and the increasing securitization of pensions, resulted in a large source of funds that were available to be invested in emerging high-risk biotech ventures (Cooper 2008). So as to develop a post-industrial economy called for by the Futurologists, the US government poured significant funding into the life sciences, dedicating more of its federal budget to science research than any other nation-state member of the Organisation for Economic Cooperation and Development in the world. In 1971, for example, the US declared "war" on cancer, pledging over $100 million to this endeavour and converted a biological warfare facility in Fort Detrick, Maryland into a cancer research center. In line with the neoliberalization of the nation-state, Cooper notes: "the emergence of the biotech industry is inseparable from the rise of neoliberalism as the dominant political philosophy of our time" (2008, 19). Cooper adds, "this focus on the life sciences has gone hand in hand with a redistribution of funds away from public health and nonprofit medical services toward commercially oriented research, health services, and for-profit applications" (2008, 27).

Sunder Rajan (2007) affirms the co-production of the life sciences and the neoliberalization of society as marked by Cooper. Biocapitalism as a continuation of capitalism for Sunder Rajan emphasizes the workings of not only the systems of exchange and circulation involved in the contemporary workings of the life sciences, but also marks the ways in which the life sciences have become increasingly dominant epistemologies of our time: what Cooper calls a "neoliberal biopolitics" (2008, 8). Morini and Fumagalli (2010) similarly argue that the transition from Fordism to biocapitalism has been marked by new immaterial processes of accumulation that are embodied in relationships involving intellectual, relational, and emotional resources and capacities, that puts life itself to work. Indeed, Morini and Fumagalli suggest that it is no longer abstract labour that is exchanged

on the labour market but "subjectivity itself, in its experiential, relational, creative

dimensions" (2010, 236). The value of experience, relational forms of communication and

networking, and other intellectual and emotional immaterial processes are further charted

by Kean Birch and David Tyfield (2013, 314) who comment that with biocapitalism, "It is

no longer simply the production of commodities that creates value; the consumption of

goods and services, along with the social and intellectual relationships this entails, also

becomes an asset for companies." Within such an economy, labour cannot always be

measured according to the Fordist mode of calculating average outputs but rather "the value

of labour loses almost any concrete definitional criterion" (Morini and Fumagalli 2010,

236). Within a biocapitalist biopolitics, life itself is at the "explicit centre of political

calculation" (Sunder Rajan 2007, 12). In capitalizing on life, neoliberal biocapital imposes

"not so much the generalized commodification of daily life... as its financialization"

(Cooper 2008, 10). And just as the financialization of biotechnology reoriented research

towards the future, speculation through finance reorganizes economies and also the

material-discursive practices of individuals, including how "risk" comes to influence

practices of "health" in diverse ways.

Central to the growth strategies of the welfare state were the middle class, the

family wage, and the notion of a standard of living. Risk was collectivized and mitigated by

the state. With the neoliberalization of the state, this system has given way to "extreme

differences in the distribution of life chances" (Cooper 2008, 62). In this situation,

"collective risks gathered under the banner of the nation can no longer be (profitably)

collectivized, normalized, or insured against. Henceforth, risk will have to be

individualized while social mediations of all kinds will disappear" (Cooper 2008, 62).

Risks are individualized as subjects are produced through, for example, biopolitical "high risk" DNA profiles that surveil, screen, and measure individual health indicators.

The relation of individual risk and health is, in part, the subject of Joseph Dumit's 2012 book, *Drugs for Life: How Pharmaceutical Companies Define our Health.* There he traces how it came to be that drug companies that once described themselves as medical companies now refer to themselves as financial companies (2012, 210). Dumit argues that this shift happened in part through changing understandings of "health" marked by material-discursive practices influenced by the neoliberalized notions of individual "risk" as a biomarker, and the development of randomized control trials that could determine minute statistical differences between treatments that might otherwise be identical. To be "at risk" through the use of biometrics requires a shift in understanding: rather than having a body that is defined as inherently healthy, the body is inherently ill and always needs to be enhanced or made better.

The development of "at risk" populations through the 1950s – 1990s led to the pharmaceutical pursuit of blockbuster drugs, or drugs that create annual sales of over one billion dollars. The push for blockbuster drugs was also in part the result of financial mergers and acquisitions that led to corporate consolidations. As such, companies took on increasing amounts of debt to survive, and needed a steady stream of innovations that would lead to immediate payout. This often resulted in the move from producing material products to owning the patents. Or, in other situations, it led to large companies waiting for small "so-called boutique companies" to do research and then acquire those companies once they had a molecule that promised "a huge market" (Dumit 2012, 210). In the US, however, patents only last for up to fourteen years, leading pharmaceutical companies to

create a constant stream of new drugs to be tested through clinical trials. The value of a clinical trial, however, is constantly evaluated in relation to the total potential treatments that can be sold over the patent life of the drug (Dumit 2012, 5). This makes products like vaccines, which prevents illnesses from occurring, less profitable than drug treatments.

The promise of huge markets as drivers of innovation also marks Sunder Rajan's (2007) research, as he argues that the speculative role played by the pharmaceutical industry in its substantial investment in research and development is based less on the manufacture of concrete products and more on the production of hopes and expectations. Building on material-discursive developments in pharmacogenomics, or "personalized medicine," the medical "risks" that current or future patients face are entangled with the hope these patients have for new medical treatments developed through biotechnological innovations. Sunder Rajan comments: "…every individual, because of his or her genomic risk profile, is a potential target for therapeutic intervention. In this calculus, every individual is a patient-in-waiting and, simultaneously, a consumer-in-waiting" (2007, 281). Thus, the discursive creation of an "at risk" patient/consumer is entangled with investments into research and development. Research no longer has to lead to the manufacturing of a concrete object for the company to make money. Instead, the patenting of knowledge will increase the value of the company on the stock market to benefit shareholders.

Pursuing these innovations so as to treat the personalized risks of some patients requires the exploitation of others. For example, Sunder Rajan's ethnography delves into the working of a research hospital in Mumbai, India, where a private company conducts pharmacogenomics studies for Western pharmaceutical companies. Most of the participating research subjects are poor or unemployed and offer their bodies as

"experimental fields for biomedical study" (Lemke 2011, 114) in exchange for a small remuneration. Most, if not all, of these research subjects will not benefit from any of the newly developed therapies because they will be unaffordable to these research subjects. Sunder Rajan convincingly explores how it is that biocapital functions to improve or prolong the lives of some at the deterioration and exploitation of others, a finding that I will further explore later in relation to disability.

We can further see the impact of neoliberal biocapitalism in the way in which the speculation of future profits has become the decisive factor in determining the price of food and pharmaceutical products (Cooper 2008). With profitability seen as the result of innovation as opposed to mass production, biotech fortunes can be made by owning the patent to the "code source from which innumerable life forms can be generated, rather than the life form per se. Hence the biological patent allows one to own the organism's *principle of generation* without having to own the actual organism" (2008, 24). As petrochemical and pharmaceutical industries look to "generate and capture production itself, in all its emergent possibilities," success depends upon the multiplicities and differentiation of the "constant transformation of (re)production, the rapid emergence and obsolescence of new life forms" (Cooper 2008, 24). Profits depend upon "the accumulation of biological futures" as opposed to "the extraction of nonrenewable resources and the mass production of tangible commodities" (Cooper 2008, 24). As the neoliberal economization of life reorganizes life for the sake of a financialized economy, biotechnology becomes a means of reorganizing the economy and life around financial speculation.

Neoliberal biocapitalism depends upon deregulation, privatization, individualized risk, and the recentering of wealth generation around immaterial financial transactions.

However, as Sunder Rajan aptly notes, "the mantra that innovation comes from the private sector hides one of the fundamental conditions of possibility that makes private innovation possible, which is the role that public institutions play to enable private research" (2007, 56). As Harvey (2005), Brown (2006), and others argue, neoliberal practices do not erase the role of the state but rather mobilize their resources in different ways. Indeed, as Sunder Rajan (2007) shows by examining the US 1980 Bayh-Dole Act and the US Supreme Court Ruling in *Diamond v. Chakrabarty* (1980), there is a very complex relationship between private and public sectors that enables massive profits to be made by the private sector on the back of publically funded research and innovation.

At the same time, the turn to innovation has not meant the end of industrial production, the production of externalities like waste, or the depletion of resources that were supposedly limiting industrial capitalism and causing the death of the biosphere. Instead, the "new life science conglomerates have… simply divested themselves of the costs" of such production (Cooper 2008, 24). While neoliberal biocapitalism continues to deplete the earth's resources and, thus, limit the future of life on earth, it nonetheless diversifies and multiplies life and, thus, the future possibilities of life. This is perhaps most visible, for example, in patented sterilization technologies such as "terminator seeds," where the capacity for a plant to reproduce itself is both mobilized and curtailed, ensuring that the plant does not reproduce itself "for free" (25).

The commodification of biological life is not new. However, the co-production of the financialized and neoliberalized economy and the boom in the life sciences has shifted labour practices, conceptions of health and risk, and ways of increasing profits. Neoliberal biocapitalism has also increasingly individualized subjects as sovereign capitalists who

seek to maximize their own individual advantage. Having to address a system that both capacitates and debilitates life has ramifications for how to critique and combat the injustices of neoliberal biocapitalism. As I will show in the next section, disabled individuals and communities are both shaped and conscripted by biocapitalism, and this has important consequences for the ongoing struggles of disability justice.

Gradations of Debility and Capacity

The disability rights and the independent living movements arose alongside the neoliberal dismantling of the welfare state and the rise in biocapitalism throughout the 1960s, 70s and 80s. While much disability activism in North America predates the emergence of neoliberalism and the expansion of the life sciences, it was not until the 1960s and 1970s that disability rights became a prominent political issue. This rise to prominence of disability as a political issue is partly due to the growing demands of war veterans after both the Second World War and the Vietnam War, improvements in technologies that enabled individuals to leave their homes to work or to attend college and university (i.e., improvements to electric and manual wheelchairs, the introduction of accessible forms of public transportation), the prominence of unions and labour-related groups fighting for safer and healthier working conditions and workplace accident compensation, the success of a number of lawsuits related to disability access and accommodation, and the growth of impairment specific organizations and associations that lobbied various levels of government for increased research funding, access to services, and to pass legislation in recognition of civil rights (Nielsen 2012; Pelka 2012; Storey 2002; Tremblay 1996; Woods and Watson 2003b; Zames Fleischer and Zames 2011). The gains

made by the disability rights movement for disabled people and the political organization of disabled people is invaluable.

However, within disability studies and disability rights movements, the everyday conceptualization of disability is typically characterized as an oppressed disabled person working against structural ableism and the medical-industrial complex that seeks to cure, alter, and rehabilitate a body that is abnormal or lacking. Disability scholars and activists who take this approach in turn characterize disability as a normal, desirable identity that should be accommodated and should not be interfered with by medicine. As Matthew Sothern (2007, 148) remarks, for these scholars and activists:

> …disability is a positive identity that demands respect and a political-economic and cultural-symbolic reckoning with physical difference. As such, disability culture is about interrupting the discursive terrain of disability and wresting it away from the medical professions and other experts to claim the space for the disabled to narrate themselves.

This position appears most obviously in popular disability rights protest slogans, such as "Ramps Not Cures" and in the disability rights and independent living movement's quest to access jobs, transportation, and participate fully in communities.

And yet, neoliberal biocapitalism at once both materially and discursively mobilizes both ramps *and* cures, and also affectively hails disabled people to participate in biocapitalism in often contradictory and ambivalent ways. These processes are partially marked by Jasbir Puar (2009; 2011) who challenges disability activists and scholars to rethink the significance that they give to disability as an oppressed identity that matters and to, instead, consider disability as part of a larger neoliberal biopolitical frame that implicates *all* embodied subjects.

Puar argues that all bodies in neoliberal capitalism are "being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, [and] enhanced capacity" (2011, 155). As such, there is no body that meets the standard of adequately able-bodied anymore, only "gradations of capacity and debility" (2011, 155) that blur the distinction between disabled and non-disabled. Puar contends that given biopolitical developments in neoliberal capitalism, normalizing the disabled body is no longer the major focus of medical intervention. She claims that a biopolitical shift has occurred focusing on the differential capacitation of all bodies, not the achievement of a normative able-bodiedness. That is, through capacitating processes like genetic therapies, surgeries, supplements, prosthetic enhancements, and healthism, there is a shift from regulative normality that cures or rehabilitates to ongoing biological control, where bodies are to be capacitated beyond what is thought of as the able-body.

Capacitating or enhancing the body beyond the traditional boundaries of what has been marked and produced as the able-body can be traced through Dumit's (2012) research. For example, Dumit attends to the ways in which cure is an intervention that occurs only once, and thus is limited in the scope of its potential profitability. In comparison, life-long interventions, such as being prescribed drugs for hypertension, diabetes, or high cholesterol are much more profitable because they are taken "not to cure the condition but to reduce the risk factor and potential future events, such as heart disease or heart attacks" (2012, 5). This profitability comes to influence our very understandings of health and the body, shifting the dichotomous terrain of the able/disabled, normal/abnormal. The imperative is for as many people as possible to constitute an "at risk" group, such as those requiring cholesterol-lowering drugs, so as to lower their risk through taking drugs. As Dumit's research shows,

through the production of risk, the use of statistics in clinical trials, and the power of the pharmaceutical industry, it has become commonly accepted within medical communities to prescribe cholesterol-lowering drugs to everyone over 30 in America (2012, 13). Even further, Dumit's research shows that not only is this practice widely accepted but that the pharmaceutical industry itself, alongside public health discourses, have managed to morally obligate the use of preventative pharmaceutical treatments for those deemed "at risk" (13).

According to Puar, neoliberalized biopolitics mobilizes the tension between capacity and debility to break down the binaries between normative/non-normative, disabled/abled because "debility is profitable to capitalism, but so is the demand to 'recover' from or overcome it" (2011, 154) through processes of capacitation, such as that of taking cholesterol drugs everyday. An economy of debility and capacity serves the interests of neoliberal biocapitalism and reshapes formations of disability. As a result, disability is not a uniformly oppressed identity category or form of embodiment that lacks or is abnormal. Although oppression may be *part* of the story, disability can be caught up in processes of *both* debility and capacity. Rather than clear distinctions being made between who is normal and who is abnormal, emphasis instead is placed on "variegation, modulation and tweaking;" (2011, 155) forms of inclusion/exclusion that involve modes of differential inclusion; and with self and other or subject and object displaced in favour of the "construction of micro-states of subindividual differentiation" (2011, 155).

In contrast to the sub-subjective nature of debility and capacity, the disability rights perspective usually focuses on the ways in which disability has been cast as an oppressive identity through structural forms of ableism that produce disability as a diminished state of being. For example, the ways by which disabled people have been excluded from paid work

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has led some disability activists and scholars to highlight the importance of disabled

people's inclusion in productive work (Gleeson 1999; Taylor 2004). This has been, and

continues to be, an important fight for disabled people, for as Wilton and Schuer (2006,

187) note, "neoliberalism's privileging of paid work as a marker of citizenship has

intensified the costs associated with failing to access the workplace."

As a result of disability activism, in some instances neoliberal social and economic

policies have come to include disabled people in the labour market. This inclusion is often

celebrated as "liberating" disabled people and as improving the human capital of individual

disabled people (Wilton and Schuer 2006). While disability may not be a desirable part of

the future-oriented speculation of "human capital" due to the risky costs associated with

something like exposing fetuses to toxic chemicals (see Chapter 4), disability is tolerated

by differential neoliberal practices of inclusion. That is, disabled persons can be included if

they can be captured by market rationality, or market values. Disabled bodies that are

profitable, that can be marketed to, can be enhanced, or incorporated into the labour force,

are debilitated bodies that neoliberalism deems worthy. These capacitated-disabled bodies

are included because they can be made productive under neoliberalism in particular ways

and as such are rewarded and trumpeted as evidence of an inclusive society (see also

Chapter 7).

A Canadian national news segment highlights this aspect of neoliberal inclusion by

presenting the ways that "disability is good for business," offering proof that there is "a

huge return on disability" (CBC 2014b). The segment features Mark Wafer, owner of seven

Tim Horton's coffee shop franchises in Toronto, Ontario. Wafer explains the "money-

making secret" of disability in that disabled workers tend to "deliver like no one else." The

segment features Clint, one of Wafer's employees. Clint is a disabled person with Down's syndrome who "hardly calls in sick and routinely needs to be reminded to go home at the end of his shift." Wafer calls his disabled staff "loyal, productive employees."

The CBC segment goes on to showcase the "huge return on disability" being made by Walgreens, America's largest drugstore company. The company's distribution plant in Windsor, Connecticut is one of the most profitable of Walgreens' twenty distribution plants in the US. The "secret" of its profitability, as the segment reiterates, is that nearly half of the workforce is disabled. Scott Sylvester, who runs the distribution plant, comments to the CBC:

> It's obvious to say it's the right thing to do [to hire disabled people] from a heart and feel good perspective, but it really is truly [the right thing to do] from a business perspective. The workforce that we have in the facility, they are dedicated, they come to work everyday, they give 100% everyday, they have good attitudes, [and] they thoroughly enjoy the opportunity to work. (2014b)

The Windsor facility is twenty percent more efficient than others in the Walgreens' chain and Sylvester comments that employing disabled people "has benefitted everybody." Here, the use of "but it *really* is truly [the right thing to do]" marks a privileging of the business rationale and a downgrading of the sentimental "feel good perspective" emphasizing that the bottom line is that these workers are efficient, reliable, and compliant. However, as I showed in Chapter 2 and will go on to show in other chapters, the affective economies at work to make disability "feel good" are a key part of the material-discursive practices of neoliberalism.

These disabled employees are neoliberal success stories: they are capacitated in such a way as to participate in the labour force, and in enjoying "the opportunity to work"

while increasing their employers' profits. Thus, through neoliberalized biopolitics, those who are "upwardly mobile" become the capacitated-disabled, but only by way of disability becoming privatized, individualized, and entangled in deregulation. This form of inclusion is also an exclusion; that is, it is a differential inclusion, a form of capacitation that does not mark disability as a clear-cut oppressed identity. Rather, this differential inclusion is a marker of the way in which neoliberalism mobilizes capacity and debility through, within, across, and between bodies.

The flip side of this independent and productive disabled worker is that if one is disabled in such a way as to not easily be integrated into the workforce, or not be able to manage their own personal assistants, such a life is deemed "not worth living" and those people are often left for "slow death" (Berlant 2007, 776). While not sentencing them to die, the removal of supports through privatization and the delegitimatization of their lives that comes with not being worth the funding or worth employing, means that those disabled people deemed unproductive have less chance of maintaining good health, let alone living what would be considered meaningful lives.

Karen Soldatic (2011) marks this tension in her work on neoliberal workfare restructuring in Canada, the US, and UK, which has "resulted in the development of a multiplicity of new classes of disability, from the 'really' disabled and thus deserving of state welfare, through to the 'just disabled' who are positioned as being more amendable to part-time, casualized, flexible, precarious labour markets" (4). These "classes of disability" themselves are constantly shifting within the neoliberalized biocapitalist market as people are employed increasingly through varying forms of immaterial labour, such as work caught under the umbrella of the biocapitalist information and knowledge economies. For

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some disabled people, this economy represents increased opportunities to participate, whereas for others, such as some people with intellectual disabilities, these shifts hold risks and disadvantages. In this regard, Leanne Dowse (2009) has found that in the UK, neoliberal biopolitical practices have actually intensified the dependency of adults with intellectual disabilities rather than increased their independence.

This has also been the experience for other disabled people in the UK. For example, Natasha Pogson, a blind woman living in Billingham, UK, had her disability benefit provided by the state revoked after being found "fit-to-work" because she is able to "cross a road" when paired with a service dog (Guillot 2014). The Department of Work and Pension, responding to neoliberal austerity measures introduced across the UK in 2010, did a Work Capability Assessment of Pogson, finding her ineligible for her "Incapacity Benefit" (now called Employment and Support Allowance) and concluded that she must actively seek work. While seeking work Pogson is able to collect £72 [120 USD] per week. This amount significantly pales in comparison to the £167 [$275 USD] per week she received under the former Incapacity Benefit. Further, to access this money, Pogson must travel 90 minutes to the Jobcenter every two weeks to show proof that she has been searching for work. In a media interview, Pogson's father stated that travelling on her own for 90 minutes "is completely unrealistic" and Pogson herself recounts experiences of falling in the street and being completely unable to get her bearings, even with the help of a guide dog (Guillot 2014).

The impact of the Work Capability Assessment in Britain has been devastating. Over 10,600 disabled people died in 2011 after the Work Capability Assessment concluded that their benefits should be terminated (Green 2012, 6). Disabled people and disability

organizations were not consulted nor involved in the development of the assessment model and have heavily critiqued and actively protested its implementation. Determining that she is fit to work because she is able to cross the road with the assistance of her dog, Pogson's Work Capability Assessment produces her body as not disabled enough or not disabled in the right way so as to receive social benefits. She is no longer legitimately disabled according to social services. Because her body is deemed able to work by social services, to continue to be a legitimate subject she must find employment. Otherwise, she may well be labeled as being part of the "lazy scrounging scum, perfectly able to work…" but instead "draining resources from an already overburdened taxpayer" (Franklin and Marsh 2011, 43). Such hostile rhetoric of disabled ill/legitimacy plays a major role in the "40% rise in disability hate crime" in the UK since 2011 (Cross 2013).

In another incident, Brandon Coats of Denver, Colorado, who was paralyzed in a car crash at 16 years old, was fired from his job in 2010 after screening positive for marijuana, violating the company's "drug-free workplace rules." Coats had been using medically prescribed marijuana to deal with pain since 2009, and never used marijuana while at work. By falling afoul of what his employer deems a company workplace standard unrelated to matters of disability, Coats' disability makes him into a deviant worker unworthy of keeping his job. Coats has filed a lawsuit against the company, arguing that the "use of medical marijuana should fall under a state law that prohibits companies from firing workers for legal, off-duty activities that might rankle an employer" (Healy 2014). Non-normative ways of being disabled, forms of disability that do not fit into the neat packages of a highly mobile, young, wheelchair user working to be independently productive, are

easily dismissed as not truly deserving of benefits or accommodations within neoliberal biocapitalist economies.

With an interest in profitability, neoliberalized policies, practices, and forms of governance are interested in capitalizing on diversity and difference. Taking debility and capacity seriously within a neoliberal biocapitalist context opens up space for analyzing the ways bodies are differentially produced, including accounting for the particular ways in which the productive disabled body cannot always be celebrated with pride. For example, Sothern (2007, 146) draws attention to "the deplorable practices of neoliberal capitalism and its failure to provide adequate protection in sweatshops and in the informal spaces of the global economy – in which avoidable industrial 'accidents' regularly maim and injure." Such injuries are also found in the stories of human "guinea-piggers," or those human subjects who submit to drug-safety trials in exchange for payment (Elliott 2008; Sunder Rajan 2007). For example, in 2006 in London, a Phase I drug-safety trial for a prospective treatment for rheumatoid arthritis and multiple sclerosis sent six people to hospital with life-threatening reactions including organ failure. One subject had their fingers and toes amputated, and all the subjects were reportedly left with long-term disabilities (Elliott 2008).

Disability studies scholar Nirmala Erevelles is interested in what Sothern terms the "deplorable practices of neoliberal capitalism," mapping out the ways in which disability and race overlap within the context of international war. Erevelles argues that the violence of neocolonialism "is instrumental not only in the creation of disability" (Erevelles 2011, 118) as when first world militaries drop bombs on third world villages to root-out terrorism, but also particularly oppresses poor disabled people of colour both socially and

economically. She asks "How can acquiring a disability be celebrated as 'the most universal of human conditions' if it is acquired under the oppressive conditions of poverty, economic exploitation, police brutality, neocolonial violence, and lack of access to adequate health care and education?" (119).

Noting the particular ways by which disabled and racialized people are prevented from flourishing through eugenic and immigration practices, Erevelles tracks how these practices mark disabled and racialized people alike as "feeble-minded," "unfit bodies," "defects," and "unworthy citizens" (Erevelles 2011, 129-130). Utilizing forced sterilization, rigid immigration screening procedures that include lengthy personal health histories and police checks, institutionalization and imprisonment, and even genocide (Erevelles 2011; Mitchell and Snyder 2003), neoliberal practices conflate disability and race so that disabled, racialized, and disabled racialized bodies are produced as undesirable citizens and thusly disposable (Chandler 2013). These authors point to the complexity and contradictions of the disability rights movement claim that disability is an oppressed – yet normal and desirable – identity. Rather, taking up disability through the framework of debility/capacity allows disability activists and scholars to engage with how one comes to disability and how disabled people are both capacitated and debilitated within neoliberal biocapitalism.

Such histories of ableist and racist practices continue today through forms of governance such as pre-natal screening for abnormal fetuses, selective abortion, the lack of a national inquiry into the 824 missing or murdered Aboriginal women in Canada (CBC 2014a), the school-to-prison-pipeline (Hing, 2014), and through structural forms of violence that enable the killings of disabled African Americans such as Eric Garner by the NYPD, and Ezell Ford by LAPD (Sins Invalid 2014). It is clear from these examples and

from ongoing disability justice work that attending to the very different capacitation or debilitation of bodies marked as variously disposable or worthy of enhancement is important for contesting the ways by which neoliberal biocapitalism acts with and on individual bodies, populations, and in addition to differentially engaging cells, molecules, genomes, and genes (Helmreich 2008; see also Chapter 8).

Rather than focusing on barriers such as discriminatory work place policies, an economy that produces few meaningful and accessible employment opportunities, the lack of financial and other supports, and the racist justice and immigration frameworks, disabled people are penalized for using medically prescribed drugs, called "benefit scrounging scum" for accessing social provisions rather than becoming productive workers, face high levels of violence, and are placed in long-term care facilities, or imprisoned, or denied citizenship, with no or few chances to flourish. It is clear that questions of being legitimate and worthy disabled persons are wrapped up in neoliberal notions of inclusion in which someone can be included if they can be captured by market rationality. Bodies that are profitable – those that can be enhanced, marketed to, or incorporated into the labour force – are bodies that neoliberalism deems worthy. Those bodies that do not fit within this particular form of inclusion or cannot be capacitated in such a way as to participate in the labour force are debilitated or rendered for "death as a way of life" (Berlant 2007, 776). With such high stakes, many disabled people work to capacitate themselves through prosthetics, medical interventions, and assistive devices so as to become productive, independent workers and so as not to fall into a pit of "slow death."

For example, with the development of bioinformatics, where bodies are not identities, but rather data or pieces of emergent information, it is relevant to ask: "which

debilitated bodies can be reinvigorated for neoliberalism, and which cannot?" (Puar 2011, 153). Such a shift changes how disability can be conceived and materialized across levels of social and material relations, in addition to questioning the presumed capacitated status of abled-bodies. The point is not to disregard the role of pathology and processes of normalization, but rather to complicate the horizon by which we come to understand disability as an oppressed identity category. Therefore, Puar's intervention into disability studies pushes at the hegemonic ways in which the difference of disability is produced and how particular forms of disability can become valorized. Intervening in the ways in which the binary of disabled and abled is produced through the lens of capacity and debility makes it possible to question how the difference of disability can reify an exceptionalism of disability that only certain privileged disabled bodies can occupy.

Utilizing a framework of debility and capacity also works to make the bifurcation traced by Bill Hughes (2009) within disability politics and theory less tenable. Hughes marks the way by which the disabled people's movement expelled biomedical approaches to disability in a "revolt of the pathological" (677). In focusing on discrimination and oppression, the disabled people's movement "has been shy about impairment, arguing that it is irrelevant to the issue of disability" (677). However, Hughes also marks the rise of biosocial identities, or groupings of people organized specifically by their diagnostic labels who have embraced the specialized medical and scientific knowledge associated with their impairments or illnesses. These biosocial communities often work towards cures for their conditions, are active in fundraising (as with the ALS Ice Bucket Challenge, or Breast Cancer Marathons, and so on), and have been advocates for patient-driven medical research. They have also been active in creating support groups, encouraging

complementary and alternative therapies, and promoting their conditions so as to be granted, for example, Orphan Drug status by the US Federal Drug Administration so as to increase the likelihood of treatment research.

The goals of biosocial communities are often at odds with longstanding disabled people's movements that tend "to have a dystopian view of medical and scientific progress" drawing attention to, for example, "the links between eugenics and new genetics" (Hughes 2009, 680). A framework of debility and capacity provides an opening to be critical and reflective about how both sides of the bifurcation, as defined by Hughes, function within neoliberal biocapitalism. One example is the way in which many people use their biological diagnoses to become part of the "deserving poor" in order to obtain income support from governmental systems (Hansen, Bourgois, and Drucker 2014), or to gain access to extended healthcare or daily attendant care services. As such, neither position should be dismissed outright, but rather they need to be further interrogated. How do these binary positions work to produce differential inclusions and exclusions of disabled people who are not all equally oppressed?

Disability's Wounded Attachments

Puar's intervention is uncomfortable for disability studies insofar as she challenges the ways in which the field reproduces disability as an oppressed identity and an aggrieved subject enacted through what Brown (1993) terms "wounded attachments." According to Brown, identity groups form wounded attachments when they define themselves through the suffering they experience within dominant society in such a way that their identity becomes the painful underside of normative culture. While Brown does not argue that

marginalized groups who are left to wither do not suffer, her concern is that such wounded attachments foreclose the freedom of a group by identifying exclusively with its "historical and present pain rather than conjure an imagined future of power to make itself" (1993, 400).

Instead of critically evaluating dominant culture and working to replace it with something else, Brown argues that wounded attachments lead groups to strive for the material, social, and political wellbeing enjoyed by the very social elites whose privilege produced their suffering and marginalization. By enunciating and making claims for themselves through "entrenching, dramatizing, and inscribing [their] pain in politics" a suffering group hold "out no future – for [themselves] or others – that triumphs over this pain" (Brown 1993, 406). Wounded attachments lead to an unproductive but self-sustaining loop: because one identifies through their own suffering, a future without suffering would cause them to cease to exist. As such, they continuously reiterate their suffering and, thus, demand that everyone put their intellectual and affective energies into the source of their suffering as opposed to alternative political relations that would produce a more just and less oppressed future.

Neither dismissing the suffering any group faces, nor abetting the social relations that are at the root of that suffering, Brown instead wants to foster ways in which a group can enunciate and perform its historical oppression so as to not entirely delimit themselves but open themselves up to modes of healing that produce new and more just social relations. And because the wound or suffering that defines a marginalized group works to detach their suffering – and, thus, their group identity – from the ways in which that group participates in dominant culture, those wounds can cause others to suffer as well. As such,

Sara Ahmed (2004) argues that enunciating and performing historical and contemporary injustices must also open up any oppressed group to the suffering they cause others through the few privileges they enjoy.

By focusing on normal/abnormal, or abled/disabled, rather than on gradations of debility and capacity, disabled people hang onto an understanding of themselves as being excluded in a way that is not productive for fighting the neoliberal biocapitalist conditions in which disabled people are situated. One such wounded attachment is expressed in the desire of disabled people to be included in the workforce, from which they are largely excluded, despite the ways in which such a goal can re-inscribe the competitive, individualized, entrepreneurial subject formation that is key to neoliberalism's success. This wounded attachment pre-empts certain critiques of the violence of neoliberalism more generally; critiques that would orient disabled subjects towards a future that rejects inequitable labour practices and the desire to be good neoliberal subjects. This wounded attachment and the desire to be included closes avenues of political discussion and action that recognize and work to counter the suffering such inclusion would perpetuate for others – including other disabled subjects.

Just as Brown wants to approach suffering from an obtuse angle and not negate it, Puar takes up debility and capacity not to "disavow the crucial political gains enabled by disability activists globally, but to invite a deconstruction of what ability and capacity mean, affectively and otherwise, and to push for a broader politics of debility that destabilizes the seamless production of abled-bodies in relation to disability" (2009, 166). In doing so, Puar asks: "How would our political landscape transform if it actively decentered the sustained reproduction and proliferation of the grieving subject, opening

instead toward an affective politics, attentive to ecologies of sensation and switchpoints of bodily capacities, to habituations and unhabituations, to tendencies, multiple temporalities, and becomings?" (2011, 157). While Puar may be interested in decentering a liberal political subject, rather than rehabilitating a grieving subject through intersectional politics, debility and capacity can be a means to open up the suffering of disabled people and their communities in multiple ways that could allow for a more just future for everyone.

Disability's wounded attachments do not just foreclose the future, but they also obfuscate the present. In particular, by arguing that the distinction between normal/abnormal and its conflation with abled/disabled continues to inform the medical field's or an employer's understanding of disability is to misunderstand the differential equations that organize significant portions of biocapitalism and neoliberal labour practices. While disabled subjects certainly do confront such ableism when they present themselves to a doctor to be authorized as "disabled enough" to receive or keep disability-specific social subsidies and services, this interaction is only one component of disability relations that does not address the ways in which biotech fields focus on manipulating incomplete gene sequences or regenerating degenerating muscle fibres to see what they can do and not if they can be made normal. Similarly, by demanding that work places be made accessible and that ableist biases not prevent disabled subjects from being hired, disability politics risks obfuscating the calculations that determine which disabled subjects are employable. By identifying through the suffering caused by a *definitively* ableist society, disability scholars and activists risk misunderstanding the mobilizations of neoliberal biocapitalism.

The question thus becomes how to let go of attachments to disabled exclusion and re-frame disability in terms of the ways in which neoliberal biocapitalism enables some to

be differentially capacitated and others to be debilitated and left for "slow death"? It is not so much about abandoning critiques of ableism or denying that disabled people face oppression. Rather, it is about being attentive to the ways in which differential inclusion functions, being attentive to who gets to have grievances, how neoliberal biocapitalism capitalizes on those grievances, and the ways in which disability activists and scholars are implicated in their (re)production.

And yet, while disability rides the profitable line between capacity and debility, it is still not a form of being that is entirely desirable. Further, disability rights, access, and accommodations had to be fought for; they were not granted through benevolence, and many gains were only possible when they also happened to be profitable. The question thus remains how to attend to differential forms of capacitation and debilitation while remaining invested in a politics that affirms disability as a life worth living and without disability necessarily needing to be made worthy through a speculatively profitable future. In Chapter 4 I turn to examining precisely the economization of future lives as created through material-discursive practices of "the toxic fetus."

Chapter 4

Toxic Pregnancies: Speculative Futures, Disabling Environments, and Neoliberal Biocapital

News headlines sounded alarm bells in early 2014: "Scientists name 6 more toxins affecting developing brains" (Ricks 2014); "Growing number of chemicals linked with brain disorders in children" (Harvard 2014); "Putting the next generation of brains in danger" (Young 2014); "Researchers warn of chemical impacts on children" (Weintraub 2014); "Toxic chemicals blamed for 'Silent Pandemic' of Brain Disorders in Children" (Berman 2014); "Doctors fear kids' brain disorders tied to industrial chemicals" (Gordon 2014); "Number of chemicals linked to autism and other disorders doubled in past 7 years, study shows" (Woerner 2014). Philippe Grandjean, a professor of environmental health at the Harvard School of Public Health, and Phillip Landrigan, an American epidemiologist and pediatrician, link chemical exposure to what they call "neurodevelopmental disabilities, including autism, attention-deficit hyperactivity disorder, dyslexia, and other cognitive impairments" (2014, 330). Based on Grandjean and Landrigan's research, all these media representations warn that "we are endangering the brains of the future" (Gordon 2014) by exposing fetuses to chemicals in the everyday spaces we move through and objects we touch. According to Grandjean and Landrigan's research that these media stories were citing, these disabilities "can have severe consequences – they diminish quality of life, reduce academic achievement, and disturb behaviour, with profound consequences for the welfare and productivity of entire societies" (Grandjean and Landrigan 2014, 33).

This chapter examines the discourses surrounding Grandjean and Landrigan's 2006 and 2014 studies that highlight the dangers of exposing fetuses in utero to toxic chemicals that are commonly present in our everyday environments. In unpacking their analysis of "neurodevelopmental toxicity" and the effects of such toxicity on the economy, I argue that the material-discursive production of disability is intimately linked to forms of neoliberal biocapitalism that have consequences for how we think toxicity and disability together. Grandjean and Landrigan's studies draw attention to the sorely lacking standards and laws regulating chemical production and distribution in the US and how everyday environmental exposure to particular toxic chemicals can debilitate certain populations more than others. However, the emphasis of their studies and the resulting media attention has focused not solely on lax regulations but rather also on the economic impact that arguably results from toxic chemical exposure to the developing fetal brain. The production of disability as economically unviable in their studies is comprehensible precisely because of the ways in which disability is entrenched in neoliberal biocapitalism and speculative futures. The question of human capital is a question of how individualized entrepreneurs can be capacitated or debilitated, or made to overcome their debilitations so as to contribute to the present and future profitability of neoliberal biocapitalism. Using Grandjean and Landrigan's studies as a starting point, and building on the work of Mel Chen (2011; 2012), this chapter develops a critical disability studies response to the material-discursive production of toxic, disabling environments by placing disability studies in conversation with feminist science studies. As such, this chapter critiques the relationship between toxic environments and neoliberal biocapitalism, attending to its forms of producing particular speculative futures of disability that also re-inscribes whiteness. I emphasize the importance

of reproducing disabled lives – future lives – worth living while still critiquing the neoliberal economies that are animated through toxicity, disability, and race.

The Silent Neurotoxic Pandemic

Enacted in 1976, the US Toxic Substances Control Act (TSCA) regulates the introduction of new or already existing chemicals, and mandates the US Environmental Protection Agency (EPA) to protect the public from "unreasonable risk of injury to health or the environment" (Schierow 2009, 2). The TSCA was formed to oversee the creation of a list of safe and approved chemicals, and to regulate the use of any chemicals determined to be harmful by limiting or banning their use in products for commercial or public consumption. However, the TSCA's effectiveness in creating safe environments remains questionable. Indeed, because some 62,000 chemicals in use prior to the TSCA have never been systemically tested by the EPA but rather were grandfathered in as "safe" (Grandjean and Landrigan 2006), less than 20% of the 84,000 chemicals registered with EPA by 2008 have had any substantial safety testing (Schierow 2009, 7; Hamblin 2014).

In 2006, Grandjean and Landrigan published a review in *The Lancet* calling for new precautionary approaches to be taken in recognition of the dangers of exposing untested chemicals to "the unique vulnerability of the developing brain" (2006, 2167). Their study compiled lists of industrial chemicals that are known to cause neurotoxic effects in humans by drawing on information from the hazardous substances data bank of the US National Library of Medicine, fact sheets created by the US Agency for Toxic Substances and Disease Registry, and information provided by the US EPA. With a compiled list of 202 known neurotoxic substances, the authors searched a number of databases for these

chemicals, identifying all available published data in English. In reviewing and collating

the publicly available data and literature on the human neurotoxicity of industrial

chemicals, Grandjean and Landrigan characterize the ways in which the developing

nervous system of a fetus is particularly vulnerable to chemical toxicity, highlighting a

number of substances that could have detrimental effects on fetal and early childhood

neurological development, warranting further study. These include: lead, methylmercury,

arsenic, polychlorinated biphenyl, solvents, pesticides, manganese, fluoride, and

perchlorate.

Grandjean and Landrigan note that while most chemical toxicity testing is done in

relation to adult humans, neurotoxicity is much more of risk for the developing brain (2006,

2167). This susceptibility stems from the fact that during pregnancy, the brain of a fetus

expands from a single strip of cells into a complex organ consisting of billions of highly

interconnected specialized cells. For the brain to "optimally develop," neurons must move

precisely along pathways to establish connections and communication with other cells

within "a tightly controlled time frame" and in "the correct sequence" (2006, 2167-2168).

As such, "windows of unique susceptibility to toxic interference arise that have no

counterpart in the mature brain, or in any other organ. If a developmental process in the

brain is halted or inhibited, there is little potential for later repair, and the consequences can

therefore be permanent" (2006, 2168).

The authors found that while the placenta acts as a protective barrier against some

chemical exposure, "many metals easily cross the placenta, and the mercury concentration

in umbilical cord blood can be substantially higher than in maternal blood" (2006, 2168).

Further, "the blood-brain barrier, which protects the adult brain from many toxic chemicals,

is not completely formed until about 6 months after birth" (2006, 2168). Indeed, because the brain continues to grow into early childhood, Grandjean and Landrigan conclude that the "susceptibility of infants and children to industrial chemicals is further enhanced by their increased exposures, augmented absorption rates, and diminished ability to detoxify many exogenous compounds, relative to that of adults" (2006, 2168).

With these toxins already present in our environments, the problem is not that the effects of exposure have not been felt, but that these environmental pollutants can exert a range of adverse effects that are not usually tracked by doctors and other officials. Referred to as "subclinical toxicity," the effects of chemical toxicity are often not obvious based on a standard examination.

The concept of "subclinical toxicity" emerged from research showing that children exposed to lead could have significant reductions in intelligence levels and changes in their behaviour "even in the absence of clinically visible symptoms of lead toxicity" (2006, 2168). Grandjean and Landrigan warn that "there is a dose-dependent continuum of toxic effects, in which clinically obvious effects have subclinical counterparts," leading to a "silent pandemic" of neurotoxicity that is "not apparent from standard health statistics" (2006, 2168). Global health statistics do not reflect actual exposure levels because the effects of exposure are often not obvious or cannot be clearly linked back to a particular toxin. This "silent pandemic" might be responsible for "impaired brain development in millions of children worldwide" (2006, 2174).

The authors conclude that systemic testing protocols for potentially toxic chemicals need to be expanded to include examination of neurobehavioural functions affecting children. Present test protocols rely mainly on more obvious physical attributes, such as

brain weight and general body formation. The authors argue that the lack of long term

research done on many chemicals significantly puts fetal and post-natal brain development

at risk, suggesting that the number of chemicals that could cause neurotoxicity "probably

exceeds 1000, which is far more than the estimated 200 that have caused documented

human neurotoxicity" (2006, 2175). However, without systematic testing, "the true extent

of the neurotoxic potential of industrial chemicals is unknown… The few substances

proven to be toxic to human neurodevelopment should therefore be viewed as the tip of a

very large iceberg" (2006, 2175).

In 2014, Grandjean and Landrigan released a follow up to their 2006 review, noting

that since 2006 further evidence gives credence to their claims that industrial chemicals

contribute to "the global, silent pandemic of neurodevelopmental toxicity" (330). Updating

the list of recognized human neurotoxins and increasing the number of such chemicals from

202 to 214, their 2014 study details the ways in which exposure to toxins like lead,

tetrachloroethylene, and phthalates can lead to IQ deficits, reduced school performance,

delinquent behaviour later in life, deficient neurological function, increased risk of

psychiatric diagnoses, shortened attention span, and impaired social interactions (331- 333).

Grandjean and Landrigan argue that more than 200 foreign chemicals have been detected in

umbilical cord blood and that many environmental chemicals are further transferred to

infants through human breastmilk (2014, 331). Throughout their review, they cite evidence

that lead exposure in early childhood reduces school performance and increases delinquent

behaviour (2014, 331); that prenatal and early postnatal exposure to arsenic is associated

with cognitive deficits that are apparent at school age and can lead to a higher risk of

neurological disease during adult life (2014, 331); that exposure to manganese reduces

mathematics scores in school children, diminishes intellectual function, reduces olfactory

function, impairs motor skills and increases hyperactivity (2014, 332); that maternal

occupational solvent exposure during pregnancy can be linked to increased risks for

hyperactivity and aggressive behaviour (2014, 332); that prenatal and early childhood

exposure to the solvent tetrachloroethylene (also called perchlorethylene) in drinking water

increases the risk of psychiatric diagnoses (2014, 332); that prenatal exposure to phthalates

shortens attention spans and impairs social interactions, particularly in boys (2014, 333);

and that both exposure to air pollution and phthalates is linked to behaviours that resemble

components of autism spectrum disorder (2014, 333). In sum, they conclude, "industrial

chemicals known or suspected to be neurotoxic to adults are also likely to present risks to

the developing brain" (2014, 331). As Grandjean summed it up to a *CNN* reporter: "we are

putting the next generation of brains in danger" (Young 2014).

Within days of publishing their 2014 review in *The Lancet,* news headlines created

a stir among other scientists, the EPA, and among families with disabled children. Mothers

with disabled children wondered in blog posts and in comments following online news

stories if they were to blame for their child's condition, while others called for increased

institutional accountability or emphasized the importance of eating organic. The attention

garnered by Grandjean and Landrigan's studies tapped into cultural preoccupations with

where disability originates from and how to stop its reproduction. These preoccupations in

turn are deeply embedded in notions of speculative futurity underwritten by neoliberal

political economy and governance.

That is, not only do Grandjean and Landrigan believe that the next generation of

brains are at risk of becoming disabled as a result of inadequate testing and regulation, but

they also emphasize how neurodevelopmental disabilities have deep and dire economic consequences. While their 2006 review made some reference to the economic impact of this "silent pandemic," their 2014 review specifically calls attention to and emphasizes the economic impact of neurotoxic disability. As I will argue, the everyday materially invisible nature of these chemical risks are embedded in the emergence of neoliberal biocapitalism and are both biological and economic, marking both the present and the speculative future. This has some troubling consequences for how ableism, racism, and environmental activism come together against disability.

Sounding the Alarm Bells

Both Grandjean and Landrigan's 2006 and 2014 reviews draw attention to the sorely lacking standards and laws regulating chemical production and distribution in the US and how everyday environmental exposure to particular toxic chemicals can affect fetal and postnatal neurodevelopment. However, the emphasis of the studies and the resulting media attention has focused not solely on lax regulations but rather also on the economic impact toxic chemicals have on the developing fetal brain. Rather than marking how exposure to toxins can result in changes in IQ or modes of social interaction that we are collectively responsible for engaging, the issue becomes about what kind of "human capital" is being reproduced with fetal exposure to toxic chemicals.

For example, in their 2006 study, Grandjean and Landrigan explain how nearly all children born in industrialized countries between 1960 and 1980 were exposed to petrol containing high levels of lead. During this period, the aggregate number of children at risk of exposure to airborne lead was about 100 million, and such exposure "could have reduced

the number of children with far above average intelligence (IQ scores above 130 points) by over 50% and might likewise have increased the number with IQ scores below 70.95," resulting in "diminished economic productivity" with costs ranging from US$110 billion to $319 billion in each year's birth cohort (2167). Grandjean and Landrigan further argue that the contemporary costs of lead poisoning "are estimated to be $43 billion in each birth cohort in the USA, whereas the costs of prenatal methylmercury toxicity are estimated to amount to $8.7 billion yearly" (2006, 2174). In their 2014 review, Grandjean and Landrigan cite evidence linking average national IQ scores with gross domestic product (GDP), a correlation they note "that might be causal in both directions" (2014, 334). As such, "poverty can cause low IQ, but the opposite is also true. In view of the widespread exposures to lead, pesticides, and other neurotoxicants in developing countries, where chemical controls might be ineffective compared with those in more developed countries, developmental exposures to industrial chemicals could contribute substantially to the recorded correlation between IQ and GDP" (2014, 334).

Grandjean and Landrigan's (2014, 334) estimate that each IQ point lost due to exposure or other causes decreases average lifetime earnings capacity by about US $18,000 is consistent with figures presented by other researchers. For example, in a 2012 study, David Bellinger determined that Americans have collectively forfeited 41 million IQ points as a result of exposure to lead, mercury, and organophosphate pesticides. Economist Elise Gould argues that a loss of one IQ point corresponds to a loss of US $17,815 in lifetime earnings. Based on this figure, "the combined current levels of pesticides, mercury, and lead cause IQ losses amounting to around $120 billion annually – or about three percent of the annual budget of the U.S. government" (Hamblin 2014). Further, Grandjean and

Landrigan note: "Since IQ losses represent only one aspect of developmental neurotoxicity, the total costs are surely even higher" (2014, 334) because the treatment of the various conditions arising from neurodevelopmental toxicity "is difficult, and the disabilities they cause can be permanent; they are therefore very costly to families and to society" (2006, 2167).

The future painted by Grandjean and Landrigan gets even bleaker. The costs to "families and to society" relate to "antisocial behaviour, criminal behaviour, violence, and substance abuse that seem to result from early-life exposures to some neurotoxic chemicals" (2014, 334). This can "result in increased needs for special educational services, institutionalisation, and even incarceration" (2014, 334). Grandjean and Landrigan posit that phasing out or banning particular toxic chemicals can reduce these costs, noting how the phasing-out of lead additives in petrol in the US "generated an economic benefit of $200 billion in each annual birth cohort since 1980, an aggregate benefit in the past 30 years of over $3 trillion" (2014, 335), figures which do not even take into account the economic benefits resulting from the " prevention of degenerative brain disorders" which "could be very substantial" (2014, 335). The benefit of preventing disability is thus produced as substantial: not only does healthy brain development mean a better economy, but it also points to a speculative future of brain cells that are economically optimized. The problem, then, as marked by Grandjean, Landrigan, and the resultant media stir, is not just that disability is an abnormality that should be prevented, but also that all forms of embodiment are entrenched in neoliberal speculative futures in dangerous ways.

Neoliberal Biocapitalism and Toxic Futures

Grandjean and Landrigan's studies encourage a neoliberal biocapitalist logic that economizes life, individualizes disability, and promotes a speculative futurity that does not include disability, or can only include disability if disability can be capacitated or enhanced.

Biocapitalism and the economization of life marks a way of talking about more and less valuable lives in economic terms rather than solely in biological terms. The economic viability of disability in Landrigan and Grandjean's studes are comprehensible precisely because of the ways by which disability has been entrenched in neoliberal biocapitalism. Neoliberalism as a social and economic reorganization of capitalism and governance intervenes extensively and invasively in every area of social life, including life itself. Michelle Murphy (2011) calls this "the economization of life," that centers on the profitability of future-oriented human biocapital. Neoliberalism is the economization of life such that the future of life is intimately tied to profitability and productivity. Life is made to live—have a future—if it is profitable, while unprofitable life has no future and is made to wither. Neoliberal biocapital, in its orientation towards multiplicity and differentiation, seizes on the economization of life to govern all forms of living being "for the sake of fostering economic development and enhancing national GDP" (Murphy 2011, 29). As such, capitalism becomes neoliberal biocapitalism, which has particular consequences for how we critically pair disability and toxicity together.

Murphy (2013) argues that neoliberal notions of "human capital" depend upon "the embodied capacities of a person that can produce future economic benefits for that person, her employer, and even her national economy." Murphy's work on the economization of life argues that as neoliberalism developed throughout the mid-to-late 20th century, it became increasingly common to render and govern lives in purely economic terms (for example, as more or less valuable). In the economization of life, normal and abnormal biology are less important than how different forms of life can be made profitable. Murphy (2011), drawing on Foucault's formula of the racial state, notes that practices of population control have been tied to GDP and GDP per capita, resulting in a "eugenic necropolitics" that "declared that some must die so that others may live more healthfully… some must not be born so that future others might live more abundantly…" (2011, 30). While embodying "human capital" means mitigating any risks to our embodied capacities as a population, neoliberalism is a system of individualization that "'privatizes' the risks and capacities of populations onto individuals, encouraging them to take charge of their own exposure to risk or opportunity in relative isolation or independence" (Hengehold 2007, 16). As Laura Hengehold remarks (2007, 274):

> The privatization or individualization of risk was a change in governmental technique, implemented by cutting back on many of the social insurance programs and legal protection programs of the welfare state. It was designed to extract a little more profit and self-care from citizens' embodied subjectivity, and to reduce the state's obligations to mediate between the rich and poor. But it did so by moralizing the act of work, by valorizing entrepreneurial risk-taking when employment was lacking, and by evaluating communities and affinities based on how well they promoted such activity.

As quality of life measures, selective abortion, pre-natal screening and other invasive reproductive medical practices highlight, in the contemporary economic and social

moment, the economic devaluation of a disabled life transforms it into a less-viable life and the source of preventable economic costs in the future.

However, individual risk is not limited to the individual but to the future life that individual produces or has the potential to produce. Economization does not just effect the present but is also speculative: embodiment becomes a value that is future-oriented. As Melinda Cooper (2008) argues, key to future-oriented human capital is reproduction. The rise of neoliberal governmentality encourages competitive behaviour and gives individuals the responsibility "for preventing or surmounting risks" (Hengehold 2007, 13). Furthermore, as Murphy argues (2011, 33-34), such risks are not limited to one generation as research has shown that exposure to chemicals can effect the future reproductive capacities of fetuses. Specifically, Murphy notes how research done on pregnant mice exposed to the estrogenic chemical bisphenol A (BPA) "has found that the significant effects occur not so much for the fetus in utero, but for the eggs being formed inside that fetus, and hence effects are manifest for the potential grandchildren…" (2011, 33-34). This kind of research precisely marks the ways by which economization does not just effect the present but also creates future-oriented speculative value.[13]

Part of this economization of life is a result of the clinical gaze being supplanted by the molecular gaze, so much so that many living in neoliberal biocapitalist economies have come to experience themselves and their individualized risks in highly profitable biocapitalist terms. This is reflected in Grandjean and Landrigan's message across various media interviews encouraging pregnant women to eat "organic," to remove wall-to-wall

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[13] This research also functions to produce the responsible mother (see Chapter 7).

carpeting which can trap chemicals, and to ensure that grass or sportsfields have not been sprayed with pesticides before children play there (Weintraub 2014; Hamblin 2014; Woerner 2014).

With normalizing discourses representing disability as the failure of the body to meet some normative standards, toxicity acts as a potentially polluting element that must be fixed, eliminated, or tolerated, all costly options. This continues neoliberal speculative futures and progress narratives as hope, mobilized in the originating moment of bodily failing (be it by accident, illness, or, increasingly, in probing human genetics), facilitates progress (optimism for cure, or miraculous medical intervention as the solution to the problematic deficient body, finding ways to integrate disabled bodies into the economy). Normative discourses of disability have not disappeared; people still want "a healthy baby" to such an extent that disability deeply disturbs this desire. There is an important relationship between the desire for a healthy baby and health cast as an economic argument. However, there are further tensions in that disabled bodies can also be a source of revenue and a site of investment. As opposed to seeing disability exclusively as the basis for exclusion and disabled bodies as objects to be normalized, Jasbir Puar (2011) has come to question how economies of disability – that capacitate some disabled bodies while leaving other unproductive disabled lives to wither – produce differential forms of disability in neoliberal economies. The silent pandemic of toxic exposure related disabilities is not outside of these economies.

This is because, while Grandjean and Landrigan warn of the costs associated with toxic-exposure related disabilities, these expenses are also key to economic profitability. This is to say, disability, as an expense is also central to the functioning of neoliberal

biocapitalist economies. The question of human capital is a question of how individualized

entrepreneurs can be capacitated or debilitated, or made to overcome their debilitations so

as to contribute to the profitability of neoliberal biocapitalism. As disabled life has become

economized, the biological difference of impairment has come to matter less in some cases

than the potential of making disabled bodies productive through therapies, drug regimes,

and assistive devices and, thus, profitable for private companies developing drugs and

producing body modifying and enhancing equipment. Joseph Dumit (2012) turns to this in

his review of the pharmaceuticalization of American life as companies come to capitalize

on new cultural health paradigms that mark our everyday lives as risky and bodies as

inherently ill and in need of chronic treatment, through continual growth in disease

categories and risk factors that can be met with medications. Dumit remarks: "Health is not

simply a cost to the nation to be reduced; contradictorily, it is also a market to be grown"

(2012, 9). Grandjean and Landrigan's "silent pandemic" of "subclinical toxicity" reflects

what Dumit has described as "a new mass health model in which you often have no

experience of being ill and no symptoms your doctor can detect" (2012, 8), where "the facts

imply that we are not doing enough screening and treating" (2012, 9).

The notion that disability is not just about being abnormal, or embodying an

absolutely oppressed identity is made clear when considering the intersectional ways by

which disability comes to appear on other marginalized and marked populations.

Importantly, many marginalized populations have long felt the gradations of debility and

capacity that underwrite neoliberal biocapitalism and toxicity. Mel Chen, for example,

notes the way in which black bodies in America have been always already presented as

"mentally deficient, impulsive and spastic" (2011, 270). But as Chen points out, studies

similar to Grandjean and Landrigan's resonate so strongly with the public not because their

studies challenge systems that reinforce structural environmental racism but rather because

present and future generations of white children are at risk. Grandjean and Landrigan's

studies break down the barriers that assume certain populations are always already toxic

while others are "safe" and draw attention to the fact that there is no absolutely safe toxic-

free zone for anyone. This is to say, while black children are "assumed to be toxic," the

threat of toxic exposure to "white children is not only that they risk becoming dull, or

cognitively defective, but also that they lose their class-elaborated white racial cerebrality

and become suited to living in the ghettos" (Chen 2011, 270-271). As environmental

hazards "encroach on zones of privilege" (Chen 2011, 272), marking the ways by which

disability is differentially capacitated and debilitated becomes pressing for how to respond

to the differential ableism and racism of toxicity as it is embedded in transnational

neoliberal biocapitalism. Chen notes:

> There are those who find themselves on the underside of industrial "development" – women hand-painting vaporous toys by the hundreds daily without protection; agricultural workers with little access to health care picking fruit in a cloud of pesticides, methane, and fertilizer that is breathable only in a strictly mechanical sense; people living adjacent to pollution-spewing factories or downwind of a refinery installed by a distant neocolonial metropolis, or in the abjected periphery of a gentrified urban "center"; those living in walls fortified with lead that peel inward in a false embrace; domestic workers laboring in toxic conditions, taking into their bodies what their better-vested employers can then avoid. (2011, 276)

While these chemicals continue to circulate and effect populations unevenly, both of

Grandjean and Landrigan's studies seek to show the ways in which "better-vested

employers" also cannot avoid toxicity. As with disability, toxicity is not to be found

elsewhere, whether that be in black bodies, the bodies of farm workers, or those working in

factories. Toxicity, like disability, is not contained in individually bounded bodies but rather, circulates, altering the life chances of future generations, as Murphy points to in her look at BPA. This circulation is entrenched in social, political, economic and environmental regulations and policies. In the next section I grapple with the circulation of toxicity and disability outside of the individualized lens provided by neoliberal biocapitalism. Landrigan and Grandjean's study provides a clear example of the ways in which disability cannot be separated from, and indeed has emerged through, neoliberal biocapitalism, emphasizing the speculative futures of human capital that pushes for individuals to take neoliberal solutions. In the next section I work against this individualized accounting.

Toxic Circulations and Desirable Disabilities

Chen poignantly remarks that "toxins are not so very containable or quarantinable; they are better thought of as conditions with effects, bringing their own affects and animacies to bear on lives and nonlives" (Chen 2011, 281-282). Toxins "as conditions with effects" mark the environment not just as the background but as what Stacy Alaimo terms "always as close as one's own skin – perhaps even closer" (2010, 2). The environment is not out there, but "is the very substance of ourselves" (4), making both disability and health not a static status that one is or isn't but rather a relation with effects.

The point is that if toxins, health, and disability are deeply embedded in the environment that is social, economic, cultural, and political, then what we are left to grapple with is how to not simply reduce toxic exposures to a "natural" healthfulness gone astray, which re-affirms what Chandler has called "an understanding of disability as individually located, with a static, singular meaning as a problem in need of a solution"

(2013, 49). Another way of suggesting this circulation of toxins and disability is put

forward by Eula Bliss when she states:

> If we do not yet know exactly what the presence of a vast range of chemicals in
> umbilical cord blood and breast milk might mean for the future of our children's
> health, we do at least know that we are no cleaner, even at birth, than our
> environment at large. We are all already polluted. We have more microorganisms
> in our guts than we have cells in our bodies— we are crawling with bacteria and
> we are full of chemicals. We are, in other words, continuous with everything here
> on earth. Including, and especially, each other. (2014, 76)

Indeed, if toxins and disability are not individual health problems of bodies or

environments gone astray but rather shared continuities of each other, then these relations

with effects can be held accountable to their differential, multiple and changing sites of

emergence (these ideas are further developed in Chapters 6, 8 and 9). This is to agree with

Grandjean and Landrigan in their desire for more intensive chemical regulation and stricter

systematic long-term testing that takes into account not just the effects of chemicals on

adults, but also on developing life forms both human and nonhuman. While I am in favour

of increased and stronger regulation, I also want to be able to desire disability differently; to

open up desire for precisely what disability disrupts, marking the particular ways in which

disability is both capacitated and debilitated at once and multiply across neoliberal

biocapitalism and embedded within structures of racism and ableism.

      The production of disability as an abnormality and as economically unviable and

unlivable must be held to account in our positing of futures yet to come. Toxins and

disability are all around us and in us and of us. If problems get the solutions they deserve,

then the problem is not toxicity or disability but rather our continued emphasis on disability

as an individually economically quantifiable toxic condition. Can we desire our animate

and inanimate, lives and nonlives of our toxic environmentally situated selves in a way that takes seriously regimes of capacitation and debilitation that unevenly affect populations, species, affects? Or to put it another way: the challenge is to speculate on different kinds of futures that welcome the black baby, the autistic baby, and the insect with three legs as a reflection of our shared and circulating toxic and disabled world all the while working to undo the very logics of neoliberal biocapitalism that is both deeply invested in the economization of life and also continues to animate whiteness (Chen 2011; 2012). That is, this is not to call for a celebration of raciality and disability as difference in themselves, but rather to continue to interrogate the ways by which toxicity functions within and through neoliberal biocapitalism so as to animate the complex relationships between toxicity, disability, and race.

Chapter 5

Neoliberal Reproductive Futurity and The Disabled Child

"One reason we do not expect people with disabilities to appear in our world is because we do not have predictable narratives of their future; we do not imagine them as having tractable futures or life trajectories" (Garland Thomson 2012, 351).

"My future is written on my body" (Kafer 2013, 1).

Paige Cunliffe, a 21 year-old woman living in Ontario, Canada, became developmentally disabled after a bout of menococcal meningitis at the age of 13 months. For most of Paige's life her mother was her primary caregiver, but found that she was no longer able to care fulltime for her adult daughter. However, after waiting on a list to be placed in a group home for over ten years, Paige was placed in long-term care home. This is not unusual. Between 2008- 2012 in Ontario alone, over 5000 people with developmental disabilities under the age of 65 were admitted to long-term care homes. While long term care is designed for people who require 24/7 care, most of the residents of long term care facilities are elderly patients who are often experiencing serious illness or disabilities like dementia that make them unsuitable peers for a social and energetic 21 year-old. With a caretaker to resident ratio of 11 to 1, Paige is often left sitting alone in soiled clothing for hours. Paige has no peers in the facility and there are no activities available to suite Paige's needs and interests. In a media interview with *CBC News*, Paige's mother states that Paige hardly eats anything in the facility, despite displaying a large appetite when she is able to come home for a visit. With the waiting list for a group home, where Paige would be with

peers, engaged in activities, and have a worker-to-resident ratio of 3 to 1, is upwards of 20 years in Ontario, Paige will be living with the very sick and the elderly until she is 31 (CBC 2014c). If she is able to find a spot in a group home, Paige would be with peers, engaged in activities, and have a worker-to-resident ratio of 3 to 1. Paige is not alone or unique in lacking adequate housing and care services to enable her to flourish as a disabled adult. By not providing suitable care facilities for Paige and thousands of others like her, it is clear from the funding structure and policies implemented by the state that dependent disabled adults are not expected to have full and dynamic futures unless they can make private arrangements for their own care. Through the lack of adequate state care, these adults are left to wither.

Paige's withering, like the withering of so many other disabled people, is not simply a story about a lack of material resources that would allow for the capacitation and thriving of disabled lives. Rather, withering and thriving are not simply a matter of resources (personal or state) but also invoke forms of futurity (ways of thinking the future) that privilege only certain forms of the future for disability and disabled people. Disabled people that can be easily accommodated, enhanced, and capacitated by forms of biocapital are much more likely to thrive. However, such thriving must still contend with a neoliberal futurity that is embedded within the logic of the suffering disabled child.

In this chapter, I explore how the withering of some disabled lives and the capacitation of others are a result of material and discursive processes that imagine the suffering disabled child as a life without a future. In other words, this chapter takes up what can be called neoliberal futurity and how it organizes disability and makes it intelligible through the suffering disabled child that is never imagined to grow up. Usually figured as

the negation of the future, or having no future, neoliberal futurity also speaks to the difference of the futures imagined for disabled children: disabled futures. Building on Lee Edelman's (2004) critique of what he calls "reproductive futurity" that privileges the Child as the image of the future, I will show how neoliberal futurity underwrites the medical procedures that prevent the suffering child from being born; infanticide and filicide; the Make-A-Wish Foundation that aids the suffering disabled child; and the Jerry Lewis Muscular Dystrophy telethon that works to cure the suffering child. By looking at these disparate discursive and material sites, I will show that as opposed to homogenizing actions and desires, neoliberal futurity is productive in that it informs economies that prevent life, end life, capacitate infantilized bodies, and re-invest a caring public in biocapitalism.

At the same time, even as a neoliberal futurity diversifies, I will also show that the suffering disabled child nonetheless re-inscribes the hope for a future without disability or, at least, a future in which disability no longer seems to be difference that matters. That is, I will show that it is at the confluence of this double lack-of-futurity – disabled children without futures and a future without disability – that disabled adults such as Paige become unanticipated lives left to wither by the state while others become capacitated as an inspirational, hopeful, and progressive success story of neoliberal inclusion. Building on my argument from the previous chapters that the capacitation and withering of disabled people within neoliberal economies are linked, I will show that some disabled people flourish in the future precisely because their futures gain traction in neoliberal society and that these tractable futures – as Rosemarie Garland Thomson (2012) calls them in the epigraph to this chapter – demand that others have no future.

Which Tractable Futures?

In *No Future: Queer Theory and the Death Drive*, Lee Edelman (2004) argues that the contemporary political order privileges heteronormativity by inciting the Child as the image of the future (2-3). Edelman calls this child-centered "ideological limit" and "organizing principle" of social relations "reproductive futurism," a cultural and political way of investing in a better future *for the sake of our children* that casts the possibility of queer resistance outside of the political domain (2). For Edelman, the field of politics is steeped in the figure of the Child, so much so that "the image of the Child invariably shapes the logic within which the political itself must be thought" (2), and is the "fantasmatic beneficiary of every political intervention" (3). He notes: "we are no more able to conceive of a politics without a fantasy of the future than we are able to conceive of a future without the figure of the Child" (11). Thus, within this heteronormative logic, the Child is the only side one can take in a political order that demands that the image of the Child is the only intended future. A better future is always a better future for the Child. Edelman comments that whomever or whatever refuses this mandate made by political institutions to compel the collective reproduction of the Child must "appear as a threat not only to the organization of a given social order but also, and far more ominously, to social order as such, insofar as it threatens the logic of futurism on which meaning always depends" (11). The ever "lengthening shadow" of the Child "terroristically holds us all in check and determines that political discourse conform to the logic of a narrative wherein history unfolds as the future envisioned for a Child who must never grow up" (2004, 21).

Edelman's reading of the way in which politics and culture rely so heavily on the Child to imagine the future is confirmed by Pope Francis, who in speaking against Israel's attack on Palestine at Saint Peter's Square on July 27, 2014, implored: "Stop, please! Brothers and sisters, never war, never war! I am thinking above all of the children, who are deprived of the hope of a worthwhile life, of a future…" (McKenzie 2014). Edelman's concern is also marked by scholars such as Lauren Berlant (1997), who traces out the ways in which American children are produced in the name of the future and as innocent citizens.

While Edelman is largely interested in the ways in which reproductive futurity figures the Child within contemporary American political discourse, I am particularly interested in the ways in which neoliberal futurity incites the child in ways that have grave social, political, and cultural consequences. Thus, in parsing out what is unique about neoliberal forms of futurity, I build on the work of social theorist Franco Berardi (2011), who argues that thinking "the future" is not about the temporal direction of time but rather a shared social imaginary of progress underwriting capitalist relations, a frame of thinking made possible by the mode of production and the ongoing pursuit of surplus value. Of this Berardi comments: "The rise of the myth of the future is rooted in modern capitalism, in the experience of expansion of the economy and knowledge. The idea that the future will be better than the present is not a natural idea, but the imaginary effect of the peculiarity of the bourgeois production model" (2011, 18). Neoliberal futurity, based on an economy of always more surplus-value to extract, always new markets to develop, always new ways to download social responsibilities onto individuals, ever-always more ways to exploit the many in order to benefit the few, requires a child that will overcome the odds and will rise up to meet the new demands of the economy. It is neoliberal futurity that inspires parents to

invest – and go into debt – to produce an entrepreneurial kindergartener that eats the right food, goes to the right school, and has all the right opportunities available to him or her so as to best prepare them for the hyper-competitive, individualistic future (for example, see Webb 2013).

What Berardi (2011) and Edelman (2004) do not account for are the ways in which the Child as the image of the future is not only central to the notion of progress, but how this Child relies on an economy of disability that is deeply entrenched in neoliberal practices. As I have marked in other chapters, this not only to alludes to the multifaceted ways in which neoliberal practices produce disability or are complicit in rising rates of disabling conditions, but also marks the ways by which the practices of neoliberalism that demand that some succeed at the expense of others cannot be fully accounted for without addressing disability. This is to say, Paige's withering is related to the enhancement of others and simply capacitating Paige within the context of neoliberal futurity does not address the myriad ways in which disability functions within neoliberal economies.

Thus, while Edelman (2004) is correct in asserting that the contemporary political order favours heteronormativity in the ways in which it incites the Child as the image of the future, this image of the Child of the future also continuously incites compulsory enhanced-bodiediness as the child of reproductive futurity is not only not to be disabled, but must be better than able-bodied. McRuer, in the context of Edelman's work comments: "'everybody,' after all, or so the saying goes, 'wants a healthy baby.' At the same time, despite this commonplace desire, the imagined future is actually inescapably inaccessible; no real, flesh-and-blood child can ever embody the innocence, health, and ability associated with the sacred Child" (2008). I agree with Edelman's sharp and scathing critique of

reproductive futurity, and while I also agree with McRuer that Edelman's Child is able-bodied, what neither Edelman or McRuer elucidate is how reproductive futurity relies on *both* a capacitated and bodily enhanced Child that shapes the ways the political gets mobilized in the name of the future, *and* for some disabled children to grow up at the expense of others who are never intended to grow up. Edelman is right, then, about the ways in which the figure of the Child re-inforces heteronormativity but he fails to take stock of the ways in which the Child is also always, already able-bodied, or how the Child is capacitated and enhanced. While McRuer is right to point out that no child can fully embody the desirable able-bodied child, and, thus, sets up disability as the impediment to a desirable future, I am interested in how the better-than-able-bodied Child requires some disabled children to grow up at the expense of other disabled children in order to give the Child meaning. Thus, the disabled child is the figure of no future, as will be demonstrated in the case of Emily Rapp (2013) desiring to terminate pregnancy on the basis of disability, and in the case of infanticide and filicide on the basis of disability. However, the disabled child is also the figure of the future in that the suffering child creates particular neoliberal futures through the mobilization of biocapital, cure, and enhancement. Therefore, as I will go on to show, we are deeply invested in narratives of suffering children, but some of those children are always supposed to remain children, never growing up, while others are celebrated, enhanced, and capacitated precisely because they can be made to slide into the neoliberal promise of the future. As I will argue, it is precisely in sliding into neoliberalism's forms of capacitation and enhancement that incapacitates and disables others.

The 'end of suffering' and 'no hope for the future'

That disabled children have no future and are the denial of the future as McRuer (2008) argues is perhaps most evidenced in instances of parents "mercifully" killing their disabled children to end their suffering. Stories of such incidences litter news and blog sites in which parents undergoing significant stress and hardship in trying to raise disabled children come to believe that there is "no hope for a future" (S.E. Smith 2013). For example, in New Malden, south-west of London, England, on April 22 2014 between midnight and 5 am, Tania Clarence suffocated to death her three year-old twin sons, Max and Ben, and her four year-old daughter, Olivia in a move "to end their suffering" (Davies 2014). The nanny of the children, Jadna Coelho, found them dead in their bedrooms of their £2 million family home (BBC 2014). Away on holiday at the time was Tania Clarence's husband, Gary, an investment banker, along with their able-bodied eldest daughter.

In October 2014, murder charges against Tania Clarence were dropped after she entered a plea of "manslaughter by diminished responsibility." The Crown Prosecution Service found Clarence to be "suffering from a major depressive episode at the time of the killings which amounted to an 'abnormality of mind'" (Davies 2014). All three children had Spinal Muscular Atrophy (SMA) Type 2, which falls under the large umbrella of variations of genetic and neuromuscular disorders of Muscular Dystrophy. SMA Type 2 is described by the media as "a life-limiting progressive disease" that can "cause fatal respiratory problems" (Davies 2014). Zoe Johnson, the Prosecutor in charge of the case, describes Tania Clarence as holding the "firm belief that the quality of her children's lives was more important than their longevity" (Davies 2014). This belief, the Prosecutor says, is

"entirely understandable" (Davies 2014). Defence attorney Jim Sturman remarked that

Tania Clarence "was manifesting stress throughout the life of the children by their

suffering, and caring for three children with this condition was exhausting, distressing,

debilitating and turned out to be overwhelming" (Davies 2014). As a result, it is

understandable that Tania Clarence did what she did because she "had no hope for the

future" (Smith 2014).

Tania Clarence's distress and lack of a hope for the future for herself and the future

of her children also seems understandable despite the Clarence's financial affluence that

allowed them to fully renovate their expensive home, hire both a nanny and a maid, and

allowed Tania Clarence to leave her job as a graphic designer to stay home to help care for

the children. Indeed, despite Tania Clarence's financial comfort, in a letter she wrote her

husband two days before the killings she noted that "I cannot face going down this path

watching Liv and the boys continue to get weaker… I am tired of it all. No matter what we

overcome, no matter what we do, it will never be enough" (Wilkes 2014). Later, in another

letter addressed to her husband, written after killing her two sons but before killing her

daughter, Clarence wrote:

> Gary, I need to tell you how difficult it is for me to take Liv's life… If I could take
> my own life and leave her to wait for you I would… My only solace is the pain and
> future suffering I am saving her from. I am so sorry… The only thing giving me
> the motivation to continue is the belief that the boys are already playing up in
> heaven like they could never play here. (Wilkes 2014)

Only through death can a future be imagined for disabled children. And in killing disabled

children, Tania Clarence produces a future without disability and, thus, one way of

fulfilling the thinking that disability has no future.

'Yes, there's hope for future children'

In the *New York Times* bestselling memoir, *The Still Point of the Turning World* (2013), Emily Rapp recounts her experience with her son Ronan, diagnosed at the age of nine months with Tay-Sachs disease, a "rare and always fatal" degenerative genetic condition "with no treatment and no cure" (Rapp 2013, 1). Tay-Sachs "causes a slow developmental regression into paralysis and sensory loss that is irrevocably fatal by the age of about three," foreshortening "an entire life-course to a chillingly compact arc" (Garland Thomson 2012, 349). For Rapp, Tay-Sachs is "the shittiest disease of all time" (2013, 33), noting:

> There is no cure for Tay-Sachs, no arguing with biology. We understood that our son would gradually regress into a vegetative state within the span of one year, and that this slow fade would progress to his likely death before the age of three. He would slowly go blind. He would never speak or walk and he would lose control over his head and never have control over any other part of his body. We understood that we would suffer as he withdrew, as he changed, as his interaction with us diminished… (2013, 24)

Before getting Ronan's official diagnosis, Rapp comments "I had been worried for some time. Ronan was experiencing development delays, missing important milestones… He was the same sweet, happy, gurgling baby – but that was the problem. He was the same at nine months old as he had been at six months" (2013, 1). Rapp was concerned because Ronan was not progressing as she expected he would.

Rapp acknowledges that if she had been aware that her son would be born with Tay-Sachs she would have selectively aborted her pregnancy to prevent the suffering of both her son and her family. She reflects: "As soon as I learned I was pregnant I became obsessed with odds. I quickly ordered every prenatal test available to me, even though I was told,

'based on my background,' were unnecessary, including the test for Tay-Sachs. I cut out

caffeine, alcohol, diet soda (chemicals!) and refined sugar. I drank buckets of water" (2013,

78). Ronan's diagnosis came as a surprise to Rapp as she had been screened for the

condition during the early stages of her pregnancy. However, she only had the standard

screening test for Tay-Sachs that detects the nine most common mutations rather than

testing for the more than one hundred known mutations (2013, 3). Unlike most children

now born with Tay-Sachs who are "born to parents who didn't know they had anything to

worry about" (2013, 78), Rapp believes she had done her part to "cover all the bases, get

the results, to *know*" (2013, 78).

Rapp sees in her son a life that has already failed. On the drive home from the

doctors office where they received Ronan's diagnosis, Rapp notes that Ronan, giggling in

his car seat is "oblivious to his wretched future" (2013, 7). She imagines herself untangling

his DNA to "restitch it, rebraid it, fix it, make it right, take it back somehow, change the

odds" (2013, 88). For without this fix, this rebraiding of Ronan's DNA, Rapp and her

husband find themselves without hope and without a future. Rapp notes:

> Rick and I went out for a Valentine's Day dinner, but it was hardly romantic. We
> struggled with what to say to each other. We were used to talking about the baby,
> planning for the future, looking forward, tracking change. Gone were our plans for
> Ronan's future. Gone was our hope. (2013, 74-75)

Rapp asks herself "How do you parent without a future[?] Could it even be called

parenting, or was it something else, and if so, what?" (2013, 11). She comments that

parenting for the sake of parenting contradicted every bit of parenting advice she had ever

read, for "parenting advice is, by its very nature, future directed" (2013, 13). With Ronan

having no future, Rapp's understanding of what it is to parent is displaced: "The dreadful

hitch in this otherwise middle-class and privileged domestic snapshot was this: Ronan would never benefit from any of Rick's and my efforts beyond what he received *in the moment*" (2013, 15). Rapp had imagined that Ronan would be "physically fearless," an "adventurous eater," "fun but levelheaded, loyal and fair and smart" (2013, 15). He would be "generous and gorgeous" (2013, 16). But as Rapp comments, whatever she did for Ronan would not matter: "organic or nonorganic food; cloth or disposable diapers; attachment parenting or sleep training; breast milk or formula – all the decisions that mattered *so much* to me in the first few months of his life, he was going to die" (2013, 16).

Rapp's memoir traces out her conflicting desires for a perfect and successful son while at the same time wanting Ronan to *just live* after he is diagnosed. She writes: "Of course we would have done anything to help him, to save him, but we didn't want him to be another, different baby… We never wanted him to be perfect. We wanted him to *live*." (2013, 69). In the next paragraph she goes on to lament: "I'd never experience with Ronan so much of what I'd been looking forward to as a mom: marveling as he acquired language, teaching him to ski, traveling with him to all of the wonderful places I have lived, helping him learn how to be a unique person in this mad world" (2013, 69). While Rapp consoles herself at times by reassuring herself that in dying young Ronan would "never experience shame, regret, fear, self-loathing, worry, anxiety, or stress… Ronan would never wish himself to be different" (2013, 69-70), she nonetheless continues to lament the lack of a future Ronan's life offered, wondering: "What about all the things I'd imagined that Ronan might be or become without Tay-Sachs in his way?" (2013, 75).

Indeed, that all investment in Ronan can only be temporary – present and not future-oriented – is completely unsettling. That the promises of successful futures that neoliberal

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futurity offers – through getting a jump on other children in choosing organic food or cloth diapering, or through starting baby sign language or music classes to develop the brain – will never lead anywhere for Ronan, is one of the biggest challenges Rapp struggles with in her memoir. Rapp teeters back and forth between wanting and imagining a future that will not come while also trumpeting living in the moment. She remarks: "He would never come sprinting at me with a Harvard diploma in his hand. He would never score a perfect SAT. He never said 'mama.'" (2013, 20). Rapp reluctantly comes to face that her "task was not to prepare my son for his future, but to make each day and each moment count" (Rapp 2014a). Battling these feelings, Rapp asserts: "I wasn't interested in music class or swimming lessons for Ronan because I hoped he would manifest some fabulous talent that would set him, and therefore *me*, apart. I wasn't searching for heaps of praise about what an amazing mom I was. I was interested in creating experiences for Ronan that would make him *happy*" (Rapp 2013, 20). Making Ronan happy was not about any future potential: "There was nothing he needed to prove or do or become. He could stay a beautiful acorn; he didn't need to grow into a tree or realize his potential… No pressure to be quicker or better or smarter than the other kids" (2013, 75). In fact, for Rapp, not only did Ronan not need to be quicker or smarter, "He didn't have to meet any milestones. He could lie on his back and sit on our laps and do nothing at all" (2013, 75-76).

Even as Rapp's son has no future, the lack of future described in Rapp's memoir reinvests her reader in the figure of the Child as the future, a figure that is not disabled, or only disabled in ways that render them a child to be cared for. Thus, while Rapp desires some future, even a disabled childhood, for her son, Rapp also reinvests in being the mother of a yet-to-born child. For as Rapp's friends in the Tay-Sach's community assure

her, "Yes, there's hope for future children" (2013, 9), and as Rapp herself comments: "After my son Ronan was diagnosed… I immediately wanted another child" (Rapp 2014b). Upon telling this to another Tay-Sachs mother, that mother approvingly comments: "Of course you want to feel life again" (Rapp 2014c). While Ronan is still alive, Rapp begins investigating fertility treatment options having no interest in having a second child with her then-husband because there would be a 1 in 4 change of having another Tay-Sachs child. And while Rapp, upon the birth of her daughter Charolette in 2014 cautions that she "can live with the joy of new motherhod without losing the memory of loving my son" (Rapp 2014a), it is also apparent that Charolette signals the hope of a non-disabled life and future that extends, as Rapp comments, "long beyond my own and [Charolette's] father's" (Rapp 2014a), even if her daughter will never replace Ronan.

In many ways, Rapp's story is not unique in the sense that there already exists a broad cultural logic of disabled children as having no future. Thus, while Ronan's "no future" came as a surprise to Rapp precisely because he was born without any indication that he was futureless, and in fact Rapp had been assured through her genetic testing that Ronan would have nothing short of a full future, culturally it is readily acknowledged that disabled children have no future, or what future they have is undesirable. Ronan, once diagnosed as disabled is imagined to not have a future not only because of Tay-Sachs, but because of the futureless-orientation to disability that dominates our shared social, political, and cultural understandings of disability. *The New York Times* best-seller success of Rapp's memoir speaks to the already circulating discourses about disability, suffering, and a lack of a future. As this chapter will go on to demonstrate, this cultural logic is grounded in neoliberal biocapitalist logic of disability as suffering and overcoming. While Rosemarie

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Garland Thomson argues that Tay-Sachs provides an example of disability that "demands that we all might imagine a subject without a future life trajectory perpetually managed in the present moment" (2012, 353), echoing Rapp's position that Ronan could "stay a beautiful acorn," I argue that this kind of imagination and cultural logic has long been at play through the social and cultural practices of things like the Make-A-Wish Foundation and Jerry Lewis Telethon. While the "we" in Garland Thomson's statement is to interpellate the non-disabled to live as if they also have no certain and predictable future, echoing again Rapp's "beautiful acorn" which suggests the same culturally ubiquitous "live in the now" outlook, I argue that the Make-A-Wish Foundation and Jerry Lewis telethon, along with cultural artefacts like that of Rapp's memoir, serve to re-inscribe disability as having no future while also capacitating some forms of enhanced disabled futures. While Rapp's story is an individual one, she wrote it as "a way of calling out to the world to see if anyone would answer with their own stories of struggle and survival" (Rapp 2014a). In Rapp's account we have both "there is no hope for the future" but also the difference of disability: that while Tay-Sachs is no future, not all disabilities offer no future. Both iterations work alongside the figure of the Child as the Future. In the next two sections, I turn to some ways in which hope for certain forms of disabled futures are built.

Share the Power of a Wish

The non-profit organization Make-A-Wish Foundation of America (MWF) grants the wishes of children with life-threatening medical conditions in order to "enrich the human experience with hope, strength and joy" (2014). The MWF was started in 1980 by Arizona customs agent Tommy Austin, and police officers Ron Cox, Frank Shankwitz, and

Jim Eaves. These officers wanted to help Chris Greicius, a seven-year-old boy who had terminal leukemia. Greicius yearned to be a police officer, and Cox and Austin, along with help from the Arizona Department of Public Safety (DPS), named Greicius an honorary DPS officer before his death on May 3, 1980. During the summer of 1980, after Greicius' death, a group of DPS officers and friends gathered together to discuss their emotionally moving experience with Greicius and ended up forming the MWF. By 1981, they had raised $2000 and granted their first official wish to seven-year-old Frank Salazar, who also had leukemia. Salazar was granted three wishes: to be a fireman, go to Disneyland, and to ride in a hot air balloon. The MWF was later incorporated in 1983 and opened chapters across the US with a mission statement of granting a wish to any child diagnosed with a life-threatening medical condition. In 2013 alone, MWF granted 14,003 wishes to children with life-threatening medical conditions, and has granted over 240,000 wishes since 1980.

Wish granting is big business. The MWF 2013 Annual Report notes that all "42 chapters had record fundraising years. Together, we raised 11 percent more funding than last year. Such gains give us the momentum we need to get to the next benchmark in wish granting, propelling us even closer to achieving our vision of granting every eligible child's wish." The average cost of a wish in 2012 was $8,141, and the MWF used 2.5 billion frequent flier miles to meet its travel needs for wish kids and their families (2014a). Further, the Walt Disney Company is involved in 50 percent of the wishes that MWF grants and US national retailer Macy's contributed 63 million dollars alone (MWF 2013).

The MWF states that a "wish experience can be a game-changer. This one belief guides us. It inspires us to grant wishes that change the lives of the kids we serve." The "game-changer" MWF describes refers to bringing about a renewed hope to the children

and their families that they will beat their life-threatening illnesses, a renewed hope that

often results in making MWF children more compliant with their medical treatments. The

MWF notes: "Health professionals treating them say the wish experience is an important

adjunct to medical treatment, and they observe their patients feel better and comply more

readily with treatment protocols when they experience their wish come true" (2014a).

Granting a wish makes the children "more willing to comply with difficult, but vital,

treatment regimens" and enables them to "take back control of their lives, and to keep up

the fight against their life-threatening medical conditions." As opposed to being solely

premised on a lack of hope for the future, the wish is premised upon a terminally ill child

continuing treatment and continuing to have hope. The wish opens up hope for the future of

disabled children or disabled futures made possible through medical capacitation.

The wish is oriented to the future, even though the premise of eligibility for a wish

is that the child has no guaranteed future. Indeed, while marking the importance of

treatment compliance and instilling hope in the child and their family, the MWF at the same

time notes that granting one wish is never enough. They state:

> But for every wish granted, another child is diagnosed with a potentially qualifying
> condition. A child who needs a wish. We all look forward to the day when no more
> children have life-threatening medical conditions. Until that time, Make-A-Wish
> remains committed to a vision of granting a wish to every eligible child. Because
> wishes make very sick kids feel better – and sometimes, when they feel better, they
> get better. (2014b)

This statement invokes a future orientation full of hope towards a time when no child will

be terminally ill. And yet, that time has not come, so it is important to support the work of

the MWF in bringing sick children hope today for they may not have a tomorrow. This is

reflected in the MWF trademarked slogan "Share the Power of a Wish" (MWF 2013).

Capacitating a life now opens up the possibility of a future without or with less medical intervention. It opens up futures of remission or liveable futures through medical compliance.

At the same time, this future is premised on the present reality that there is no future for disability. That is, to be eligible for a wish, the child must face having no future. That the child has no future invokes an excitement of how important the work of the MWF really is:

> It's hard not to get excited about our work. The wishes granted to children with life-threatening medical conditions across the country bring hope to wish kids, strengthen families, and make life better for everyone involved in those wishes. (2014c)

The idea that granting wishes to terminally ill children is exciting is re-affirmed in *Wish Granted* (2014), a book featuring the experiences of famous American athletes such as basketball doyen Michael Jordan and figure skater Scott Hamilton granting wishes, who find "that the child changed them" in making a wish come true. In his introduction to the book, Michael Jordan, who is also Chief Wish Ambassador, writes: "It's tough sometimes as an athlete to decide which charities you should dedicate your time and influence, because the need is so great and there are so many wonderful causes out there. One of the many reasons that Make-A-Wish in particular is so near to my heart is that they aren't 'specialized' in terms of who they serve… They don't focus on one type of disease or one specific age group" (2014, 7). Rather, "they empower hope" allowing for "every encounter with a wish child" to be "a gift of some form" (11). Of his experience with a wish child, NFL football star Larry Fitzgerald writes:

I remember arriving home after practice that day and getting on my knees, thanking the Lord that my son was healthy… I realized that I could not care less what my son decides to be when he grows up. I don't care where he decides to go to college. I don't care how he wears his hair. Provided that he is growing to be a healthy young man who makes good decisions, knows he is loved, and is happy, I have absolutely no room to complain. It's amazing how quickly all the other little worries of life fall by the wayside when you realize what truly matters and what a gift you have really been given with a healthy child. (2014, 90)

Wish-kids are expected to die, and granting wishes to these dying children brings hope, strength and a renewed commitment to fighting life-threatening illnesses. Both fighting life-threatening illnesses and granting wishes involve large sums of capital that are dependent upon children having no future and, thus, are in need of living their lives to the fullest while they still live. Furthermore, disabled futures require renewed investment in medical treatment even if the hope is that that such an investment will only be temporary. Through MWF, the suffering child becomes the hopeful child that must always remain a child. Sharing the "Power of a Wish" is limited to the disabled child for there is no MWF for adults. The hope is that the future of the wish child is a future of remission, or a future of medical enhancement. It is not a disabled future.

Jerry's Kids

The cultural logic that there are no disabled futures that makes Tania Clarence's actions understandable rubs up against biomedical advances in care for SMA. As some news stories have noted, "most people with the condition go on to live productive adult lives" (Smith 2014).[14] Clarence was sentenced on November 18, 2014 to a mental health treatment program. Just days before Clarence's sentencing, in Southern California, *Cure*

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[14] It is telling that "productive lives" is the common modifier.

SMA, formally known as *Families of Spinal Muscular Atrophy*, held a "Gala of Hope…

with one goal: To fund a cure for Spinal Muscular Atrophy" (FSMA 2014) reinforcing the

slogan of *Cure SMA* that "We can see a future without SMA" (Cure SMA 2014). The

futureless future of SMA thus comes in many forms, whether through cure or what has

elsewhere been deemed "mercy killing" (Evans 2014).

The simultaneous play of no future that mobilizes hope for a cure and also posits no

future for disabled people and disability at the same time imagines a future for some

disabled children. This is nowhere more evident than in the Jerry Lewis Labour Day

Telethon. Indeed, the Jerry Lewis Labour Day Telethon has popularized cultural

understandings of disabled children as both a site of hope and overcoming disability, and as

a site of disabled suffering and tragedy.

The annual 22-hour Jerry Lewis Labour Day Weekend Telethon was first broadcast

in 1966 to raise money for the Muscular Dystrophy Association (MDA) whose goal it is to

fight neuromuscular disease. Broadcasting over 1,000 hours of live television hosted by

Jerry Lewis and featuring an array of celebrities and entertainers, the telethon has been

deemed the "most successful fund raising event in the history of television," raising over $2

billion over its first 46 years of broadcasting, and boasting a viewership that exceeds that of

the Superbowl and Oscars (MDA 2014). In his 45 years hosting the telethon, Lewis worked

toward getting "one dollar more" than the previous years so as to get "closer than ever to a

cure" for "Jerry's kids." As a result of such enormous funding raising efforts, the MDA

became the first non-profit organization to receive a "Lifetime Achievement Award" from

the American Medical Association "for significant and lasting contributions to the health

and welfare of humanity" (MDA 2014). Lewis himself was also nominated for the Nobel Peace Prize in 1977 as a result of his work with the MDA (Walton 1997, 65).

The MDA telethon produces disability as "a fate worse than death" and of disabled people "suffering" from Muscular Dystrophy as people "waiting for a cure, without which their lives are worthless" (Johnson 1992). For example, in the 1973 telethon, Lewis held up a child with Muscular Dystrophy and announced: "God goofed, and it's up to us to correct His mistakes" (Wiener 2011), affirming the belief that disability is a deviation and a mistake that must be corrected. During the 1991 telethon, Lewis commented that upon receiving a diagnosis for Amyotrophic Lateral Sclerosis (ALS), a form of Muscular Dystrophy, that "you might as well put a gun in your mouth" (Hershey 2003), signifying that living with ALS is worse than death. During the 1992 telethon, Lewis stated: "My kids cannot go into the workplace. There's nothing they can do. They've been attacked by a vicious killer. I'm begging for their survival" (Hershey 2003). Statements such as these re-affirm the popular cultural belief that disability is a "monolithic fact of the body" (Kafer 2012, 3) that stops people from living their lives and that it is disability that needs to be cured rather than social structures or relations that need to be changed. On this point, disability rights activist and former poster child Laura Hershey (1993) comments: "The telethon certainly doesn't encourage viewers to think of other options. If the person can use equipment and personal assistance to live more independently, then viewers may not feel as sorry for her."

Cure, rather than changing social structures and relations, has long been how Lewis promotes disability as suffering. For example, in 1990, just weeks after the US government signed the civil rights landmark Americans with Disabilities Act, Lewis penned an article in

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Parade Magazine entitled "If I had Muscular Dystrophy." In this piece, imagining himself

to have Muscular Dystrophy Lewis wrote: "So I decided, after 41 years of battling this

curse that attacks children of all ages… I would put myself in that chair… that steel

imprisonment that long has been deemed the dystrophic child's plight… I just have to learn

to try to be good at being half a person." He goes on to write: "I may be a full human being

in my heart and soul, yet I am still half a person, and I know I'll do well if I keep my

priorities in order. You really cannot expect the outside world to assist you in more ways

than they already do, and I'm most grateful for the help I receive" (Lewis 1990). That you

cannot expect "the world" to "assist" masquerades a common-sense approach that is deeply

socially and politically saturated.

The MDA telethon seeks to "pry open wallets" through the objectification of

suffering children, despite the fact that "two-thirds of MDA's 1 million clients are adults"

(Hershey 1993). The telethon does not represent "the real lives of people" but rather works

to "paint a picture of a victim so tragic, and at the same time so cute and appealing, that

viewers will be compelled to call in a pledge" (Hershey 1993). While appearing tragic and

cute, the "victim" must also appear "utterly unable to help him/herself, so that the giver can

gain a personal sense of virtue and superiority from the act of giving" (Hershey 1993).

Additionally, the "victim" must display a form of "courage" that results in a depreciation of

oneself, an acceptance of "other people's versions of one's own reality," and a rejection of

the value of oneself as a disabled person in favour of "an eagerly anticipated cure"

(Hershey 1993). All this is done to "encourage the assumption that life with a disability is a

life scarcely worth carrying on with, except for the generosity of Jerry Lewis and everyone

involved in the telethon" (Hershey 1993).

To promote just how grateful "Jerry's Kids" are for the help they receive, the telethon features MDA poster children who have been featured in MDA ad campaigns, National Goodwill Ambassadors who are "young people fighting courageous battles against muscle disease" who publicly share their stories, host events and campaign "to defeat muscle disease" (MDA 2014b) and patient profiles of afflicted children and the their families, all of which serve through "emotional interviews, heart-wrenching images and sorrowful soundtracks" (Smit 2003, 693) to express the difficulties and challenges of living with Muscular Dystrophy. The stories told by the children and their families highlight the urgency and need for the audience to call and donate immediately, "before it's too late" (Smit 2003, 687). Reviewing hundreds of hours of telethons, disability historian Paul Longmore found few segments featuring successful disabled adults, reinforcing "the Tiny Tim persona" as "central to framing the cultural, social, and political meaning of disability. The charities depicted the representative disabled person as a vulnerable child, one of 'the most weak'" (2013, 38).

In 1968 Ben Mattlin, diagnosed with Type 2 Spinal Muscular Atrophy like Olivia, Ben, and Max Clarence would be, appeared on the telethon and was a poster child featured in an ad for MDA that appeared in several magazines and newspapers. In the ad Mattlin is positioned standing in leg braces (which at the time of the photograph he no longer used), staring up at the camera with his big blue eyes wide open, a head of unruly blond curls, and his head tilted to the left. Above his head, printed in large black bold letters it reads: "If I grow up I want to be a fireman." Mattlin later wrote of this experience in *The Washington Post* remarking: "*If?* My prognosis was a normal life expectancy. Besides, I didn't want to be a fireman!" (Mattlin 2007).

Starting in 1981, some of "Jerry's kids" became "renegades" who called themselves "Jerry's Orphans" and began protesting outside of telethon filming locations with placards calling for an end to telethons, "rights not pity," and demanding support for universal healthcare and a national research agenda. Holding these placards, and in some cases, storming into the live-filming of the telethon, the protestors chanted: "Jerry Lewis, you're not funny, you're using people to raise money! Stop the pity, stop the lies, stop to think – don't patronize!" and "Don't cry for us, don't weep and pout! Change the channel, tune Jerry out! He sells pity day and night! Equal time for civil rights!" (Walton 1997). The protestors particularly focused on having Lewis removed as MDA telethon host for insisting on calling children and adults alike with Muscular Dystrophy "Jerry's kids."

Protestor Evan Kemp notes that the telethon "makes disabling conditions seem overwhelmingly destructive" emphasizing "the desperate helplessness of the most severely disabled. In doing so, it reinforces the public's tendency to equate handicap with total hopelessness" (Kemp 1981). As Hershey (1993) notes, "the telethon encourages viewers to project their own worst fears onto people with muscular dystrophy," encouraging them to "imagine what it would be like if your child couldn't play baseball." Further, "families are described as 'courageous'; and they all seem to bear total responsibility for the care and support of the person with MD" marking disabled bodies as burdens.

Responding to disability rights activists, in the 1990s the MDA began changing some aspects of its telethon. It began showcasing more successful disabled adults and significantly shortened the programming to just a few hours rather than 22 consecutive hours. And yet, despite these changes, pity and paternalism remained. For example, during the 1992 show, Matt Schuman, a former poster child was showcased as a successful adult

sports reporter. While highlighting Schuman's success, Lewis stood tall over Schuman's wheelchair, as if playing "parent to the person with a disability as child" (Haller 1994). Of this scenerio, Beth Haller comments: "When Schuman completes his short speech, Lewis rubs and pats the back of Schuman's head. It is not a 'good job' touch from one adult to another as a pat on the back or a shake of the hand might be. It is a parent patting the head of a child to indicate the child has pleased him" (1994, 145). As Lewis pats Schuman's head, he says: "Any one of your healthy children could be one of my kids tomorrow" (quoted in Haller 1994, 146). The fear and pity ingrained in that statement is made all the worse as Lewis juxtaposed his own family to the poor disabled cripples in order to garner more donations. During the 1992 telethon, Haller notes how Lewis' baby daughter Danielle served "as an example of what the cure can provide" (1994, 146). Danielle appears on camera to have no physical disability and is used to show what a beautiful baby "money for a cure can buy" (1994, 146). That is, if a cure is developed for "God's goofs" then all babies born could be as beautiful as Danielle.

Despite some of the structural aspects of the show changing, and despite the fact that many other charities had long abandoned the telethon as a means of raising money (e.g. both the Easter Seals and March of Dimes stopped using telethons in the 1980s) in 2001, Lewis in an interview with the CBS Morning Show defended his pity approach to raising money. He stated "I'm telling you about a child in trouble. If it's pity, we'll get some money. I'm giving you the facts. Pity. You don't want to be pitied because you are a cripple in a wheelchair, stay in your house" (Kurtz 2001). While the MDA released a statement explaining that Lewis' remarks did not reflect the views of the organization or its leaders, Lewis went on to host the telethon for another 10 years.

On May 16, 2011, "Jerry Lewis announced that he was retiring as host of the annual MDA Labor Day Telethon" (MDA 2014). Citing the need to adapt to changes in "viewer habits and the television broadcasting industry," MDA has partnered with ABC to exclusively broadcast their newly named MDA Show of Strength Telethon. The two-hour prime-time telethon is shown on "ABC affiliates nationwide," ensuring a large viewing audience, maximizing "MDA's ability to spread the word about its fight against muscle disease." Re-branding the muscle-diseased disabled people as "strong," MDA (2014) notes:

> The telethon has consistently enjoyed robust support from thousands of the biggest stars in show business. But – as always – the real stars on the broadcast are the MDA families who have graciously agreed to open their homes and hearts to America and tell their stories of strength. The telethon will introduce the general public to several remarkable individuals whose "stories of strength" will raise public awareness of the effects of neuromuscular disease and the unprecedented scientific and medical advances currently being made against these devastating diseases.

Therefore, despite activists relief that Lewis is no longer hosting the telethon, and despite the MDA re-structuring the telethon so as to feature some of the successes of adults with MD, the new "Show of Strength" continues to feature cute and loveable children in search of a cure for this "devastating muscle disease" (MDA 2014). Successful adults are shown to be successful "in spite of" their debilitating disability, rather than as an aspect of their being, and as courageously "overcoming the odds" through their inner-strength. The MDA's slogan "Making Muscles Move" is readily in juxtaposition to the wasting muscles of people with MD that fail to move, and that fail to hope for a future without MD.

Here we find that the suffering child and the adult that overcomes disability are rebranded in the Show of Strength so as to participate in an economy of always more enhancement, always more treatment options, always more adaptive equipment. The

suffering child and the overcoming adult is a site of medical consumption, where the goal is not merely to cure so as to have an able-body, but to cure and enhance the body, to end the suffering of muscle disease through enhanced and capacitated strength – through technologies and treatments that create better-than-able-bodies.

The MDA telethon arose during both the beginnings of the disability rights movement that emphasized the social and structural forms of ableist oppression and during the development and implementation of neoliberal policies and governance that promoted charity and individual forms of fundraising to solve structural problems. The issue I raise here with the MDA telethon is that it produces and promotes the suffering of disabled children as an object of consumption and of pity, while also marking these children as having no future. A future is only possible for these children through cure and enhancement, and without cure-enhancement, or without the possibility of hope for a cure, there is no future for disability.

Not fighting for the Children

Edelman's contention is that reproductive futurity disavows all that threatens to end the future, particularly emphasizing the role of the queer as that which "names the side of those *not* 'fighting for the children,' the side outside of the consensus by which all politics confirms the absolute value of reproductive futurism" (2004, 3). While the Child represents the heteronormative future, the queer can only signify "the negativity opposed to every form of social viability" (2004, 9) and threatens the social order because the queer "raises the spectre of, not just a worse future, but precisely 'no future.'" (White 2013, 23). Edelman calls on queers to embrace the negative and to "fuck the social order and the Child

in whose name we're collectively terrorized" (Edelman 2004, 29), suggesting that the ethical value of queerness is precisely in "accepting its figural status as resistance to the viability of the social" (2004, 3). Edelman (2004, 17) comments:

> I am not for a moment assuming that queers – by which I mean all so stigmatized for failing to comply with heteronormative mandates – are not themselves also psychically invested in preserving the familiar familial narrative of reproductive futurism. But politics, construed as oppositional or not, never rests on essential identities. It centers, instead, on the figurality that is always essential to identity, and thus on the figural relations in which social identities are always inscribed.

For Edelman, queers who seek gay marriage, military service, or adoption "jump on the bandwagon of reproductive futurism" (McRuer 2008) and reproduce "the conditions of queer abjection" (White 2013, 23). Instead, Edelman calls on queers to "acquiesce to the charge that we are society's worst nightmare and to embrace our figuration as the negative force working against the social order" (McRuer 2008), for "queerness can never define an identity; it can only disturb one" (Edelman 2004, 17). Edelman thus provocatively asks: "while not seeking to refute the lies that pervade . . . familiar right-wing diatribes [about our capacity to destroy society], do we also have the courage to acknowledge, and even embrace, their correlative truths?" ((2004, 22). While asserting that his anti-social strategy "promises, in more than one sense of the phrase, absolutely nothing" (2004, 5), and further notes that his project is "impossible," (2004, 4), he does argue that embracing queer negativity "can have no justification if justification requires it to reinforce some positive social value; its value, instead, resides in its challenge to value as defined by the social, and thus in its radical challenge to the very value of the social itself" (2004, 6). For queerness "exposes the obliquity of our relation to what we experience in and as social reality, altering us to the fantasies structurally necessary in order to sustain it and engaging those

fantasies through the figural logics, the linguistic structures, that shape them" (2004, 6-7).

Edelman suggests that queer is what can challenge "futurisms unquestioned good" (2004,

7) and can challenge the idea that if there is no baby, there is no future, and without a

future, social organization, collective reality and life itself is undone (2004, 13). Edelman

asserts "that we do not intend a new politics, a better society, a brighter tomorrow" and

choose instead to "*not* choose the Child" and "insist that the future stop here," for the future

is "is mere repetition and just as lethal as the past" (2004, 31).

There are compelling reasons to follow Edelman when thinking through the forms

of neoliberal futurity open to disability. Consider, for example, if embracing the withering

no future of Paige Cunliffe opens possibilities that are not readily apparent when

advocating for a future, especially a future that is entrenched in neoliberal futurity of cure

and enhancement? Is there a way to read Paige as failure, dysfunction, loss, tragedy, or

suffering so as to avoid turning her into a form of difference that can be capacitated or

simply left to wither?

This is to say, there are good reasons to embrace suffering, especially if being

mindful of Anna Mollow's comments that some disabled people, such as "people with

chronic pain, rather than contending with maudlin displays of pity, must often labor to

convince others that they are genuinely suffering, not just 'looking for attention'" (2012,

303). Proving to be "legitimately" disabled, or proving that one experiences social

suffering, is an important political task. Within disability studies and disabled communities,

physical impairments that lead to the use of a wheelchair or other adaptive device are often

prioritized as embodying what disability *is*, as the hegemony of the ISA demonstrates (see

Chapter 2). Our cultural conceptualization of disability always already leaves out the

particularity of other's experiences. Suffering can be mobilized as a way to highlight that

which is not only left out of common conceptualizations of disability, but also to draw

attention to the ways in which not all forms of disability can be easily accommodated, or

slid into neoliberal forms of capacitation. Using suffering to draw attention to the forms of

withering that many disabled people experience can be a helpful political strategy, but must

be used with caution given the historical mobilization of suffering as a way to mark

disabled lives as those not worth living.

Aside from expanding our shared cultural notions of what marks legitimate

disability, embracing a politics of suffering can also challenge neoliberal futurity in its

emphasis on the individual. For example, positioning disability as suffering can highlight

the exact ways in which not all disabled people suffer equally, exposing the structural

forces at play in the capacitation and withering of disabled bodies. Some disabled people

are capacitated in ways that are counter-productive to radically refiguring the world

whereas some people are debilitated through violent processes that should not be

celebrated. Jasbir Puar's remarks about processes of capacity and debility remind us that

there is no one way to experience suffering, nor can we reduce or trivialize particular

instances of suffering. Although it is not possible to entirely escape the frame in which

disability-related suffering has been historically shaped and mobilized to render lives as not

worth living, shared social experiences of suffering can push us to think more critically

about the ways in which suffering is mobilized and for the benefit of whom.

However, as this chapter has shown, disability cannot operate in a full negation of

the figure of the Child, or unequivocally embrace "no future" because disability is always

already embedded in the production of the future as a future of technological and medical

advances, of a future to be found through the saving grace of biocapitalism. The future is accessible, happy, hopeful, and inclusive, even when it is not (see Chapter 2). Disability, through neoliberal processes of capacitation and withering, participates in the formation of the figure of the Child, and this is precisely an important site of contestation.

Commenting on Edelman and negating the future, the late Jose Esteban Muñoz writes in *Cruising Utopia: The Then and There of Queer Futurity* (2009): "…when I negotiate the ever-increasing sidewalk obstacles produced by oversized baby strollers on parade in the city in which I live, the sheer magnitude of the vehicles that flaunt the incredible mandate of reproduction as world-historical virtue, I could not be more hailed" (92) by the queer imperative to *not* fight for the children. But, Muñoz notes: "as strongly as I reject reproductive futurity, I nonetheless refuse to give up on concepts such as politics, hope, and a future that is not kid stuff," (2009, 92) for "all children are not the privileged white babies to whom contemporary society caters" (2009, 94). Muñoz furthers "Racialized kids, queer kids, are not the sovereign princes of futurity. Although Edelman does indicate that the future of the child as futurity is different from the future of actual children, his framing nonetheless accepts and reproduces this monolithic figure of the child that is indeed always already white" (2009, 95). In addition to McRuer's critique of the Child as always already able-bodied, other queer and disability studies scholars have echoed Munoz's critique. For Alison Kafer writes that "this always already whiteness is a whiteness framed by and understood through regimes of health and hygiene" whereby racialized and queer kids cast out of reproductive futurity "have been and continue to be framed as sick, as pathological, as contagious" marking the co-constitution of race, class,

and disability as delimiting reproductive futurity (2013, 32). This conclusion is also echoed by Chen (2011; 2012).

Kafer (2013) and Muñoz agree that "It is important not to hand over futurity to normative white reproductive futurity" (Muñoz 2009, 95), for "The dominant model of futurity is indeed 'winning,' but that is all the more reason to call on a utopian political imagination that will enable us to glimpse another time and place: a 'not-yet' where queer youths of colour actually get to grow up" (Muñoz 2009, 96). Indeed, Muñoz comments that "The way to deal with the asymmetries and violent frenzies that mark the present is not to forget the future. The here and now is simply not enough" (Muñoz 2009, 96), leading Kafer to suggest that the task at hand is to "imagine disability and disability futures otherwise" (2013, 34).

Following Muñoz (2009) and Kafer (2013), it is important to fight for the future, but to do so requires addressing the ways by which neoliberal futurity depends upon both negating the futures of disability while also promoting particular inclusions of disability. Thus, to underscore the epigraphs of this chapter, while the ableism that underlies the ways in which Kafer's (2013) future is written on her body and the ways in which disabled lives are not tractable, these accounts do not mark the ways in which neoliberal futurity promotes and capacitates certain disabled lives so as to affirm particular forms of biocapitalism and the circulation of good feelings that has implications for the way in which disability can become in the world. It is not enough then, to invest in the neoliberal forms of capacitated futures of disabled people, but rather it is imperative to turn away from the future that is currently being served to us in the form of neoliberal biocapitalism that strives to foreclose the possibility of other worlds.

Unlike Edelman (2004), I am interested in negating reproductive futurity not simply to negate the social order that relies on the Child, but rather to invest otherwise in social relations that complicate both this horizon and that of neoliberal biocapitalism that underlies our current interest in the future. What I want to suggest is that futurity is about the neoliberal imperative to manage risk, individualize access, and mobilize hope. The fight then, is not an anti-social turn away from the future entirely, but a negative turn away from the future that is currently forecloses the possibility of other worlds. It is a question of struggling for a better world, and demanding a better future, not for our individual selves, or for our children, but as an ethical jester of being of and within the world, whereby disability itself can only ever emerge within intracorporeal relations (see Chapter 6). Muñoz notes: "The act of accepting no future is dependent on renouncing politics and various principles of hope that are, by their very nature, relational" (2009, 94). If it is indeed within relations that disability emerges, then that is where the fight is to be had. In the next chapter, I explore this idea of disability being in and of the world and posit the important consequences re-imagining disability relationally has for both disabled people and others. Negating neoliberal reproductive futurity is thus not simply a question of "fucking the child," but, as I will outline in my next chapter, is to heterotopically and intracorporeally invest otherwise in social relations that complicate this horizon.

Chapter 6

Desiring Disability Differently: Neoliberalism, Heterotopic Imagination, and Intracorporeal Reconfigurations

More than 20 years have passed since the introduction, in 1990, of the ground-breaking Americans with Disabilities Act (ADA) in the United States and the introduction, in 1992, of the Disability Discrimination Act (DDA) in Australia. More than 15 years have passed since the introduction, in 1995, of the Disability Discrimination Act (DDA) in the UK. And yet, it "is still not fashionable to be disabled" (Goodley, Hughes, and Davis 2012, 1). Despite changing legislation, increasing levels of public accessibility, the push to productively employ disabled people, and even the inclusion of disabled people on fashion runways (Spencer 2014; Winter 2014), something about disability remains unfashionably undesirable. I maintain that this undesirability of disability stems from what disability theorist Alison Kafer calls "an ableist failure of imagination" (2013, 4). This ableist failure of imagination exposes how it is the case that disabled people are increasingly included and integrated into western neoliberal economies and social life and, yet, disability simultaneously remains a deeply and profoundly undesirable category of being. The best evidence of the undesirability of disability is the prevalence of the public sentiment that the majority of people would rather die than be disabled (Young 1997; Silvers 1995; Clifford 2012; Bednarska 2009), or would not want to have a disabled child (Rapp 2000; Ford 2002; Karlberg 2011, 2010). Although some disabled people both have and produce value within neoliberal economies, and despite the fact that many people enthusiastically support the rights of disabled people to access education, work, and have meaningful social lives, disability remains stubbornly undesirable. Indeed, even many disabled people would agree with

Kafer who cautiously comments that she does not wish to become "more disabled" than she already is (2013, 4).

Challenging the undesirability of disability is a shared responsibility and goes beyond the inclusion of disabled people within the exploitative and individualized relations of neoliberal capitalism. That is, challenging the undesirability of disability requires more than individualized access to education, employment, or vibrant social lives. Challenging the undesirability of disability requires that disability be imagined differently, that is, imagined in ways that ensure that disability can be collectively practiced and experienced differently. In order to imagine disability differently, it is imperative to understand how the neoliberal hegemonic social imagination both works to curtail who is considered desirable and informs the production of a good, individualized neoliberal subject that limits disabled and able-bodied people alike. Neoliberal policies and practices individualize both able-bodied and disabled bodies through forms of debility and capacity (Puar 2011) and through the economization of social relations and life itself (Murphy 2013) such that being critical of these forms of social, economic, and political relations is not enough to extricate ourselves from our role in maintaining and reproducing these relations. In order to desire disability differently, we must begin with marginal, heterotopic imaginations whereby disability is practiced as not something to overcome or merely tolerate, but rather as a part of a life worth living. Building on Michel Foucault's concept of heterotopia (1998), a concept that marks "outside places" by their discontinuity and multiplicity, and drawing on the work of Mel Chen (2012) and Rod Michalko (1999), I argue that the heterotopic imagination reconfigures how disability emerges, with whom it emerges, and where. When disability is viewed through the lens of the heterotopic imagination, it becomes an intracorporeal, non-anthropocentric, multiplicity that exceeds the individualized human body inscribed by

neoliberal biocapitalism. To elaborate on disability as this emergent multiplicity, I read Chen's and Michalko's work alongside Thomas Lemke's (2015) work on Foucault's concepts of the milieu and government of things, as well as the agential realism of feminist materialist Karen Barad (2007; 2008). Desiring disability differently does not merely allow the current formulation of disability to become desirable. On the contrary, desiring disability differently through the heterotopic imagination *radically alters* what disability is, how it is practiced, and what it can be.

The Hegemonic Social Imagination

As a field of study, disability studies has thoroughly charted the contemporary history of disability in western societies, marking the ways in which disabled people have been significantly excluded from social and political communities (for example, Campbell 2009; Davis 1995; Gleeson 1999; Nielsen 2012). Despite the fact that disabled people are increasingly integrated into the neoliberal labour force (CBC 2014b; see Chapter 3) and have become an emerging and lucrative consumer population, the contemporary neoliberal hegemonic social imaginary remains firm in its ableist assessment that disability is not a desirable form of being. Although the difference of disability can be, and in some contexts is, celebrated in terms of "disability pride," it is commonly assumed that disabled people would rather be able-bodied (McRuer 2006, 9) or would be "better off dead" (Hayward 2009), or never born at all (Rapp 2000; Ford 2002; Karlberg 2011, 2010).

The contemporary neoliberal hegemonic social imagination privileges and compels able-bodiedness above any form of disability to the extent "the value of a disability-free future is seen as self-evident" (Kafer 2013, 3). The value of a disability-free future is taken as self-evident due to the force by which disability has been linked to a life of "suffering," "unhappiness," "dependency," "poverty," "disadvantage," and "incapacitation." Insofar as many disabled bodies

fail to meet standards of independence, rationality, autonomy, or are not adequately productive, many disabled people thus fail to meet perceived standards of what it is to be a worthy subject, a failure that denigrates disabled lives. Although many states have made tremendous strides towards formal integration of people with disabilities, disabled people continue to be excluded from full social participation because disability remains stubbornly outside of what is considered a life worth living. Kafer's "ableist failure of imagination" or what I call "the neoliberal hegemonic social imagination" cannot fathom a future that includes embracing the *desire* for disability. Note that the neoliberal hegemonic social imagination does not refer to a faculty of the human mind that pre-exists any given subject, but rather is a process of signs, discourses, material relations, and feelings that are simultaneously constituted by, and constitutive of, subjectivity. Thus, the neoliberal hegemonic social imagination does not merely exist in the mind of any given subject, even as it shapes how people understand themselves and others, impacts expectations, goings-on, and norms of relating, including the capacity to mark a life as one worth living.

In *The Body Problematic*, Laura Hengehold (2007) argues that it is our imagination that unifies and stabilizes our otherwise fractured and discontinuous embodied experiences. To make this argument, Hengehold begins with Kant's notion of imagination and how, for Kant, imagination is constitutive of a body. In the *Critique of Pure Reason*, Kant (1998, B93) names the transcendental imagination as a faculty that actively forms a concept for every intuition, and creates the unity of "different representations under a common one." In Kant's theoretical framework, the faculty of reason requires that our apprehensions of particular experiences ultimately form a whole, even though we are never able to experience the whole as such because our level of analysis or description limits any knowledge that we may have and, thus, prevents us

from knowing a thing-in-itself (Hengehold 2007, 14). For Kant, because we cannot know reality

in its totality nor can we know things-in-themselves, we use the imagination to stabilize and

transform discontinuities into a seamless whole. This is true of bodies as much as of the world.

In other words, in order for the world and our reality to make sense as a whole, some details

must always be left to the imagination (Hengehold 2007, 14).

People are not unrestrained in how they fill in the gaps of this fragmented and uncertain

reality; that is, they cannot fill in the gaps with whatever imagined unity that they choose.

Rather, relations of power delimit and determine what constitutes wholeness in order to give

value to the fragments of the world that people experience. Currently, the neoliberal hegemonic

social imagination is mobilized through institutional practices, symbols, discourses and

representations that work to stabilize and unify the neoliberal subject. Foucault's genealogical

histories map the ways in which modern forms of administration, knowledge production, and

power take "advantage of the very fact that we have no access to our bodies as 'things-in-

themselves' in order to tell us what those bodies *really are* and what they *really need* or *really

can do*" (Hengehold 2007, 117). For instance, power works on bodies so as to produce and

naturalize a self-governing subject who subscribes to neoliberal individualism and

economization and ableist configurations of disability.

When disability is taken as a simplified, biological, and undesirable "monolithic fact of

the body" (Kafer 2013, 3), what disability *really is* and *really can do* is delimited by the very

historical configurations of knowledge/power that depoliticize how disability came to be

naturalized as such in the first place. Kafer argues that disability is overwhelmingly

"depoliticized, presented as a fact of life requiring determination and courage, not as a system of

marking some bodies, ways of thinking, and patterns of movement as deviant and unworthy"

(2013, 89). As Robert McRuer has argued (2006, 18), although it is true that disabled people do not embody *absolute* deviance, they nevertheless remain subordinated within a system of compulsory able-bodiedness. As a result of this subordination, the normative able-body masquerades as a neutral nonidentity: the autonomous, rational subject that can smoothly move *his* body in accordance with what is considered acceptable and appropriate within the social sphere (McRuer 2006, 1). Such ability signifies a body that deserves recognition and is enabled to participate in social life. Disability, in contrast to this normative, neutral, nonidentity, is given meaning through the neoliberal hegemonic social imagination that defines disabled people as unworthy, inadequate, and dependent, while naturalizing disability as excessive, contaminated, helpless, pitiable, deviant, tragic, and inferior.

In general, people avoid disability. When disability is thought about at all, however, questions of desirability quickly arise. Most quality-of-life measures assume that disability is ontologically problematic (Goering 2008) and are deeply embedded in neoliberal processes of individualization and the economization of life (Murphy 2013). In medical literature and practices, disability is associated with flaw and deficit and is hierarchically distinguished from the norm. Indeed, questions of selective abortion, pre-natal screening, euthanasia and physician-assisted suicide cannot be untangled from normative sentiments according to which a disabled life is not a life worth living (Tremain 2008; Hubbard 2013; Saxton 2013; Berube 2013).

In a shift away from medicalization and configurations of knowledge/power that depoliticize disability, and in order to claim a political presence, disabled subjects have asserted themselves as having viable, worthy, and intelligible bodies, as bodies that matter, and as lives worth living. The success of such assertions has led to the emergence of the disability rights movement, disability pride, and the development of a positive minority identity, uniting persons

with various impairments in the common experience of able-bodied oppression. Such able-bodied oppression has been articulated through a conceptual distinction made between disability and impairment, positioning disability as a social disadvantage that is imposed on top of a neutral physiological impairment. The problem is thus located in the interaction between bodies and the social and material environments in which they are situated. People are made to be disabled by external barriers, like stairs, lack of accessible, affordable housing, inaccessible work environments, transportation systems, or social services.

The disability rights movement has done a great deal to politicize the ableism that disabled people experience; in doing so, however, the disability rights movement tends to replace the heterogeneous world of impairment with a homogenized (and homogenizing) disability identity. As Rosemarie Garland Thomson (1997, 24) puts it, social and political circumstances have forged disabled people as a "highly marked, heterogeneous group whose only commonality is being considered abnormal." Similarly, Simi Linton (1998, 4) comments:

> We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on our breathing tubes, following our guide dogs, puffing and sipping on the mouth sticks that propel our motorized chairs. We may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system. We are all bound together, not by this list of our collective symptoms but by the social and political circumstances that have forged us as a group.

The focus on an exterior environment as the site for the production of disability threatens to depoliticize the difference of impairment and bodily aspects of disability, as well as homogenize the diverse differences within disabled communities. In other words, when disability is construed as something externally contributed to bodies, biological impairment threatens to be naturalized as an already existing interior identity upon which culture and other factors external to the subject act.

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Regardless of how politically useful the distinction between impairment and disability has been to assertions of rights and demands for access to work, transportation, and community life, this strategy of political sameness is caught up in the neoliberal hegemonic social imagination that organizes bodies to make them productive within a neoliberal economy; that is, the disabled body of the disability rights movement is rendered intelligible and valued as a body that matters in order to claim its status as a body that can work and produce. Both the US ADA and the UK DDA promote disabled people as potentially productive workers, framing such promotion of disabled people as an act of social justice (Taylor 2004). To be regarded as a productive worker does not, of course, create a secure position for the disabled subject within neoliberalism; it does, however, make disabled people available to the labour market, that is, available to the *precariousness* of the labour market. Within the logic of neoliberalism, disabled subjects, insofar as they remain juxtaposed to the rational, independent, individualized and economized neoliberal subject, teeter between these circumstances: forced to live or left to die. That is, either disabled subjects become productive subjects and thus are valued as lives worth living or they risk exclusion altogether. Mapping out the power relations of the neoliberal hegemonic social imagination moves away from the construal of disability as a problem of exclusion to interrogate how worthiness itself is produced both economically and socially, interrogations that aim to highlight the dangers that are interwoven with potential gains for disabled people who become productive subjects. In order to move away from this neoliberal approach that makes disability intelligible by capacitating some disabled bodies to make them economically and socially productive and, in addition, to disrupt these particular social renderings of disability as excessive, contaminated, helpless, deviant, tragic, and inferior, we

must take up the political aspect of impairment; the production of the physiological and material reality of impairment is part of the social production of disability.

Shelley Tremain (2002) has innovatively drawn on Foucault's mechanisms of disciplinary power/ knowledge (1977) and Judith Butler's performativity of embodiment (1993) in order to argue that, like sex and gender, the materiality of the impaired body cannot be dissociated from the practices that bring it into being. Impairment cannot be a value-neutral fact of the body or merely a biological description because it is always already saturated in medical, legal, social, and cultural constructions of disability. Both impairment and disability are effects of historical conditions, contingent on relations of power/knowledge. Tremain notes that to link impairment to disability in this way does not amount to a denial of important material or biological differences between bodies, but rather points to the ways in which "these differences are always already signified and formed by discursive and institutional practices" (2001, 627). In short, Tremain's argument is that the impaired disabled body appears through historically-specific practices that naturalize impairment as an already existing interior biological identity upon which culture acts.

The turn toward the ways in which power/knowledge has naturalized impairment is not a turn away from the social production of disability. Biomedical practices have been complicit in the emergence of the category of impairment, which, in turn, has informed the production of disability. Through impairment as a power/knowledge relation, disability becomes about both barriers to *doing* as well as barriers to *being*. In this vein, Eli Clare writes: "in defining the external, collective, material nature of social injustice as separate from the body, we have sometimes ended up sidelining the profound relationships that connect our bodies with who we are and how we experience oppression" (2001, 359). Bodies matter because we live in them and

because the disciplinary power/knowledge relations that constitute the self—both as impaired and as disabled—are embodied. Thus, as Tremain remarks, "When we recognize that matter is an *effect* of historical conditions and contingent relations of power… we can begin to identify and resist the ones that have material-*ized* it" (2002, 35).

Barriers to *doing* require changes to the built environment, access to resources, funding and supports such as a guaranteed living wage and affordable, accessible housing. In addition, *doing* requires dismantling barriers to *being*, that is, barriers that end up foreclosing and delimiting what is considered a life worth living. Thus, in order to remove barriers to *being* and *doing*, we must transform the neoliberal hegemonic social imagination and dismantle the investment in neoliberal subjectivities that sustains it. Inasmuch as we imagine disability through both medicalization and neoliberalism as an individualized problem, we fail to engage disability as an emergent intracorporeal multiplicity. In order to build on Tremain's insights, and in an effort to set out a position that grounds disability as an emergent intracorporeal multiplicity and thus diverges from the neoliberal hegemonic social imagination of disability, I shall now turn to the work of Lemke (2015), Foucault (1978; 2007) and Barad (2007; 2008). Taking up disability as an intracorporeal multiplicity in this way opens up space for the heterotopic imagination of desiring disability differently.

Intracorporeality, Agential Realism, and the Milieu of a Government of Things

The notion of intracorporeality, a notion which builds upon both Stacy Alaimo's concept of trans-corporeality (2010) and Gail Weiss's concept of intercorporeality (1999), posits that bodies are formed *within a relation*, rather than formed "across" or "between" already-formed bodies. To perceive how bodies emerge within a relation is to emphasize that any given body only ever emerges from, and is constituted by and within, always already entangled relations.

Such an intracorporeal emergence suggests that any enactment of a body is ontologically and epistemologically saturated, never stable, or final.

Barad introduces the neologism of intra-action to signify "*the mutual constitution of entangled agencies*" (Barad 2007, 33). In contrast to the notion of interaction, whereby separate entities precede their coming together, the "notion of intra-action," Barad explains, "recognizes that distinct agencies do not proceed, but rather emerge through, their intra-action" (2007, 33). Such "distinct agencies" are distinct only in their mutual entanglement and do not otherwise exist as individual elements (2007, 33). Thus, the "agency" of matter in general or of any given thing in particular is not an attribute or property of matter or of the given thing, but rather an ongoing reconfiguration of the world (2007, 141). As such, matter is a dynamic and shifting entanglement of relations that in each specific enactment reconfigures the world. Matter is not simply a passive property of things (2007, 35).

Following Barad, and building on Tremain's denaturalization of impairment, I want to argue that disability is not a property of a thing and does not biologically inhere in one body. In other words, the "essence" of disability is neither a genetic mutation nor a wheelchair blocked by a flight of stairs; rather, disability emerges as an historically-specific onto-epistemological materialization of intra-active matter. Onto-epistemology highlights knowing as a material practice of engagement that is of the world in its differential becoming (Barad 2007, 89). Epistemology and ontology, like impairment and disability, cannot be separated because practices of knowing are material in ways that are saturated in power relations that constitute how a subject or object emerges, though they do not fully determine its emergence. In this way, impairment/disability is not a biological or social identity that inheres within a body, but rather is a material practice. This understanding of disability *as a practice* builds upon Foucault and

Butler insofar as it moves away from linguistic representationalism towards the "constitutive aspects of discursive practices in their materiality" (Barad 2007, 57). As Barad states, "Neither discursive practices nor material phenomena are ontologically or epistemologically prior. Neither can be explained in terms of the other. Neither is articulated or articulable in the absence of the other; matter and meaning are mutually articulated" (2007, 152).

Barad is clearly indebted to both Foucault and Butler: as a posthumanist, however, Barad explicitly departs from their anthropocentrism by emphasizing the import of both the agency of matter to continually reconfigure the world and the role of the nonhuman in shaping practices, such as the practices of disability. In addition, Barad contends that Foucault is unclear about "the material nature of discursive practices" (63) and fails to account for how "materiality plays an *active* role in the workings of power" (65). For Barad, what is important is for the materialization of a body to actively include nonhuman forces to the processes of materialization (2007, 65).

Barad's contentions with Foucault have been taken up by Thomas Lemke (2015), who argues that the concepts of milieu and the government of things, concepts that Foucault introduced in his 1978 lecture series at the Collège de France, leave open a way to go beyond his anthropocentric limitations by accounting for the relational entanglement of "men and things, the natural and the artificial, the physical and the moral" (4). While it is true that Foucault's analyses of power/knowledge focused primarily on the human sciences and what Barad calls "the social," Lemke argues that a posthumanist approach is "implicit but not developed in Foucault's work" (2015, 8). In these lectures, Foucault's "interpretation of the art of government does not conceive of interactions between two stable and fixed entities – 'humans' and 'things.' Rather, Foucault employs a relational approach" (Lemke 2015, 9) that deals with a "complex of men and things" including resources, means of subsistence, climate, customs, habits, and ways of acting (Foucault

2007, 96). The relational emphasis that Lemke finds in Foucault is further substantiated by the concept of the milieu that, according to Foucault, "is needed to account for action at a distance of one body on another…" (2007, 20-21). Foucault remarks:

> The milieu is a set of natural givens – rivers, marshes, hills – and a set of artificial givens – an agglomeration of individuals, of houses, etcetera. The milieu is a certain number of combined, overall effects bearing on all who live in it. It is an element in which a circular link is produced between effects and causes, since an effect from one point of view will be a cause from another. (21)

The milieu marks the way in which individuals "only exist biologically bound to the materiality within which they live" (Foucault 2007, 21). Lemke concludes that "Foucault quite clearly accepts the idea that agency is not exclusively a property of humans; rather agential power originates in relations between human and non-human entities" (2015, 10). If the concepts of the milieu and the government of things imply an implicit posthumanism in Foucault's work, they nonetheless remain unfortunately underdeveloped.

Barad's "agential realism," which works to explicitly develop a posthumanist performativity, focuses on humans *of* the world, rather than *in* the world. That is, human thought, knowledge, practices, embodiments and subjectivities are not just in relation to the world outside of humans, but rather emerge through and as part of their entangled intra-relating. Barad's focus on being *of* the world, rather than being "in" the world, points to the ways in which nonhumans play a role in (what she terms) "naturalcultural practices" (2007, 32) and how matter itself has agency and intra-acts with the human. Barad writes that humans are not "simply located in particular places *in* the world; rather, we are part *of* the world in its ongoing intra-activity" (2008, 146). In other words, human "existence is not an individual affair" (Barad 2007, ix); on the contrary, it is only through entangled intra-relating that individuals emerge at all (2007, ix). In short, *"agencies are only distinct in relation to their mutual entanglement; they don't exist as*

individual elements" (Barad 2007, 33; emphasis in Barad). In this way, bodies are not simply in the world, but rather are engaged in a reconfiguration of what exists by intra-actively co-constituting the world. The dynamism of matter – human and nonhuman – brings forth new worlds (Barad 2007, 170).

When we conceive disability as an intracorporeal practice, we recognize that it is the onto-epistemological emergence of the world, rather than any one thing (see Chapter 1). As such, it is an emergence based on particular discursive-material practices that are informed by ever-shifting framings of what it is to have a body and what that body can do. The neoliberal hegemonic constitution of disabled bodies as lives not worth living would be one such specific discursive-material practice of the disabled body. The way in which neoliberalism makes disabled bodies worthy through production and consumption would be another discursive-material practice of the disabled body. If the neoliberal hegemonic social imagination limits what it is to have a body and what that body can do, then the heterotopic imagination must work to open space for desiring disability differently, so as to be able to collectively practice and experience disability differently.

Taking account of the intracorporeality of embodiment (disabled or not) requires both a social imagination and an ethic that works counter to contemporary logics of what constitutes a worthy subject. Thus, heterotopic imagination becomes an important tool with which to open up space to desire disability differently, as well as to be accountable to the nonhuman upon which any emergence depends.

The Heterotopic Imagination

For Foucault, any possible world involves a multiplicity of spaces. For Foucault, furthermore, a multiplicity of spaces involves what he (1998, 178) calls heterotopias:

> [R]eal places, actual places, places that are designed into the very institution of society, which are sorts of actually realized utopias in which the real emplacements, all the other real emplacements that can be found within the culture are, at the same time, represented, contested, and reversed, sorts of places that are outside all places, although they are actually localizable.

Foucault offers an example to illustrate his notion of heterotopias. A mirror is a heterotopia, he explains, insofar as a mirror "makes this place I occupy at the moment I look at myself in the glass both utterly real, connected with the entire space surrounding it, and utterly unreal – since, to be perceived, it is obliged to go by way of that virtual point which is over there" (1998, 179).

In a move that suggests a shift in his work toward biopolitics, governmentality, and the management of the life of populations, Foucault outlines two types of heterotopias: crisis heterotopias and heterotopias of deviation.[15] Regardless of type, however, what is key for Foucault is that each heterotopia "has the ability to juxtapose in a single real place several emplacements that are incompatible in themselves" (1998, 181). He notes, furthermore, that "heterotopias are connected with temporal discontinuities" (1998, 182) and "always presuppose a system of opening and closing that isolates them and makes them penetrable at the same time" (1998, 183). Thus, heterotopias are marked by incompatibility, discontinuity, and difference.

Heterotopic imagination, then, emphasizes incompatibility, discontinuities, temporal differences, and offers a space that is both open and closed. Foucault suggests that struggles over subjectification should not attempt to form an overarching imaginary for themselves (1997b, 316). Hengehold (2007, 219), drawing on Foucault's *History of Sexuality, Vol. 1* (1978),

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[15] Each heterotopia "has a precise and specific operation within the society" (Foucault 1998, 180). Crisis heterotopias are privileged, sacred, or forbidden places reserved for "individuals who are in a state of crisis with respect to society and the human milieu in which they live" (179). Of crisis heterotopias, he gives examples of adolescents, menstruating women, women giving birth, and elderly people. For Foucault, crisis heterotopias are being replaced by heterotopias of deviation, which are spaces "in which individuals are put whose behavior is deviant with respect to the mean or the required norm" (180). Hospitals and prisons serve as examples of heterotopias of deviation.

comments that "this approach is exemplified by his reluctance to treat sexuality as a source for identity or a general object of liberation, affirming, instead, the plurality of 'bodies and pleasures.'" The lesson to draw from Foucault's reluctance is that disability itself should not be marked as a liberatory subjectivity, but rather should ignite the heterotopic imagination as a vehicle of multiplicity, where desiring disability differently is to attest to the incompatible, discontinuous, and temporal difference of disability as a way to approach the intracorporeality of embodiment and a relational ethic that accounts for the nonhuman, rather than doing so in the name of new economic markets.

The heterotopic imagination that opens up disability as a multiplicity changes "the range of actions people believe are possible in a given historical situation," and the ability of people "to envision a way of life or quality of life" (Hengehold 2007, 282-283). Heterotopic imagination provides the space to ask "In what is given to us as universal, necessary, obligatory, what place is occupied by whatever is singular, contingent, and the product of arbitrary constraints?" (Foucault 1997b, 315). It is impossible to know what a singular, contingent body can do until it becomes clear what bodies it can combine with, and what the constraints of those combinations are.[16]

I want to offer two examples to elaborate how the heterotopic imagination works to desire disability differently and elide the hegemonic social imaginary that neoliberalism sustains. The first is drawn from Mel Chen's (2012) temporally altered couch experiences and the second is drawn from Rod Michalko's (1999) experiences with his guide dog. In both cases, disability is desired differently through the heterotopic imagination by reconfiguring how we consider disability to emerge, with whom it emerges, and where.

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[16] This is true of all bodies, disabled or not: the future is unknowable and it is important to unsettle imaginaries at the centre and the margins.

In *Animacies: Biopolitics, Racial Mattering, and Queer Affect*, Mel Chen (2012) engages

with Chen's own mercury toxicity, an involuntary intoxication that "may not register its own

pleasure or negativity in recognizable terms" (198). For Chen, toxicity is "a *condition*, one that is

too complex to imagine as a property of one or another individual or group or something that

could itself be so easily bounded" (2012, 196; emphasis in Chen). Chen's toxicity emerges

through onto-epistemological intra-action. Such an emergence cannot be separated from Chen's

own situatedness as an ambiguously-gendered Asian person, who, through toxicity, turns

increasingly away from human sociality and toward the comfort of inanimate things:

> Given my condition, I must constantly renegotiate, and recalibrate, my embodied
> experiences of intimacy, altered affect, and the porousness of the body. The nature of
> metal poisoning, accumulated over decades, is that any and every organ, including my
> brain, can bear damage. Because symptoms can reflect the toxicity of any organ, they
> form a laundry list that includes cognition, proprioception, emotion, agitation, muscle
> strength, tunnel perception, joint pain, and nocturnality. (2012, 201)

Chen narrates how a "day of relative well-being" leads to an exploration of Chen's new

neighborhood and ends with Chen lying on a couch, unable to rise. Chen, who takes readers

through this day, connects the ways in which movement, racism, chemicals, affects, and a couch

all intra-act in the emergence of Chen's disability. Upon setting out in Chen's new

neighborhood, Chen remarks:

> I have forgotten for the moment that I just don't go places 'on foot' because the results
> can be catastrophic… It is for a moment free—in its scriptless version of its future—to
> return to former ways of inhabiting space when I was in better health. Some passenger
> cars whiz by; instinctively my body retracts and my corporeal-sensory vocabulary starts
> to kick back in. A few pedestrians cross my path, and before they near, I quickly assess
> whether they are likely (or might be the 'kind of people') to wear perfumes or colognes
> or to be wearing sunscreen. (2012, 198)

As the pedestrians pass, Chen longs for a chemical respirator that Chen can wear "with love" and "effect a smile" from behind, even if the Chen-mask is read by others as "a walking symbol of a contagious disease like SARS" (2012, 200). Chen remarks:

> When I used to walk maskless with unsuspecting acquaintances, they had no idea that I was privately enacting my own bodily concert of breath-holding speech, and movement; that while concentrating on the topic of conversation, I was also highly alert to our environment and still affecting full involvement by limiting movements of my head while I scanned. (2012, 199)

Chen notes that in some of these interactions, Chen would run out of breath and be compelled to "scoot ahead" in order to avoid particular hazards, quickly explaining, "I can't do the smoke" (2012, 199). Of this, Chen remarks: "the grammatical responsibility is clear here: the apologetic emphasis is always on I-statements… Yet," Chen observes, "the individuated property assignation of 'I am highly sensitive' furthers the fiction of my dependence as against others' independence. The question then becomes which bodies can bear the fiction of independence and of uninterruptability" (2012, 199).

A body that must "follow the moment-to-moment changes in quality of air" cannot bear the fiction of uninterruptability, and will never "walk in a straight line" (2012, 202). As such, Chen's body could be read by way of the hegemonic social imaginary that tries to unify and solidify the meaning of a masked ambiguously-embodied Asian person; however, Chen turns towards heterotopic imaginations of the body of the world in which "humans are to a radical degree no longer the primary cursors of my physical inhabitation of space. Inanimate things take on a greater, holistic importance" (2012, 202). The import of inanimate things is made clear as Chen lies on the couch. Chen's lover comes home and greets Chen, who offers only a grunt in return. Of Chen's lover, Chen remarks:

> She comes near to offer comfort, putting her hand on my arm, and I flinch away; I can't look at her and hardly speak to her; I can't recall words when I do. She tolerates this

because she understands very deeply how I am toxic. What is this relating? Distance in the home becomes the condition of these humans living together in this moment, humans who are geared not toward continuity or productivity or reproductivity but to stasis, to waiting, until it passes. (2012, 202)

In such a toxic period, Chen comments on how "anyone or anything" that Chen connects with are all "the same ontological thing" (2012, 202). Chen is shocked when the body of Chen's lover does not acknowledge that Chen snuggled against her earlier that day. Chen realizes later, however, that the "snuggling and comforting happened in the arms and back of my couch" (2012, 202). This startles Chen who questions: "What body am I now in the arms of? Have I performed the inexcusable: Have I treated my girlfriend like my couch? Or have I treated my couch like her, which fares only slightly better in the moral equations?" (2012, 202). Or, Chen further wonders, "have I done neither thing?" (2012, 203). Upon feeling better, Chen finds the conflation unbelievable; nevertheless, it is only because Chen has regained a "human-directed sociality" that the couch is an unacceptable partner (2012, 203). Before Chen becomes centered back on the human moment, Chen and the couch are, as Chen says, "interabsorbent, interporous, and not only because the couch is made of mammalian skin" (2012, 203). And further: "The sentience of the couch, in our meeting and communing, becomes my own sentience as well" (2012, 204).

Within toxicity, masks, and couches, desiring disability differently emerges. Chen's disability is a practice, not a stable unified identity, a practice that involves the mingling of chemicals, a mask, a couch, and change in time. Toxicity emerges in intra-action and is intracorporeal. To read Chen by way of the heterotopic imagination that emphasizes discontinuities and temporal differences is to see how toxicity emerges with Chen on the couch and behind the mask. The heterotopic imagination does not unify or stabilize this toxicity, which becomes readable as both open and closed, as differently desirable.

While Chen snuggles in the arms of the mammalian-skinned couch and is shaken from an anthropocentric centering, disability emerges in the relation, a relation that is at once comforting and unacceptable. To be shaken from "human-directed sociality" requires a change in imagination and an opening to the discontinuities of what is acceptable. To experience disability as *of* the world, as an emerging multiplicity, rather than just *in* the world as a stabilized individualized object, is a space of heterotopia.

The thrust of this heterotopic reading of Chen's situation does not aim to valorize any sufferings that may be associated with disability in general or with Chen's toxicity in particular. Heterotopically imagining disability does not valorize suffering, but rather takes sufferings seriously by not stabilizing disability as a fact of an individualized body, by not imagining a type of suffering that can be embraced by a neoliberal market logic, and by not imagining a suffering that is over-determined by the hegemonic social view of a life not worth living. To point to the heterotopic space that an intracorporeal, relational emergence of disability opens, is to value what is *of* the world, and acknowledge the ways in which hegemonic social imagination imposes sameness upon difference, as well as the ways that neoliberalism seeks to pull profit from suffering.

Creating a world where particular forms of suffering can be alleviated requires a shift away from the social hegemonic imagination and embrace of the heterotopic. A heterotopic imagination opens the space where multiple futures are possible. Such a shift changes how suffering can even be considered, opening space for non-anthropocentric sufferings that are interwoven with disability. Thus, the point is to acknowledge and work to alleviate sufferings while opening space in which to desire disability, a space where it is easier to effect a smile behind a mask, where comfort can be found in the arms of a couch without alarm, and where

toxicity is found in relation, rather than attributed to an individual. As an intracorporeal

emergence, toxicity becomes a responsibility of the many, not one, and the agencies involved are

multiple.

My second example of a heterotopic opening that highlights the intracorporeal emergence

of disability is the relation between Rod Michalko and his guide dog Smokie. "Alone together,"

Michalko (1999) and Smokie form intracoproreally as disability becomes multiple, partial, and

transitory. Michalko, in discussing his relationship with Smokie, remarks that Smokie "gave me

a sense that blindness meant something more than the inability to see" (ix). With Smokie,

Michalko experiences blindness as an occasion to "make a place in the world" (xi), a place that

emerges within the relationship of Smokie and Michalko and extends out, implicitly imparting "a

conception of the world" (6). That is:

> A blind person needs a guide who will not merely move her through the world but also
> *bring* that world *to* her and *take* her *to* it. Guides bring blindness and sightedness together
> in a world which is neither 'blind' nor 'sighted' but within which they both appear and
> live. (1999, 32)

When Michalko visits a Canadian guide dog school to inquire about attaining his first

guide dog, he is introduced to a Labrador Retriever named Leo. Michalko, in learning how to

hold a harness, comments that he experiences "a sense of *distance*, an *expansion* of my

immediate environment. It seemed as though my 'sense of touch' was enhanced by Leo and his

harness. I could 'feel' further than I ever had before. Harness and Leo in hand, I felt my tactile

sense replacing my sense of sight" (1999, 25-26).

With Leo, Michalko is *taken* to the world and has the world *brought* to himself (1999,

32). Blindness and sightedness do not exist in two individual bodies—that is, blindness in

Michalko and sightedness in Leo—but rather both emerge within them together and are of the

world together. Furthermore, both Michalko's and Leo's sensual experience is re-arranged,

expressing a different tactual intra-action. It is not that Michalko is able to walk forward *as if he had eyes* while in contact with Leo. Rather, a different sort of sightedness and a different sort of blindness emerge within the two.

Shortly after Michalko's experience with Leo, he is partnered with Smokie who becomes his guide for many years. Michalko remarks: "Whatever Smokie and I do, whatever kind of life we experience together and whatever else we mean to each other, we are 'person and dog' sharing a life together. We are 'human and animal' living in the world and moving through it together." (1999, 9). The relation of Michalko and Smokie blurs the borders of the autonomous human self that feels and acts. There is an alone togetherness that has its own affect, experience, movement and speed. Michalko and Smokie compose a body-together that is defined by zones of intensity and proximity, a body in which it is unclear exactly where Michalko's "own" physical body ends and Smokie's "own" physical body begins as they create their intracorporeal emergence. When Smokie and Rod come together in an intracorporeal emergence, disability is a property of neither human nor animal. Disability is of the world in this emergence. Michalko remarks: "Smokie and I walk alone together 'in blindness.' Whether Smokie knows that I am blind in the way that I or other people know it, I cannot say. But he does know" (1999, 104). In Smokie's knowledge of blindness, Michalko and Smokie "live *in* this differentiation," they are, as Michalko puts it, "together in our movement as one" (1999, 183; emphasis in Michalko). They mark the shifting boundary of an affective and dynamic relationship that goes beyond any sentimental discourse about dogs' devotion and unconditional loyalty to their masters, displacing the primacy of the visual. As Barbara Noske (1989) notes:

> Not many people have seriously tried to imagine what it must be like to perceive and conceive the world in terms of 'olfactory images' (such as dogs must do) or 'tactile images' (as horses do to a large extent), or 'acoustic pictures' (as dolphins and whales

must do)… We humans are heavily biased towards the visual… But for a dog scenting is believing. (58)

To imagine Rod and Smokie heterotopically, is to take their intracorporeal emergence together as a mark of different sensorial and perceptive capacities that alter what a body can do. The neoliberal hegemonic social imagination reduces the relationship between Michalko and Smokie to the normative explanation according to which Michalko has a vision deficit that is then compensated by Smokie's sight. In normative terms, guide dogs are prosthetic devices that compensate for a loss or lack. Often portrayed as "heroic," the guide dog restores autonomy to the human partner so that they can work, shop, and socialize. In contrast, through a heterotopic imagining, Smokie and Michalko intra-act, composing a movement that is within each of them, but belongs to neither of them. One does not become the other, but rather intra-acts within the two.

The social hegemonic imaginary posits a conception of blindness that understands it is an undesirable state of being, an understanding according to which "blindness is an uninhabitable home" (1999, 102). Michalko remarks that this conception "is how I understood my blindness before I had Smokie – as a condition that I had to overcome – and I believed that Smokie would help me do so" (1999, 102). However, Michalko's experience of blindness in intra-action with Smokie alters the *being* and *doing* of blindness. Michalko remarks: "Blindness is an occasion to *make* the visual present through means other than sight. The senses of touch, smell, and hearing can bring one into touch with the never-ending movement of the visual" (1999, 123). Such a remaking of blindness is a moment of heterotopic imagination.

Alone together, Michalko and Smokie navigate their city. "Our aloneness begins with our need to concentrate. Smokie needs to attend to an endless stream of stimuli – vehicular and pedestrian traffic, curbs, obstacles of various kinds on the street, the location of buildings,

direction, and so on" (1999, 104), while Michalko concentrates on Smokie's every move. "Like him, I am concentrating on a vast array of stimuli I attend to sounds, smells, and changes in air flow that often indicate that we have moved past a building and toward an intersection. Alone together, we concentrate" (1999, 104). In this concentration, Michalko finds that "*My* self is now *our* self. Smokie's self too is *our* self. We are 'at home together,' which means that we are continuously making a home for our self" (1999, 91; emphasis in Michalko). Michalko explains the construction of an "our self" with Smokie in this way: "Smokie and I are not merely side by side. We move together as one, touching and imaging both each other and our world… We depict a world to each other generated by our difference and sameness. We communicate this world to one another through the ineffability of the togetherness" (1999, 185). As Michalko's world emerges as a relation within himself and Smokie, the spaces that Michalko had previously inhabited are altered. Michalko notes: "I became familiar with each and every corner of the bars and cafés in my neighbourhood, and Smokie showed me the tables in these establishments that held the most space for him to lie down besides me" (1999, 94). The world that Michalko and Smokie generate "springs from [their] communication in the midst of the world and from [their] movement through it" (1999, 187). As Michalko puts it, "I also became more familiar with those streets I already knew, as Smokie showed me stretches of grass, bushes, hedges, and trees that I had not been aware of" (1999, 94).

Taking up Michalko and Smokie's experiences as a space of heterotopic imagination opens up the possibility of desiring disability differently, a possibility enabled by a different imagination of bodies. This new form of imagination and its different spatial arrangement of imagination, speaks to Barad's conception of intra-action. Michalko and Smokie, along with Chen and Chen's mask and couch, show through their various practices of disability that within

disabled communities there are ways to imagine disability differently. It is here, in practices of disability, that the heterotopic imagination arises. And yet, it is not enough to simply celebrate the openings that Michalko and Smokie provide. Heterotopically imagining disability's desirability requires an opposition to the neoliberal hegemonic social imaginary. Despite the fact that Smokie is a dog, Michalko often feels that Smokie "is more easily accepted by society than I am" (1999, 110). In this vein, Chen, too, comments that "the statement that someone 'treated me like a dog' is one of liberal humanism's fictions: some dogs are treated quite well, and many humans suffer in conditions of profound indignity" (2012, 89). Thus, heterotopic openings must be utilized to do more than merely oppose the neoliberal hegemonic social imagination that governs the ways in which disabled people themselves wish to be included within the neoliberal social relations.

Desiring Disability Differently

Hengehold (2007) argues that for both Kant and Foucault, bodies are located at the interstice of certainty and uncertainty that characterize human existence and subjectivity. The point is to affirm the fractured and discontinuous, rather than escape into an imposed unity of the same. This affirmation of the fractured and discontinuous is a political project because, as Hengehold notes, "those who have certain kinds of bodies tend to live, and to believe themselves bound by, the fictions created by other groups" (2007, 11). Although we live according to the myth of stability, we never actually experience stability. The body tries to compensate for the persistence of fractures and discontinuities and the imagination becomes bound to this compensated reality.[17] Heterotopic imagination begins with the experience of discontinuity, the

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[17] On another register, we are never "the same" because of constant cellular, immunological and epigenetic flux (see Chapter 8 and the work of Aryn Martin).

incompatible, and the multiple. Such a starting place necessitates a whole other ethics of being of the world where it may be possible to desire disability differently. Clare (2001, 364) comments:

> the goal isn't to make irrevocable difference disappear.... Every time I walk down a street and someone stares, trying to figure out my body, to make sense of my shaky hands and slow speech, or to determine whether I'm a man or a woman – and if a woman, surely a dyke – I know nothing has changed. What has changed is how I perceive my irrevocable difference, how I frame it, what context I place it into... I want to grow to a place where I can fill my skin to its very edges. For any of us to do this work, we need all the allies, lovers, community, and friends we can gather, all the rabble-rousing and legislation, all the vibrant culture and articulate theory we can bring into being.

When intracorporeality is taken seriously, the skin becomes a permeable organ with no stable edges. Filling one's skin to the edges is thus a practice of masks, couches, and dogs. Reading those masks, couches and dogs as something other than SARS, tragic, or man's best friend, is the work of the heterotopic imagination. The heterotopic imagination matters for disability if there is to be a *we* forged that is able to desire ways of living that have not yet been within the frame of possibility. An "ableist lack of imagination" (Kafer 2013, 4) effects how disabled people understand and practice disability, in addition to how it impacts on the ways in which able-bodied people approach disability. Disabled people need to think about their own self-perceptions and futurity and how to disrupt the oppressive imaginaries within disability communities, including the neoliberal hegemonic social imaginary in which many disabled people seem to have been caught. In this way, the import of Chen and Michalko is to posit the role of the heterotopic imagination for all in re-shaping ableist, neoliberal social relations. Regardless of each of our own forms of embodiment, all of us are implicated in the hegemonic social imaginary that shapes our lives; thus, the challenge of disability and heterotopic imagination is a shared responsibility.

Kafer (2013, 12) suggests that "we must trace the ways in which we have been forged as a group… but also trace the ways in which those forgings have been incomplete, or contested, or

refused." The "we" that must be forged, must be forged in opposition to the homogenized "we" of the disability rights movement that suggests disability identity coheres through a shared experience of ableism (Garland Thomson 1997; Linton 1997). Rather, the "we" must be forged as an intracorporeal emergent multiplicity whereby disability is *of* the world. In this forging of disability, multiple agencies are differentially implicated and involved. As such, it is a "we" that must be forged so as to take account of how some of us are capacitated by neoliberal capitalism while others are left to slow death. In doing so, it is a "we" that must be forged against neoliberalism and against the neoliberal hegemonic social imagination. Foucault remarks (1997a, 114-115):

> The problem is... to decide if it is actually suitable to place oneself within a 'we' in order to assert the principles one recognizes and the values one accepts; or if it is not, rather necessary to make the future formation of a 'we' possible, by elaborating the question. Because it seems to me that the 'we' must not be previous to the question; it can only be the result—and the necessarily temporary result—of the question as it is posed in the new terms in which one formulates it.

Kafer (2013, 8) contends that disability is experienced in and through social relationships. I would highlight that those relationships emerge intracorporeally and are relationships of both the human and nonhuman world. A heterotopic imagination takes intracorporeality seriously and forces us to reckon with the ways that disability is not just something that tragically appears in the world that we must tolerate or include, but rather that disability is an emergence of the world; that is, disability is a practice. As an intracorporeal practice, disability is a life worth living.

Fredric Jameson (1994) has remarked that "It seems to be easier for us today to imagine the thoroughgoing deterioration of the earth and of nature than the breakdown of late capitalism; perhaps that is due to some weakness in our imaginations" (xii). As Jameson sees it, on the terms of our current social imagination, it is easier to imagine the end of the earth than to imagine the end of capitalism. In our current neoliberal individualized moment, furthermore, it seems to be

easier to imagine the elimination of disability through expensive techno-scientific solutions like genetic therapies, invasive surgeries, or other medical interventions than to imagine desiring disability differently. This ableist failure of imagination affects all people, even disabled people themselves who wish that they will not become "more disabled," or who desire to be able-bodied. Taking the sufferings and intracorporeal possibilities of disability seriously challenges the neoliberal hegemonic social imaginary that privileges corporeal stability and gives space to heterotopic imaginings grounded in relationality and intracorporeal multiplicities. Such spaces imagine bodies differently. In that difference, a space for desiring disability emerges.

Chapter 7

Neoliberal Affects of Disabled Parenting: Towards an Intracorporeal Emergence of Disability

On a sunny afternoon in September 2012, I wrapped up my then six-week old daughter in a sling, got onto my mobility scooter[18] and headed out to the local drugstore. Just a few blocks from my apartment, an elderly woman stopped me on the street to admire the sleeping creature on my chest, exclaiming: "Look at you! It's so nice to see people like you being included!" In just the few short weeks after my daughter's birth, her comment – or something like it – had become a common refrain: of the many places I travelled while carrying my daughter on my lap, people nodded approvingly, remarked how great it was to see a visibly disabled person with a child, and more often than not, gestured towards just how far our society had come in including people historically discouraged or prevented from becoming parents. There I was, a rolling success story full of good feelings for all to witness.

The barriers I, like many disabled parents, face on a daily basis are numerous. Rather than my physical limitations characterizing my individual failure to be an adequate parent, my limitations are social and relational: they are failures of my communities, even my disability communities, to address a lack of access to sustainable forms of disabled parenting. Nonetheless, it can be difficult to specify how the physical limitations I face as a mother are not just mine. Part of the trickiness in marking these failures is a result of the ways in which normative notions of both mothering and disabled mothering circulate to figure individual mothers as the site to determine whether one is good or bad, rather than placing mothering as always embedded within broader social relations. In addition, another impediment to marking the social barriers I

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[18] Perhaps aptly named the Go-Go Pride, so that my neoliberal entrepreneurial self can take my pride to the streets.

experience as a mother is the way in which the inclusion of disability within neoliberal economies makes systemic barriers out to be individual problems that can be solved within neoliberal market logics. That is, it is hard to develop a relational understanding of disabled mothering because of the ways in which disabled mothers are capacitated in neoliberal economies to become good mothers, and how the good and bad feelings that circulate around becoming or failing to become a good disabled mother individualize disability. As opposed to working outside of disabled communities, neoliberal logics are pervasive, contradictory, and insidious, orienting even the most critical, radical, or social-justice-oriented communities towards celebrating the neoliberal capacitation of disabled parents.

This chapter addresses the ways in which dominant cultural discourses of disabled parenting, with a particular focus on disabled mothering, re-enforce disability as located in an individual body. I begin by mapping out the extensive social barriers faced by disabled parents. Then, in tracing out the narrative accounts of disabled mothers appearing in popular media, I show how neoliberal processes of capacitating disabled people as parents sustain and celebrate disability as an individual problem that can be overcome by an inclusive society. I show how disabled people are hailed to feel good about being capacitated into ideal normative mothers through neoliberal forms of care. The problem then, is that disabled mothers, by coming to feel good about themselves, or in being hailed to feel good by others in order to feel like good mothers, re-inscribe normative forms of parenting that support neoliberal forms of care that capacitate some as the successful abled-disabled, while leaving others to wither. In contrast to these individualizing cultural discourses of mothering, in the last section of this article I take into account the capacitating and debilitating logic of neoliberalism to think though how disabled mothering emerges intracorporeally within and between bodies. In this relational model, disabled

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mothering marks the barriers some disabled parents face as not individual problems to be solved, but rather as social relations in which we are all implicated in. Such an approach to disability, I argue, contests the affective neoliberal forms of good feelings that re-enforce individualizing uptakes of disabled parenting.

Barriers to Disabled Parenting

Nearly 10 percent of American children have one or more disabled parent (Frederick 2014). Despite their prevalence, disabled parents are often considered incompetent, put under increased scrutiny and surveillance, and face significant systemic barriers that often lead to social isolation. Not only do inaccessible playgrounds, parent-and-tot groups, and school buildings limit disabled parents, but disabled parents are also significantly constrained by poverty, inadequate and inaccessible housing, transportation, and daycare (Through the Looking Glass 2006; Evans and de Souza 2008). Systemic ableism leads to disabled parents as a group having less access to educational and occupational opportunities and heightens the chances of living in poverty which in turn contributes to increased social marginalization and vulnerability, further opening the disabled parent up to negative judgments about their capacities to parent. Disabled mothers in particular frequently face stigmatizing public perceptions that serve to challenge their capacity to mother adequately (Track 2014; Frederick 2014; Malacrida 2007, 2009; Blackford 1993; Grue and Laerum 2002). If, as Malacrida (2007) notes, the normative relationship between motherhood and femininity is a "tightrope upon which to balance dependency and nurturance" (469), for disabled women, this "tightrope" can be "particularly difficult to negotiate" because disabled mothers are more often embedded in relations of material and social dependency (470).

Malacrida's research on disabled mothering shows that disabled women "are more likely to experience dependency on institutional supports as a result of their unequal access to education,

their difficulties in obtaining adequate employment and their higher likelihood of living in poverty" (2007, 471). If disabled mothers are employed, often the accessible transit service is "unreliable, inflexible and unsuited" to the responsibilities of working mothers (McKeever et al. 2003, 191). And while physical access may not typically be a barrier to disabled mothers with cognitive impairments, "these women are more likely than others to be lone parents, living with poverty and unemployment" (Malacrida 2007, 481) and face higher levels of stigmatization, social isolation, and charges of incompetency (Booth and Booth, 1998). Disabled women are also at an increased risk of having a partner who is emotionally or physically abusive (Asch and Fine 1992; Asch, Rousso and Jefferies 2001). Of course, disabled parents have varied experiences depending on social factors such as marital and socioeconomic status, geographical location, race, age, gender, sexuality, and access to social, cultural, and symbolic capital. However, according to Malacrida's research, racial, economic, sexual difference intensified the negative outcomes for disabled women. For while disabled women as a group are more likely to experience poverty, discrimination, and violence, "women who are poor, queer, living in rural isolation or members of racial and ethnic minority groups are likely to experience disability oppression that is complicated by their raced, classed, geographical, sexual and social locations" (Malacrida 2007, 473).

Regardless of social position, however, all disabled mothers (differentially) experience the cultural pressures that accompany the idealization of motherhood within a western context as a gendered role of selfless devotion and natural seamless attention to the needs and desires of her child. Sara Ruddick (1989) argues that mothering involves protection, nurturance, and responding to the needs of children with care and respect, qualities that Claudia Malacrida notes are "stereotyped as core attributes of hegemonic femininity" (2007, 471). Women are expected

to nurture their children "through active, involved and expert mothering," and are "ideally expected to be all things, at all times, to their dependent children" (Malacrida 2009, 99). Martha McMahon (1995) underscores the ways in which women are re-socialized in becoming mothers and transform into "loving, caring, responsible" parents (130). Thus, motherhood can be understood as a learned set of behaviours that is continually reproduced through performing normative forms of mothering-femininity that imbues women with a sense of themselves as naturally devoted, attentive, and nurturing (Malacrida 2009).

Sharon Hays (1996) first coined the term "intensive mothering" to express how normative mothering is "*child-centered, expert-guided, emotionally absorbing, labor-intensive, and financially expensive*" (8). Women are "expected to create child-centered homes that shield children away from responsibility and hardship" (Frederick 2014, 33) and are tasked with being all things to their children whether it is being immediately available, a strong role model, endlessly nurturing or completely child-focused. Despite longstanding feminist critiques of naturalized gender roles, mothers in modern western societies continue to be "idealized as 'natural' and limitless caregivers for their children" (Malacrida 2009, 101). Despite feminist attempts to challenge and denaturalize normative mothering and politicize intensive mothering discourses, failure to meet this normative standard of selflessness often results in "mother-blame" (Malacrida 2009, 99) especially when the mom's behaviour becomes a means of explaining the aberrant behaviour in their children (O'Donovan 2012).

While it is common for all parents to struggle with doubts about their parenting abilities and to live up to normative gender roles and expectations, for disabled mothers in particular "these doubts are repeatedly confirmed in the comments of strangers, health-care professionals, even family members" (O'Donovan 2012, 95). Such doubts are reinforced through various levels

of community and state surveillance, which often results in the removal of children from their care (Malacrida 2007), or creates additional burdens through the fear and threat of possibly losing the right to care for one's child (Track 2014; Frederick, 2014; O'Donovan 2012; Prilleltensky 2003; Grue and Laerum 2002; Kent 2002). As Malacrida points out, "Because ideal mothering includes women's responsibility for the protection and care of their children – even against their husbands and partners – women who are vulnerable to abuse are likely to be blamed for failing to live up to cultural norms relating to ideal mothers as protectors and guardians against any and all harms that may befall their children" (2009, 100).

As Angela Frederick's research shows, "Many mothers with disabilities report living with a sense of fear that they will be scrutinized by medical authorities. At times, when members of the public see a disabled woman out with her children and become concerned, they report the family to child protective services" (Frederick 2014, 34). In 37 US states, disability, as an identity status, can in itself be the legal grounding to terminate parental rights (Frederick 2014). Too frequently "safety" is a guise used to question the abilities of disabled parents and disability status ends up being used as a proxy for real evidence that the parent cannot adequately care for their children (Frederick 2014). Of her experience as a disabled parent, Deborah Kent comments: "The exhaustion and isolation I felt are common to many, if not most, new mothers in middle-class America. Yet I had one added burden sighted mothers did not share. I knew that wherever I went people were observing me, wondering about me, at times doubting my abilities. All too many people, both strangers and acquaintances, questioned my capacity to care for my daughter and to keep her safe" (Kent 2002, 85).

Surveillance and questioning of capacity plays a role in how disabled parents present and monitor themselves and their children. Carol Thomas' 1997 study marks the ways in which

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disabled mothers feel pressure to demonstrate that they are "good enough mothers" (624), above

and beyond the normative pressures placed on non-disabled mothers. Thomas also found that

disabled mothers desired to present themselves as managing normally in order to avoid attention

or judgement. Grue and Laerum (2002) affirm this finding, noting that several of the disabled

mothers in their study found it important to "work hard in order to convince other people that

they were competent mothers" (677). One participant in their study, Lise, stated: "There are very

few children who are as nicely dressed and well-kept as my children. I was the first parent to put

nametags in my children's clothes when they started at the nursery. Nobody should have a reason

to criticise me" (677).

Kent comments on her own experiences of being a "blind mother" in a similar way:

Many a new mother lives with "performance pressure." When the baby won't stop crying, she notes her mother-in-law's disapproving frown or her husband's sigh of exasperation. But I feel that in my case such anxiety was heightened. In public places I could seldom forget that the critical eyes of the world were upon me. If my daughter fussed, if she had a spot on her dress, or if any minor accident befell her, I knew it would be attributed not to the ordinary ups and downs of babyhood, but to the fact that I, her mother, couldn't see. I tried to keep Janna immaculate, cheerful, and of course safe from all the perils of childhood – not only for her sake, but in order to fend off the naysayers, to prove myself worthy for the parental role. (2002, 85)

Grue and Laerum note that disabled mothers often feel that they need to "demonstrate a better

than ideal performance of motherhood in order to pass as socially acceptable" and often monitor

their gender performance in order to appear "as a mother in a way that makes them equal to other

mothers" (2002, 678). Crucially, however, they point out that such attempts at "passing" were

more difficult for disabled mothers who have speech impairments or difficulty maintaining their

balance while walking, as these types of disabilities can appear as intellectual disabilities or as

related to alcohol or drug consumption (2002, 678). Grue and Laerum additionally found that

"mothers who had asked for practical help found that this was sometimes used as proof that they

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were inadequate mothers, and any difficulties that their children had at school or kindergarten had been interpreted in the same way" (2002, 678). As Frederick concludes: "Disabled mothers are more likely to experience unwarranted investigations from social service agencies. They are more likely to have their parental rights terminated, and when children are removed these families receive fewer supports for reunification" (2014, 35).

That is, often when children are removed, "agencies offer disabled parents few supports to ease the effects of structural barriers such as lack of access to transportation and quality housing, and they rarely offer parents the opportunity to acquire adaptive training and equipment that might help them care for their children" (Frederick 2014, 34). Frederick (2014) describes the 2010 experience of Mikaela Sinnett of Independence, Missouri, who was taken into the American foster care system at just two days old. A nurse reported Mikaela's blind parents to a social worker after Mikaela's mother experienced difficulty breastfeeding. Frederick writes: "Mikaela's parents cooperated with the social worker, answering questions about the care they would provide for their newborn. They could take their daughter's temperature with a talking thermometer; they had access to transportation; and they could take Mikaela to the hospital if she needed immediate medical attention. The one response the social worker wanted, which the parents could not provide, was that someone with sight would be with the child at all times" (2014, 31). Mikaela's parents spent two months entangled in legal proceedings and court hearings during which time they were only able to see Mikaela during supervised visits for up to a maximum of three hours each week. After 57 days of fighting, the state finally dropped the case. Mikaela's story underscores the way in which disability and incompetency are so culturally entrenched.

Because disability is so often associated with incompetency and lack, and because disabled

mothers often require assistive devices or assistance to aid in their parenting, "the combination of cultural ideals of mothering as selfless devotion with visible indicators of attending to one's own needs and relying on institutional support increases the vulnerability of mothers with disabilities to the charge of bad parenting" (O'Donovan 2012, 94). As such, disabled mothers "pose a threat to the intensive mothering ethos as they can make visible the realities of imperfection, risk, and even pain and suffering – the very hardships from which mothers are now expected to shield their children" (Frederick 2014, 33). This threat is more or less neutralized by representing the relationship disabled parents form with their children as unhealthy for the child. Indeed, disabled parents, and mothers in particular, are often depicted as having an "upside-down" relationship with their child (Malacrida 2007, 472), as it is assumed that the child is "burdened" with the responsibility of caring for the parent (Prilleltensky 2004). The notion of an 'upside-down family' presumes that "disabled mothers not only fall short of ideal mothering, but that they depend on their children for care and services, exploiting these 'young carers' and robbing them of their childhood" (Malacrida 2007, 472).

In Grue and Laerum's study, they found that the majority of disabled mothers were very conscious of the role of their children as helpers. Even if able-bodied people expressed "how important it is for children to have certain obligations," these same people often saw a child helping a disabled mother as a different matter than when a child helped a non-disabled mother. That is, a child helping a disabled mother "was seen within a discourse of disability and not within a discourse of socialisation" (2002, 679). It was questionable to these observers whether the child helping a disabled mother was indeed good for the child's development.

Whether healthy for the child or not, such help is often necessary is an ableist world. McKeever et al. (2003) found that it was often "the unsuitability of the home and community

care services," rather than the individual disability of the disabled parent which instigated the need for the child to help or care for the parent. Additionally, women without spousal support and those who relied on rental housing that could not easily be modified "appeared to be at the highest risk of requiring problematic levels of assistance from their children" (193). For many of these parents, assistance from their children was "the regretted detour" by which they were able to overcome limitations to full parenting.

There is agreement across the research on disabled parenting on the need for nurturing assistance and increased personal and homemaking services for disabled parents. In a US national survey of 1,200 disabled parents, 79 percent of respondents reported a need for daily personal assistance and 57 percent reported needing help with parenting tasks. Additionally, 60 percent of parents with psychiatric and/or physical disabilities reported that they would benefit from assistance with parenting activities, and 50 percent of parents with sensory or developmental disabilities said they would benefit (NCD 2012, 240-241). According to the survey, 43 percent of respondents reported needing the most help to enjoy recreational activities with their children, 40 percent reported needing help with "chasing and retrieving their children" and an additional 40 percent reported needing assistance with traveling outside their home. Other significant areas of assistance included lifting/carrying children, organizing supplies/clothing, disciplining children, playing with children, bathing children, childproofing the home, and advocating for children (NCD 2012, 241). And yet, while many disabled parents tout hiring an attendant as the best solution to the barriers they face, when disabled parents do hire someone to help care for their child, the disabled parent's ability to be a parent is questioned. Christina Minaki, a disabled woman reflecting on her intention to hire a nanny to care for a child she wishes to adopt writes: "if it is acceptable for an able-bodied mother to hire a nanny, to make

juggling parenting, career and domestic responsibilities possible, why is this course of action

assumed taboo for me?" (2014, 32).[19]

In addition to being judged, getting help from non-family members is increasingly a

problem of funding. As neoliberal changes to policy continue to download costs of caring for

dependents onto the non-profit and voluntary sector, families and individuals, funding and other

supports for disabled parents are often hard to secure, under-resourced or non-existent. For many

disabled mothers, publicly funded assistance is not available and their families are forced either

to privately pay for help or not receive any services at all. In many cases where disabled parents

were receiving funding for attendant care, the terms of their funding did not allow them to use

their assistants to aid with the care of their children. For example, "a mother with a full-time

caregiver might reasonably expect her worker to feed and clothe her but she could not ask that

caregiver to put a bowl of cereal on the table for her child or to help that child button his shirt."

(Malacrida 2007, 484).[20] McKeever et al. further found:

> Agencies that provided personal and homemaking services clearly viewed women as
> clients in need of individual assistance and often overlooked or refused to support their
> mothering roles. After repeated requests, only one of two mothers with very young
> children was provided with temporary outing assistance and then for only 4 hours per
> week. Several mothers were unable to receive adequate assistance with those
> housekeeping activities typically associated with mothering such as the cleaning of
> children's rooms, grocery shopping and laundry. (2003, 183)

As the US National Council on Disability (NCD) notes (2012), personal care workers, who have

been found to be a cost-effective solution to the needs of many disabled parents, would greatly

enhance the ability of many disabled parents to parent, improving the quality of life for these

families. In the US, some states that have offered support so as to keep the children of disabled

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[19] Through a disability justice framework, it is possible to recognize that neoliberalism is a system in which both a
nanny and a disabled mother are separated from their children.
[20] Interestingly, homecare policy in Ontario allows for care for a disabled mother's children, but not for any others in
the household.

parents out of the foster care system have saved almost two dollars spent on institutional care for every dollar spent on the program (242-243). The NCD also found that funding adaptive equipment and simple home modifications can also "prove cost-effective" (243).

While the sum of all these findings about disabled parenting and the challenges disabled mothers in particular face is largely to draw attention to and chart out the precise barriers faced by disabled parents, what is missing from these studies is mapping out the ways in which disabled parents are welcomed and included as parents, and secondly, how these forms of inclusion and many of the 'solutions' purported to aid disabled parents, actually serve to reinforce neoliberal logics that individualize disability and care, capacitating some as the successful abled-disabled, while leaving others to wither.

What Kind of Mother? Charting the Neoliberal Affects of Disabled Parenting

Sarah Erdreich, in her 2015 *Slate* magazine article asks: "What kind of mother refuses to pick up her child?" At once both appealing to and resisting normative western maternal standards she answers her own question bluntly: "A mother with chronic pain."

Born with damaged nerves that have led to a lifetime of muscle spasms, scar tissue, atrophied muscles, and days where "even blinking hurts," Erdreich (2015) notes the ways in which following the birth of her daughter, her health further deteriorated. She writes: "The early months of changing diapers and clothes, nursing, and lifting her in and out of her crib caused irreparable damage to my wrist and shoulders." As a result of the intense physical labour of taking care of a baby, Erdreich describes the ways in which she was left unable to push her daughter's stroller "much farther than the three blocks between home and day care" and how she is unable to dress her daughter, tie her shoes, brush her hair, help her daughter write out the alphabet, or make the hand motions that accompany the children's song 'Itsy Bitsy Spider.' With

this laundry list of limitations, she marks herself off as a failed mother when she admits that because she cannot do these things she does not feel that she is capable of properly caring for her daughter by herself for more than an hour. And because "raising another child would take a much greater toll on my health than I am willing to accept," Erdreich feels she is further failing her daughter because she is unwilling to provide her with a sibling and, thus, preventing her daughter from having the experience Erdreich and her husband enjoyed of growing up in a larger family (2015).

Erdreich goes back and forth describing her disability in relational and individualistic terms. On the one hand, Erdreich notes that by the time her daughter was two Erdreich had taught her "how to scoot down stairs, climb onto the couch, and get into her stroller." In this telling, Erdreich's relationship with her daughter was developed through her disability and her disability re-experienced through these lessons. On the other hand, Erdreich continues to fall back into individualistic and blaming accounts of how *her* chronic pain stops her from being the ideal parent she desires to be. She comments that she knows her daughter will soon be more independent and that it will be become easier to take her to the "the playground or library or a restaurant without needing another adult present" (2015). But Erdreich feels so strongly that her condition makes her a failed parent that she has a hard time believing that the future might be easier. Ultimately, as opposed to taking a relational approach that emphasizes how disability is produced between her and her daughter—let alone within the wider socio-political context and environment, Erdreich instead stresses her own failure as a mother. And for Erdreich, failure at being a good mom stems from her individualized disabled body.

In another account of disabled mothering published in *The Atlantic*, Rachel Rabkin Peachman (2014) writes of feeling like "her back would break" if she cradled her sick daughter's

"squirming 25-pound body any longer." Leaving her toddler crying in her crib, Peachman notes that she was causing her daughter "additional suffering" as a result of her individual back pain commenting that "Before having children, I didn't consider how my pain might affect my parenting" (2014). But as she goes on to describe, "Within two years of hoisting my precious cargo into her stroller and high chair, and yes, standing and rocking her to sleep – my body buckled under the strain. Back spasms made it impossible for me to stand or walk for long stretches and sometimes put me out of commission all together" (2014). Despite Peachman's increasing pain and debilitation, she states: "whenever my daughter reached for me, I was there with open arms" because "How does a mother suppress her instinct to hold her child when those little arms reach out?" (2014). Of course, by severely limiting when she can act on this maternal instinct, Peachman sees her disability as an individual condition that prevents her from being a good mother.

Interestingly, both Peachman and Erdreich express how their disabilities have negatively affected their family life on the whole. Referring to studies on the adverse effects on a child's emotional and behavioural development, Peachman states that when a parent has chronic pain, the "whole family suffers" (2014). Erdreich comments that her condition affects her husband "in profound ways" as his life has become completely inflexible after the birth of their daughter, noting that "he is the only reliable and consistent parent our daughter has," leading her to describe her marriage as frustrating and unbalanced. Erdreich comments: "If I had known how tough this would be before getting pregnant, would I have made the same choice? I want to say yes without hesitation or qualification, but that's not the honest answer. The honest answer is, I don't know. I love my daughter. That has never been in doubt. But I hate what a toxic combination motherhood and chronic pain are for me" (2015).

Erdreich's and Peachman's sense of failure is consistent with the literature on parenting with chronic pain on the whole. A number of studies note the ways in which parents express a sense of missing out on social events and leisure time with their children as a result of their chronic pain, often labelling themselves as "burdens" (Evans and de Souza 2008, 494). Evans and de Souza found that "Most mothers felt that dealing with pain and bringing up children was difficult. Either children suffered and had to brave their mother's unavailability and distress, or mothers taxed themselves by performing parenting duties even when their pain made functioning difficult" (2008, 497).

While I do not suffer from chronic pain, I, like many disabled parents, can identify with the frustration and pain both Peachman and Erdreich express in caring for their children. I also appreciate how both Peachman's and Erdreich's accounts of being disabled parents with chronic pain are important for disability studies because of the way in which chronic pain is often a kind of disability that many do not take seriously, or consider to be "real" (Mollow 2012). It is often an impairment that people need to prove over and over again because those with chronic pain don't always "look disabled." As O'Donovan comments, when disabilities are not visible, or not always visible, disabled parents "may find themselves excluded from the community and support provided to those with [visible] physical disabilities" (2012, 96). Disabled parenting is governed by a normative understanding of disability that is dominated by visible forms of impairment and adaptive devices like that of the wheelchair (Fritsch 2014). In this way, both Peachman and Erdreich provide a compelling account of some of the barriers to mothering when one does not "look disabled" and as such, are expected to be fulfilling their normative roles of intensive mothering.

However, while their narratives begin to contest normative notions of disability, both narratives deeply entrench disability as an individual experience, with the authors blaming only themselves for not living up to ideal mothering norms. Failing to examine the barriers they face as social barriers, the individualizing narrative also reiterates a neoliberal logic that "individuals are primarily responsible for their own fates" and that "families and voluntary agencies, rather than local states, should bear the onus of responsibility for assisting persons in need" (Chouinard and Crooks 2005, 19-20). Having privatized formerly public services and resources, the primary role of the state is to discipline those who fail to maintain economic independence and to reinforce divides between those who are deserving of social welfare programs and benefits and those who are not. Increasingly informing common sense understandings of disability as an individual condition or form of impairment while also underwriting policies and practices concerned with disabled people and modes of access, disabled persons are hailed to become independent entrepreneurs who manage their own needs.

Michelle Murphy's work on the economization of life argues that as neoliberalism developed throughout the mid-to-late 20th century, it became increasingly common to render and govern lives in purely economic terms (for example, as more or less valuable) rather than through biological terms. As disabled life has become economized, the biological difference of impairment has come to matter less in some cases than the potential of making disabled bodies productive through therapies, drug regimes, and assistive devices and, thus, profitable for private companies developing drugs and producing body modifying equipment. As opposed to seeing disability exclusively as the basis for exclusion and disabled bodies as objects to be normalized, Jasbir Puar (2011) has come to question how economies of disability that capacitate some

disabled bodies while leaving other unproductive disabled lives to wither, produce differential forms of disability in neoliberal economies.

While the objective of capacitation is not necessarily to transform disabled bodies in the image of able bodies but, instead, to create newly enhanced and productive bodies that often have the potential to exceed the capacities of able bodies, ableism has not, of course, disappeared. That some disabled bodies are capacitated and included in their difference does not mean that ableist norms no longer define disabled people as lacking. Instead, within neoliberal economies disability emerges in the ambivalent position between being capacitated or left to wither and normalizing standards. With particular forms of disabled lives capacitated and marked as worthy for valorization, while other disabled lives are denigrated and left to wither, disability as difference works alongside ableist norms.

In the mothering literature, this ambivalence is best expressed in the tension between the logic of intensive mothering in which being a mother is its own reward and the neoliberal logic that requires parents to take on the full cost of parenting. For disabled parents, more often than not, this effectively results in the neoliberal state disciplining those who are unable to afford this task through measures such as removing children from their care.

The ambivalent economies in which disability is both valued and capacitated, and policed and debilitated, inform non-disabled persons' understanding of disability and feelings towards disabled people as well as disabled persons' desires. For example, the woman who took such pleasure in me being both disabled and being a mother as I carried my infant daughter on my scooter expresses this ambivalence as she both celebrated my capacitation as mother—my scooter, my ergonomic sling—and the image of being a competent, independent mother like other mothers this form of capacitation produces. I can only wonder what she would have said if

my daughter were fussing or appeared to be in danger of falling off my lap? I can only imagine

what type of mother I would have been if my child were older and struggling with the bags of

groceries I could not carry myself?

Erdreich's and Peachman's desire to be good mothers by both overcoming their

disabilities that prevent them from always being good mothers and also by embracing the

moments in which they can be good disabled mothers through participating in affective

neoliberal economies. As their individualized disabilities continue to sit more or less nicely

within affective neoliberal economies of disability, it is perhaps no surprise that the pain and joy

Erdreich and Peachman feel in being mothers continues to circulate within neoliberal relations.

Presumably not wanting to end on a sour note or to be a killjoy, but instead to leave their readers

hopeful, both Erdreich and Peachman end their articles by expressing their determination to be

good mothers *despite their individual challenges*. For Peachman, this is expressed in two key

statements. In the first, she states: "I'm still the one my girls reach for – and I refuse to let the

pain take that away from me. Motherhood may have weakened by body but my love for my

daughters has strengthened my spirit" (Peachman 2014). And in the second, she notes: "I know

there are days when I'm sidelined and short-tempered. But I'm determined to raise children who

feel supported, secure, and loved. I don't know what my future holds – surgery, therapies, or a

lifetime of pain. But I have to believe that despite a deteriorating body, it's possible to be a

successful mother" (Peachman 2014). For her part, Erdreich makes the best of her limited

situation by commenting:

> And even though there is so much that I can't do with my daughter, and more that I might
> not ever be able to do, there is still this: She can sit on my lap and listen to me read
> *Harold and the Purple Crayon* and *Hop on Pop* over and over. I can lie on the floor of
> her room and make her giggle just by letting her cover me with stuffed animals and toy
> ducks. And when we get home from day care and stand at the bottom of the porch steps
> and she lifts her arms to be carried, I can sit down on the lowest step and put my arm

around her as she leans against me, and we can watch the evening settle around us until we're both ready to walk into our house. (2015)

Pervasive cultural discourses such as those expressed by Peachman and Erdreich re-inscribe the good feelings of disability as an individual who will persevere and overcome their challenges. In doing so, the grounds upon which the individual grins and bears their situation are not contested but rather re-enforced. Similarly, Erdreich and Peachman both place hope for a better future in what they can do as individual mothers. That is, for Erdreich and Peachman, hope is found in their individual capacities to still provide the selfless care – although somewhat adapted to suit their disabled bodies – that good, able-bodied mothers provide.

While normative and ideal motherhood is "both unachievable and blaming for all women" (Malacrida 2009, 100), it also creates additional barriers for non-normative family formations, including, but not limited to, families with one or more disabled parent. However, in contrast to Erdreich and Peachman's individualizing narratives that isolate them as lone outcasts, their experiences as disabled parents are not unique. And yet, their accounts are compelling precisely because of the ways in which they participate in ambivalent neoliberal relations.

In Hilde Zitzelsberger's 2005 study of how 14 disabled women accounted for their embodiment, one participant who was visibly disabled when using her mobility scooter commented:

> When people see me or even get to know me and they know that I'm married and have a family… they're really surprised and they'll say… *'That's great.'* Well, you wouldn't go up to somebody and say, *'That's great you have children.'* (396, emphasis mine)

Many contemporary accounts of disabled parenting describe similar encounters as the one I described at the beginning of this chapter in which able-bodied persons tell disabled people its great they are having kids. In the disabled parenting literature more generally, this celebration of disabled mothers gets expressed in comments like: "disabled women choosing to have children

are resisting preconceptions of what social roles they may fulfill" (Grue and Laerum 2002, 673), or "To imagine one's self as a mother, making the decision to become a mother, and acting on this choice is an act of bravery for disabled women" (Filax and Taylor 2014, 1). Even as these positive remarks stand in stark contrast to past eugenic-like projects of sterilizing disabled persons, these good feelings and celebratory remarks are nonetheless problematic because they tend to make the inclusion of disabled women in mothers the desired end of having kids. As a result, becoming a good disabled mother does not necessarily challenge the normative production of ideal intensive mothering, or the way in which some disabled people are capacitated within neoliberal economies at the expense of others who are left to "slow death" (Berlant 2007). In short, extoling the virtues of disabled parents does not necessarily challenge or change the inequitable neoliberal social relations in which intensive mothering is normalized and in which disabled parents parent.

Disability studies scholars O'Toole and Doe (2002), disabled parents who adopted disabled children, confirm these neoliberal discourses. They note that they did not receive any kind of state support to enable them to parent but rather created mutual support themselves, remarking: "We are, surprisingly, everywhere. Though not exceptionally visible, we are very good at mutual support" (2002, 93). Such mutual support is evident in Kent's account of being a blind mother. She searched out and met other blind mothers, who shared adaptive tips with her such as using a baby-carrier so that her hands would be free for a cane or a guide-dog harness, and attaching bells to the clothes of crawling infants or walking toddlers so as to be able to keep track of their whereabouts (2002, 83-84). Of this experience, she comments: "For the first time in my life I was hearing a new and welcome message… I would need to be well-organized, to plan carefully, and to build a strong support network. But… blindness was not an obstacle to

motherhood" (Kent 2002, 84). Further as one participant wryly comments in Ora Prilleltensky's

2003 study on becoming a parent: "If I can't go in the front door I go in the side door. Or the

back door. Or I create a door." (45).

Stories of mutual support, resistance to ableism, and finding solutions to create "ramps to

mothering" (Prilleltensky 2003) are important, marking the creative means disabled people

utilize in order to live their lives. However, these stories do not fall outside of neoliberal logics

and we must continue to attend to the ways by which disabled people are in/excluded within such

troubling logics. In contrast to these discourses, in the next section I mark the relational,

intracorporeality of disability to show how disability emerges within and between bodies so as to

mark the barriers some disabled parents face as not individual problems to be solved, but rather

as social relations in which we are all implicated.

Towards an Intracorporeality of Disabled Parenting

Heather Kuttai, in *Maternity Rolls: Pregnancy, Childbirth and Disability*, recounts a

story of going swimming with her two year-old daughter who asks to be taken down the

waterslide at the pool. Kuttai, a paraplegic, tells her daughter that she is unable to take her up the

stairs, to which her daughter says "I need a walking person" (2010, 99). In this moment Kuttai

feels like she is letting her daughter down. She comments: "I feel compelled to say, 'I'm sorry' a

lot – to my husband, for costing us more money, to my children, when I cannot go to the places

other moms go, to the earth, for making more pollution" (100). Kuttai not only intensely feels the

ways in which her limitations affect her family, but also is aware of the impact her mobility and

adaptive equipment has on the environment. And yet, these feelings and expressions of sorrow,

which are familiar to so many disabled people, are very much wrapped up within an

individualistic logic of disability that is continually reaffirmed and reproduced within neoliberal

relations. Later in the text, Kuttai notes the sociality of her disability, stating: "I need a park in

our neighbourhood without gravel or sand so I can push Chelsea on the swings and catch her

when she comes down the slide. I need curb cuts" (2010, 128). And yet, the interactional

sociality of Kuttai's needs remain couched in an individual accounting: "*I need...*"

Such individualistic accountings of disability lead disabled parents to feel out of place in

an ableist society. McKeever notes: "The experiences that mothers reported were fundamentally

embodied. As women moved through physical and social spaces primarily designed for adults

who can walk, they were often made to feel 'out-of-place' as mothers" (McKeever et al. 2003,

183). Indeed McKeever et al. further found:

> One mother commented that while parenting is an equally difficult task for all, parenting
> from a mobility device is 'more of a production', given the significant complexity of co-
> ordination required to maneuver the bodies of herself and her child, a wheelchair, and a
> stroller during the conduct of mothering and homemaking activities. This production of
> motherhood is embedded within the demands and structures of a socio-spatial context of
> social exclusion and discrimination, inadequate home care services and awkward or
> inaccessible built environments. Hence, recognition and amelioration of the challenges to
> successful mothering with a disability requires an understanding of its embodied and
> emplaced nature, and the recursive relations of people and places. (2003, 195)

The embodied and emplaced nature of disability is not simply to invoke the social model by

which external barriers disable an individually impaired body. Rather, building on Chapter 6,

taking disability as an intracorporeal emergence contests the affective neoliberal forms of good

feelings that re-enforce individualizing uptakes of disabled parenting. To further elaborate on

this point, I briefly turn to the oft-cited solution of nurturing assistance, or having direct funding

for attendant care apply to disabled parenting so as to overcome its structural barriers.

Elsewhere (Fritsch 2010), I have marked the ways in which attendant care provides an

opening to consider the problematic foundation of independent living models that assert a

normative encounter between autonomous and sovereign selves. In complicating the usual ways

in which the attendant is considered an employee and as such is expected to be a "detached tool" (Gibson 2006, 192), performing a series of mechanical tasks (Hughes et al. 2005) in facilitating the needs and desires of the disabled person, I argued for the importance of approaching the interaction between a disabled person and an attendant as a relation that extends both bodies into one another, displacing the limits of their assumedly contained individual selves. In relation, both the disabled person and the attendant experience a leaking of their identities, a mingling of their sexualities, and multiple intimate slippages of their bodies as the attendant participates in the daily work of feeding, bathing, shopping, facilitating sex, and numerous other activities.

It is important to take a relational approach when considering attendant care because of the way in which the independent living model of direct funding figures disabled employers and personal attendants within neoliberal agendas that commodify care (Kelly 2014). It is of no coincidence that the disability movement's stress on independent living has emerged alongside the neoliberal privatization of many health services (Fritsch 2010), for "neoliberalism does not only 'happen to' social movements in a top-down fashion, but also in and through their actions" (Kelly 2014, 125). While independent living programs may provide many advantages for disabled people, they must be contextualized as part of a larger trend to privatize social services and download responsibilities onto individuals. Hughes et al. (2005) argue that the disability rights movement has placed too much emphasis on gaining equal access to the marketplace and on fighting for the right to be "wage slaves" (263-264). Being employed and a productive member of society is seen as a form of empowerment, capacitating the disabled as the abled-disabled, rather than fighting to dismantle the oppressive system of capital all together, which systematically produces disability and abandons some disabled bodies to wither. In calling into question the modes by which disabled people seek better lives, we discover that the struggle of

disabled people is also the struggle of those people who have been racialized or gendered, those who are queer, those who have tenuous immigration status, and so on, as they also experience disproportionate assault by the state and capitalism. All too often the struggles of disabled people are individualized and seen as a problem to be solved within the realm of social services, or understood as a medical problem that resides outside of the collective social body.

What I wish to add to these previous conclusions, in the context of barriers to parenting, is to mark nurturing assistance as a site of the intracorporeal emergence of disability that can contest the neoliberal individualizing of disability. This is to say, the intracorporeal emergence of disability highlights the ways in which disability does not reside in an individual body that requires help to parent, but rather marks the ways in which disability is always already within our relations. Thus, to return to Minaki (2014) who is critical of the taboo of hiring a nanny to help care for a child she wishes to adopt: what should be taboo is not the desire for a nanny, but rather acquiring a nanny in order to achieve intensive mothering, or as a way to overcome her individual problem. Displacing disability away from the individual body of the failed mother and emphasizing instead the macro and micro ways in which disability emerges within relations that have social, political, economic and cultural consequences opens up room for reflection and concerted political action.

I do not want to be a good disabled mother if it means re-inscribing the ableism of intensive mothering and supporting the neoliberal economies of capacitation that promise to enhance my individual difference so as to be a good mother without being the same as able-bodied mothers. I want to be able to take advantage of assistance and attendant care but I do not want to participate in neoliberal economies of providing care. The point is not to ignore inequitable social relations but to highlight how we are always already producing disability and

how we can hold the state, our communities, and each other accountable for the kinds of production that rest on and reproduce inequitable social relations. This is to place the emphasis, then, not on what an employee can do for me as a disabled parent but rather what we can create together that does not re-inscribe individual accounts of overcoming disability, nor simply evoke creative individual solutions in the face of austerity. The goal is not for the re-emergence of the welfare state, but rather to mark and mobilize the intracorporeal emergences of disability as a way to hold ourselves accountable and work collectively to overcome the ways by which neoliberalism individualizes disability and leaves parents to rely on market-based solutions to achieve and celebrate intensive mothering.

Chapter 8

Blood Functions: Disability, Biosociality, and Facts of the Body

My first medical diagnosis came in 1986 not too long after Donna Haraway had first penned her controversial *Cyborg Manifesto*. At four years old, after walking up and down the hallways of specialists, clad only in my underwear so as to enable the doctors to analyze my "troubling" gait, I was subject to a painful electromyography test that involved inserting electrified needles into my muscles to test for abnormalities of denervation. I cried out with such force and intensity during this test that I had to be forcibly restrained and moved into a sound proof room because I was "upsetting" the other medical staff and patients in nearby rooms. Despite the insistence from doctors that this painful procedure was important, the test results were not enough to provide a firm diagnosis. I later lay on the table of an operating-room looking at an image of a blue hippopotamus while an anesthesiologist asked me to count down from ten. After I drifted off, a 3-inch incision was made in my right thigh to extract a sample of muscle. I awoke in a room full of other groggy patients, our beds all lined up in a long row. As I tried to sit up, dizziness overtook me and I banged my head hard against the metal railing of the bed. A chirpy nurse came over and excitedly handed me a popsicle. As a permanent scar formed over my incision, the results came back. The muscle biopsy was decidedly a success; my diagnosis, unbeknownst to me, was me.

I went back to the hospital every June to spend an entire day in a windowless room meeting with neurologists, occupational therapists, physiotherapists, social workers, and a blur of others. They made me stand up, sit down, push, pull, walk down the hall, go up the stairs, go down the stairs, breathe into a tube, draw circles, squeeze my hands together, clap, jump, all the

while using a stopwatch to record every move, rating the pressure of my hand squeezes on a continuum. Was I trying my hardest? they asked. Could I go faster? they questioned. Why don't we try it again, they said. I got sized for splints that I refused to wear, and had x-rays taken of my back to watch out for scoliosis. They took notes, wrote reports, compared and contrasted the amassed results from year to year. They gave me piles of papers with stretches I should do, in the hopes of staving off the future that my biology prescribed: I should get weaker, my back should get curvier, growth spurts could cause trouble.

Years later, as it turned out, the results of my muscle biopsy were not as firm as had been previously suggested. At 18 years old, I was exceeding the expectations of my diagnosis. In doing so, I drew the attention of my grouping of specialists who wondered if my diagnosis was accurate. With no interest in ever coming close to another electrified needle or being put under to receive another scar, I declined further testing. "Does it matter?" I asked. The neurologist suggested that did indeed matter, and that those previous procedures wouldn't be necessary. It was the late 1990s by then, and with significant developments in genetic testing all that was required of me was a sample of blood.

Putting my disdain for needles aside, I consented. Weeks later, when the results came back from the lab, I met with two genetic counsellors who sat me down, slid a piece of paper across the table and looked at me expectantly. I looked at the paper. In its slightly blurred photocopied form it confirmed my previous diagnosis: a molecular analysis of my blood marked the deletion of exon 7 of the Survival Motor Neuron gene consistent with a diagnosis of Spinal Muscular Atrophy (SMA). I looked up at the genetic counsellors and they asked: "Do you feel any different?"

My initial reaction to this question was to wonder who the "you" was that might feel different. My blood had confirmed the facts of a diagnosis of SMA. All this time that I had been living with my blood and my scar and my disabled body, it had not been obvious that walking down hallways in my underwear, receiving an electromyography test, or undergoing a muscle biopsy, had yielded the correct diagnosis. I had been doing "too well." I didn't look like the other kids in the medical pamphlets that described the apparent lack of futurity for those afflicted with SMA. Even at the disabled-kids summer camp I attended every year, the pre-med camp counsellors frequently told me (presumably as some sort of compliment) that I didn't look like their conception of SMA. In that moment with my genetic counsellors, the statements made by those camp counsellors ran through my mind. And yet, the facts were on the table, presented in a way that could not be denied. My blood confirmed what others weren't sure they knew or not, despite of, or perhaps because of, my thick medical file full of stair climbing and descending statistics. The genetic counsellors excitedly told me how happy I should be because according to the facts on the table, I should be using wheelchair "by now." My blood confirmed who I should be, but this confirmation also confirmed what I wasn't. In being both what I was and wasn't, the counsellors asked again: Do you feel any different?

This chapter explores the constellation of factors in place in order for the question "Do you feel any different?" to be asked. Building on Ellen Samuels' (2014) work on biocertification, I examine how blood has historically functioned to legitimate stable identity categories through charting the ways in which blood functioned within racial science in the US in the nineteenth and twentieth centuries. I then trace how with the rise of genomic research, this biologically-based stable-identification has become what Paul Rabinow calls a form of "biosociality" (1996), pointing to the novel alliances between patients, scientists, politicians, doctors, and biotech

companies that give rise to new kinds of disability socialities. And while new forms of disabled biosociality have had the potential to break down the way in which biology has historically been inscribed in a nature-culture divide that has located impairments in individual bodies, following the work of Thomas Lemke (2015a), I argue that disability studies has left biology far too untouched as an active agent in the social production of disability. Building on the work of feminist materialists like Aryn Martin (2008; 2010), Annemarie Mol (2002), and Karen Barad (2007; 2008), I note the ways in which disability as an intracorporeal emergence is both materially and socially "natureculture" all the way down to the very human-nonhuman molecules of the body. I end by summing up what I perceive to be the consequences for disability studies of thinking the biological facts of the body as shifting entanglements of the human-nonhuman.

The Matter of Facts

In her 2014 book, *Fantasies of Identification: Disability, Gender, Race,* Ellen Samuels unpacks the ways in which a crisis of identifiability and governability of individuals emerged out of the 19th century. While this crisis of identification was the result of a constellation of factors including urbanization, colonialism, racial and class hierarchies, "intensifying anxieties" around social identities, particularly about women, disabled, and racialized people, marked a larger ontological concern regarding the labelling and classification of individuals moving "within and across categories of meaning" (1). Samuels notes that "*fantasies of identification* seek to definitively identify bodies, to place them in categories delineated by race, gender, or ability status, and then to validate that placement through a verifiable, biological mark of identity" (2). She argues that fluid social identities become fixed, verifiable, legible and categorizable through the practices of modern science. This fixing occurs, she argues, in a few key ways: claiming a scientific and medical authoritative frame despite often exceeding or contradicting scientific

evidence, such as the way in which 19th century American racial medicine buttressed the institution of slavery and settler colonialism and naturalized the superiority of the white race (Samuels 2014, 11); influencing law, policy, and representations, operating at once on the level of common-sense all the while hailing experts to discern proper meanings, such as with the conflation of disability with a wheelchair user (see Chapter 2); the fantasies of identification "stubbornly persist, despite being disproved, undermined, or contradicted" (Samuels 2014, 3) such as with the persistent claims of genetically based racial difference; are "haunted by disability even when disabled bodies are not their immediate focus" (Samuels 2014, 3) such as with "the proliferation of disability imagery in debates over slavery and the postbellum status of African Americans as well as women's education and suffrage" (Samuels 2014, 14); and are actualized through desires that have material effects on lives and bodies (Samuels 2014, 3).

For our purposes here, an important aspect of the way in which disability comes to be considered as a "knowable, obvious, and unchanging category" is through processes of what Samuels calls "biocertification" (122), which describes the modern bureaucratic ways by which individual identity is authenticated through biology: "Biocertification materializes the modern belief that only science can reliably determine the truths of identity and generally claims to offer a simple, verifiable, and concrete solution to questions of identity" (122). Such processes of biocertification, Samuels argues, are nowhere more apparent than with the "institutionalization of blood quantum identification for Native people of the United States" (141). Samuels notes the ways in which racialized blood quantum, which charts the "amount of" Native or Indian heritage in a person in the US and has been deployed through the Certificate of Degree of Indian Blood (CDIB) since the 1930s, functions through and with the historical emergence of categories of disability in the US. In particular she notes how The Dawes Rolls, emerging out of the General

Allotment Act of 1887, parceled 160-acre land allotments to valid Indian claimants on the basis

of competency. As Samuels notes, "It was deemed that only a sufficient percentage of *white*

blood conferred competence upon the Indian landholder" (163). Thus, while "a substantial

degree of Indian blood was required to *receive* a land allotment… a majority of white blood was

required in order to have full legal *control* over that allotment" (164).

Requiring a certain percentage of white blood for a Native people to be fully capable

emerged out of a colonial characterization of Native people as inferior. Such characterizations of

inferiority drew centrally from ideas about disability, where Native people were described as

"wards", "weak", "helpless", or "stupid". Indeed, as Samuel points out, a court decision of 1912

marks a family having one-eighth Indian blood as having sufficient blood to "substantially

handicap them in the struggle of existence" (qtd. in Samuels 165). As such, the scientific truth-

rendering of blood quantum and impairment status, as marked through processes of

biocertification invoke and stabilize categories of race and disability, functioning to create

knowable social identities so as to govern them accordingly. It is not that the biocertification of

Native and disabled people are analogous, but rather that the racialized historical, cultural, and

legal processes that produced biocertification were also embedded and mutually constitutive of

the production of modern understandings of both "disabled" and "normal" bodies (Samuels

2014, 162).

The relationship between blood, biocertification and the co-production of race and

disability can be further charted through the history of the *Ugly Laws* in the US (1860s-1970s;

see Schweik 2009) and through the flourishing of eugenic policies, laws, and practices that mark

biology as a way of stabilizing otherwise fluid identities. For example, in 1882 the first eugenic

US immigration law barred Chinese immigration but also people deemed undesirable such as

convicts, "lunatics", "idiots," and those unable to take care of themselves without becoming "a public charge" such as the disabled, pregnant women and the poor. Medical officers were tasked with certifying and excluding immigrants who had a "*loathsome* or dangerous contagious disease" (Schweik 2009, 167). As Susan Schweik notes "At Angel or Ellis Island, any immigrant body might be understood as inevitably diseased, infectious, and loathsome, a danger to the entire nation" (168). Or as Douglas Baynton argues, disability has been "instrumental in crafting the image of the undesirable immigrant" (2001, 45). The growth of eugenics between 1890 and 1930 in the US as an etiology of abnormality that can be passed from one generation to the next "anchored" to what Snyder and Mitchell have called "diagnostic regimes" that pathologize groups viewed as nonnormative (2006, 71).

These diagnostic regimes functioned through biocertification, marking both racialized bodies and disabled bodies in varying ways. For example, the "division of Native people into categories of full-blood/unimprovable and mixed-blood/improvable was notably mirrored by developments in disability policy during the same period, particularly in the case of the feebleminded" (Samuels 2014, 176). By the late nineteenth century it was assumed that "no amount of education or good environment can change a feeble-minded individual into a normal one" (176). The characterization of "the feebleminded person's 'brutishness', 'animal nature', and 'child-like dependence' closely corresponds to terms used to describe Native peoples throughout U.S. history" (176).

Biocertification today largely functions to regulate Native identity in the US rather than measure competency, and for disability, it primarily works to limit or grant access to resources and accommodations (Samuels 2014, 179). In both contexts, however, biocertification works to stabilize the identity of a knowable subject. Biocertification also works through mundane testing

practices, and also by proxy – a way of classifying populations biologically even if they have not actually been biopsied; the certification works as if they have. In the case of disability, biocertification is part of a process of biological diagnosis, where, following Lennard Davis, it becomes possible to know diseases apart from other diseases or apart from anything else (1995, 85). Impairments become discrete categories of existence that can be known and governed. Blood has long been a way of forging identities, and this forging has continued in new ways post-genomic mapping of human DNA. That is, blood is being used to create new forms of disabled biosociality that have consequences for how the biology of impairment itself enacts disability.

The Biosocial Facts of the Matter

The question whether the result of my blood test made me feel different was posed just a few years after the introduction of Paul Rabinow's neologism of biosociality (1996), what Thomas Lemke describes as "one of the most influential contributions in science and technology studies in the past twenty years" (2015a, 2). Rabinow's biosociality refers to two key shifts. In the first, biosociality marks the way in which biological and material life processes and social and cultural practices are entangled, breaking down the border between nature and culture. Secondly, biosociality charts the various ways in which novel alliances have formed between patients, scientists, politicians, doctors, biotech and pharmaceutical companies that produce new kinds of entangled relationships formed through genetic knowledge. To mark this shift towards biosociality emerging out of breakthroughs in genomic research, Rabinow draws on Foucault's concept of biopower, noting that with the advent of the human genome project and the increasing role genomic research plays, a "post-disciplinary rationality" is emerging and re-articulating what Foucault had understood as two regimes of biopower: the disciplining of an individual

human body and the regulation of populations through "strategies concentrating on knowledge, control, and welfare" (Rabinow 1996, 91). In Rabinow's view, genetics are revolutionizing and transforming both life processes and social practices to such a degree – and supplanting the division between nature and culture – that we are in the midst of a post-disciplinary rationality that operates on the micro-level of molecular interventions. This is not to suggest the complete biologization of the social, or that social projects be translated into biological categories (as is the case with socio-biology or social Darwinism), but rather a re-configuration of social relations by means of biology (Lemke 2015a) where biology is also a social practice: "Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural" (Rabinow 1996, 99).

Many scholars working in science and technology studies have long marked the continuum of the social and the natural. For example, in *Simians, Cyborgs, and Women: The Reinvention of Nature,* Donna Haraway argued that there are no natural objects separate from social relations (1991, 10). Rabinow's "dissolution of the category of 'the social'" and his interest in marking society as "a way of life" is consistent with other STS scholars who hold that "society" should be avoided in favour of multiple and diverse processes and relations between a variety of social and natural actors and networks (Lemke 2015a; see, for example, Latour 2005). However, as Lemke (2015a) argues, the take up of Rabinow's notion of biosociality has largely been not to explore how the disruption to natureculture for biologicalized subjects has functioned but rather to explore the ways in which genomic research has lead to the "formation of new group and individual identities arising out of these new truths" (Rabinow 1996, 102). Rabinow suggested in the early 1990s that increasingly precise genetic testing will make it possible to detect, prevent, and treat diseases in ways such that new forms of biosocial identities will emerge

based on particular genetic markers. Rabinow noted: "it is hard not to imagine groups formed

around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution.

Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy

panoply of pastoral keepers to help them experience, share, intervene, and 'understand' their

fate" (1996, 102).

Much research has followed Rabinow's hunch, charting the many and multiple ways in

which patients are biosocially hailed, producing new forms of subjectivity. Research on

biosociality has covered the ways in which the practices of self-help groups and patient advocacy

organizations produce, legitimize, and appropriate genetic or biomedical knowledge. Further

research has traced the ways in which new kinds of biosociality have emerged "from below"

rather than by way of expert or medical authority, through shared knowledge about genetic

properties and risks, in communicating medical options for treating diseases, and in engaging

with ethical conflicts (Lemke 2015a). Self-help groups and patient organizations seek to increase

public awareness and interest in their causes and attract funding for research and treatments

related to their conditions. Secondly, these groups are also often concerned with the regulation of

research and seek to work with scientists and government in pushing the agendas of their

respective conditions. Callon and Rabeharisoa chart how French patients become biosocial

through human and nonhuman "socialization" (2007, 240), noting for example how the gene that

is responsible for the exon deletions in SMA "links patients and their families to various actors."

These relationally linked actors include the researchers who successfully located and identified

the gene, the clinicians who perform prenatal tests to identify the condition, the researchers who

publish articles on various interactions and activities of the proteins that are produced by the

gene, or who publish on results emerging from drug testing, and so on. Callon and Rabeharisoa

remark that this "sociotechnical network" that has implications and ramifications across the globe "would never have existed without the activity of this gene that appears in cell banks, is expressed in the inscriptions produced by instruments, influences decisions during prenatal diagnoses, appears in articles published by researchers, and makes tracheotomies acceptable and bearable" (2007, 240). Indeed Callon and Rabeharisoa further note that this "sociotechnical network" would not have emerged in the same form nor had the same kind of distribution "if the patients and families had not invested in each stage of the research, from the gene hunt, to the diffusion of knowledge, through the creation of research facilities." For it has been precisely through this biosocial "process of inclusion, in which one of the most powerful operators is the gene itself, that patients exist as recognized actors and progressively shape their own evolving multiple identities" (2007, 240). Callon and Rabeharisoa conclude that it is through the mediation of the human-nonhuman "that the social proliferates and human persons are produced" (2007, 24). The SMA gene, "hunted, inspected, tamed, or in the process of being tamed, participates in the construction of long and highly differentiated sociotechnical networks" (2007, 240).

Finally, research has charted the ways in which risk and prevention have become key sites of subject formation for biosocial subjects. For example, Taussig, Rapp and Heath chart the development of forms of embodiment and subjectivity emerging between biomedical experts and lay health advocates in an era of genetics. They note that genetic and eugenic thinking is part of "technologies of the self.... the practices by which subjects constitute themselves, and work to improve themselves, while living within institutional frameworks of power" (2003, 59). Charting the development of the Little People of America, the first US national organization formed on the basis of phenotypical difference, the authors note that "we all live inside a world saturated by

genetic discourses" (2003, 60), and that "long-standing discourses on individualism and choice are now filtered through newer interventions that include the molecular or genetic, as well as older and constantly escalating ones provided by pharmacology and surgery, all in the service of sculpting flexible bodies" (2003, 66). For Taussig, Rapp and Heath, this kind of genetic organization represents a new mode of "flexible eugenics" that brings together free choice and the marketplace, where "long standing biases against atypical bodies meet both the perils and the possibilities that spring from genetic technologies" (2003, 60), in order to use "technologies of the self through choosing and improving one's biological assets" (2003, 65).

This rise in the entrepreneurial biopolitical subject marks another major shift in biosocial identities that invokes Rabinow's post-disciplinary rationality. Rabinow marks this post-disciplinary shift in two distinct ways. First he notes that a change in social technologies minimizes direct therapeutic intervention and is "supplanted by an increasing emphasis on a preventative administrative management of populations at risk" (1996, 99). Secondly, he argues that a post-disciplinary biosocial subject promotes "working on oneself in a continuous fashion so as to produce an efficient and adaptable subject" (Rabinow 1996, 100). These trends, Rabinow notes, incite an instrumentalized approach to both the environment and to the individual: prevention and risk. "Risk is not a result of specific dangers posed by the immediate presence of a person or group but, rather, the composition of impersonal 'factors' that make risk probable. Prevention, then, is surveillance not of the individual but of the likely occurrences of diseases, anomalies, deviant behavior to be minimized, and healthy behavior to be maximized" (Rabinow 1996, 100).

Rabinow notes there is a shift away from the surveillance of individuals "toward projecting risk factors that deconstruct and reconstruct the individual or group" (1996, 101). Risk

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is about a population where it is "not who one is but what one does that puts you at risk" (100).

Rabinow suggests that more and more forms of pastoral care, "ranging from behavior

modifications, to stress management, to interactional therapies of all sorts" will emerge to

overcome and prepare for risks associated with disabilities, diseases, or conditions (103).

Further, "post-disciplinary practices will co-exist with disciplinary technologies; post social-

biological classifications will only gradually colonize old cultural grids" (103). Haraway labeled

this the "death of the clinic" in her *Cyborg Manifesto* where normalization and medicalization

are replaced with networking, communication redesign, and things like stress management. In

other words, medicalization and normalization continue even though "the meanings and practices

that constitute them certainly are changing" (Rabinow 103). Lemke notes: "In principle,

everyone is affected by genetic risk and potentially 'ill', current eugenic practices no longer focus

on 'purification of a collective genetic pool, but on 'government' of individual genetic risks.

Instead of eugenic programmes enforced by state institutions, relying primarily on repressive

means, we find apparatuses of risk, aiming at the productive enhancement of individual human

capital in the name of self-determination and choice" (2002, 283). For Clarke et al., health

becomes, paradoxically, more biomedicalized through such processes as surveillance, screening,

and routine measurements of health indicators done in the home, and seemingly less medicalized

as the key site of responsibility shifts from the professional to the individual (2003, 173). Both

the extension of medical jurisdiction over health and the commodification of health are

fundamental to new processes of biosociality.

These ways in which patients are biosocially hailed, producing new forms of subjectivity,

are important in the constellation of how it is possible to ask the question of "do you feel any

different?" My individual blood marks me as part of a group that can advocate, be part of drug

trials, go to conferences, wear swag expressing hope for a cure, and promote my "biological citizenship" (Petryna 2002). But I am also hailed to feel different in the prognosis of my very individualized risky body. I need extended health insurance. I should exercise proactively to ward off the future degeneration that is coded into my genes. I am hailed to enhance and capacitate so as to be a better neoliberal consumer. And yet, after reflecting on how this question can come to be asked, and further, what kind of answers it contains within its very framing, I am inclined to conclude that my very individualized disabled identity is actually quite relationally natureculture all the way down to the missing exon in my molecules, as I will chart through the rest of this chapter. This relational natureculture aspect of my biosociality has largely been elided by much of the literature taking up biosociality, and yet has some interesting consequences for how we continue to think about the biological facts of disability beyond the scope of the well-trodden social model/impairment debates.

Disability's Natureculture

Lemke (2015a) argues that while important work has been done to chart biosociality as a collective form of action, a group identity, as a form of political activism or as a way of socially engaging patients' associations and self-help groups, biosociality runs the risk of overemphasizing the social processes while fixing the biological as a stable material foundation. As Lemke further suggests, this stable biological material foundation contradicts the very tenet of biosociality as dissolving the separation between nature and culture. While this is not the case across the board, it certainly resonates as a problem within disability studies where both the agentive nonhuman and the biological are largely left out of the tellings of disability. To address some other ways of thinking about the biological as agentive or as multiple, I turn to the work of Aryn Martin and Annemarie Mol.

Martin, in her discussion of human chimeras and microchimeras – people who have multiple distinct cell populations – marks the ways in which genetic essentialism has become a proxy for personhood in that a genome is a property one is considered to have as a marker of identity. Instead, presenting evidence from interviews with scientists as well as through a popular accounting, Martin shows how chimeras biologically challenge the idea of a singular "intact and inviolable personhood" (2008, 222). The body is never self-complete, bounded against otherness but is caught up in a web of connections that disturb the very idea of individual human being. In telling the story of Mrs. McK, the first human blood chimera with a blood mixture of both type O and A, alongside others who have genetic chimerism where two (or presumably more) cell lines can be found throughout the body rather than being limited to the blood, Martin notes "it is clear that chimerism causes people to flirt with notions of multiplicity in a more than trivial way" (2008, 222).

In another article investigating microchimerism, Martin describes a woman whose liver was found to be partially composed of cells derived from a male fetus. Genetic markers were used to show that the cells actually originated from a prevsiouly terminated pregnancy (2010, 33). Research such as this marks the potential for the cells of others to be found in what we take for granted to be our bodies as "pure collections of genetically identical, self-same cells" (34). This resonates with other research, like that done by Margrit Shildrick showing how the incorporation of donated organs retain their own DNA signature:

> What returns biology itself to the realm of the unsettling, however, is the occurrence of chimerism within the recipient body, not simply at the immediate site of the graft – where the donor DNA is supposed to stay in situ maintaining its non-self materiality at the cost of a life-long hostile response from the recipient's own immunological system – but in the form of circulating cells that code for the donor. According to the standard biomedical game plan, this simply is not supposed to happen, it is little reported, and there is as yet no clear explanation of what is going on. (2010, 19)

Similarly, Catherine Waldby and Robert Mitchell (2006) have traced how our bodies are full of bacterial others, that when read alongside Hannah Landecker (2011) marks how food that enters the body never leaves it, transforming both "the body" and the various organisms within it.

While biology must not be the only basis for identity and collective action, neither should it be rejected for conjuring up a stable, individualized and dividable subject. Rather, a turn to blood – my blood – is a chance to consider the biological as a shifting entanglement of relations such that we recognize how the truth-effects of blood, genes, and diagnoses function to create not only stable identities of disability as something you are or are not, but also stabilizes biology itself as a fixed material foundation for political activism or social mobilization (Lemke 2015a). As Martin's work on chimeras demonstrates, what we thought we knew about genetic identity changed, and very well may change again. The biology of disability is itself a site of contestation and shifts: the way in which a disease is defined, the way in which causal mechanisms are explained, or the strategies developed for intervening are scientifically and medically contested and contingent.

For example, in *The Body Multiple: Ontology in Medical Practice,* Annemarie Mol (2002) traces the way in which atherosclerosis is diagnosed and treated. Through her ethnographic work, Mol finds that "no object, no body, no disease, is singular" (6) for "*ontologies* are brought into being, sustained, or allowed to wither away in common day-to-day, sociomaterial practices" (6). Mol's book is not about what is known about an object but rather the ways in which medicine attunes to, interacts with, and shapes its objects through practices. In these practices, Mol finds that what appears to be a single object may be more than one: "If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead, objects come

into being – and disappear – with the practices in which they are manipulated" (2002, 5). Because the "object of manipulation" will differ from one practice to another, "reality multiplies" (2002, 5). But this multiplication is not a fragmentation: "far from necessarily falling into fragments, multiple objects tend to hang together somehow" (2002, 5).

Rather than epistemologically approaching atherosclerosis to find an accurate representation of what it *is,* Mol theorizes medicine's ontological politics as "a politics that has to do with the way in which problems are framed, bodies are shaped, and lives are pushed and pulled into one shape or another" (2002, viii). The body and disease are more than one, but argues Mol, "this does not mean that they are fragmented into being many" (2002, viii). Mol thus asks "what is atheroscleroses in practice?" which ends up intertwining both the biomedical and social side of the disease. Mol notes: "This illness is something being done to you, the patient. And something that, as a patient, you do" (2002, 20). Further, in order for the disease to exist, it must be be enacted in practice, as in order for a patient to become a patient with a disease, the patient must visit a doctor. For example, as Nikki Sullivan notes, "The meaning of the disability for the patient must be incorporated into the very definition of that disability as disease" (qtd in Mol 2002, 46).

The body multiple hangs together - in this way it is not fragmented. "If we no longer presume 'disease' to be a universal object hidden under *the* body's skin, but make the praxiographic shift to studying bodies and diseases while they are being enacted in daily hospital practices, multiplication follows. In practice a disease, atherosclerosis, is no longer *one*" (2002, 83). A body in a hospital is more than one but less than many. It hangs together, but does not form a whole, marking the common-sense singularity of objects as an accomplishment: "The

relative scarcity of controversy in daily practices, where so many different objects go under a single name, is likewise a remarkable achievement" (2002, 119).

Blood, genetics, diagnosis are typically practiced as ways to stabilize identities so as to be able to know and govern them. As a practice, however, taking up disability biosocially is to figure it as an intracorporeal emergence. The notion of intracorporeality posits that bodies are formed *within a relation*, rather than formed "across" or "between" already-formed bodies, where not all bodies are human ones. To perceive how bodies emerge within a relation is to emphasize that any given body only ever emerges from, and is constituted by and within, always already entangled relations. Such an intracorporeal emergence suggests that any enactment of a body is ontologically and epistemologically saturated, never stable, or final.

Following Karen Barad (2007), and building on Shelley Tremain's denaturalization of impairment (2002), I want to argue that disability is not a property of a thing. In other words, disability emerges as an historically-specific onto-epistemological materialization of intra-active bodies. Onto-epistemology highlights knowing as a material practice of engagement that is of the world in its differential becoming (Barad 2007, 89). Epistemology and ontology, like impairment and disability, cannot be separated because practices of knowing are material in ways that are saturated in power relations that constitute how a subject or object emerges, though they do not fully determine its emergence. In this way, impairment/disability is not a biological or social identity that inheres within a body, but rather is a material practice: natureculture all the way down. The question, then, of "Do you feel different?" is important for forging an ethos of disability as an intracorporeal emergence of the human and nonhuman.

The Biosocial Matter of Facts

If I didn't feel different years ago upon receiving a piece of photocopied paper confirming my diagnosis, I do feel different today. Today, I am hailed in many and multiple ways by my diagnosis, by the blood and molecules circulating inside and outside of me, in part, perhaps because I have long stopped exceeding the expectations of my diagnosis. As some of my physical capabilities deteriorate, I am aware of the ways by which degeneration has always been part and parcel of my diagnosis, of my future predicted, of my orientation to what disability is and becomes, even during the period when my diagnosis was questioned. The story of my physical degeneration was predicted by my blood as a body always already becoming "more" disabled. This future arrives for me everyday, even if it can only be marked in hindsight. But importantly, the details of my embodiment cannot be limited to the "facts" of my blood. What the details show is precisely that my disability is not found in my blood or in my muscle denervation, but rather is an intracorporeal emergence, that invokes a complex constellation of needle production, biopsy procedure, genetic counseling ethics, race, class, gender, sexuality statuses, curb cuts, cyborgs, the human-non-human, conferences, fund raising, cures, pharmaceutical development, neoliberal entrepreneurial individualism, motherhood, *and*, *and*, *and*. My disability is not mine, it is *of* the world, of others both human and nonhuman. And as such, it is not my individual problem, but always already an incredibly complex entanglement: an intracorporeal emergence that in its various entangledness marks the question of "do you feel any different?" anew again and again because these feelings, these deleted exons, these capacities and debilities, are not just mine. They extend in and out of me. That is the point that we must continue to grapple with in our tellings of, and worlding-relations with, disability.

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Chapter 9

Conclusion

Sidewalk Stories I.

In the winter of 2009, I was walking along St. George Street in Toronto when I slipped on a patch of ice just outside the entrance to the subway. From my new vantage point, the sidewalk appeared to be a sea of ice surrounding all sides of my body as I struggled to get to my feet. Students with backpacks stepped around me as they entered the subway station. As I got increasingly wet and cold, I looked around to figure out what to do. A woman approached me with a smile and asked if I needed any help. I looked up at her, noting the many grocery bags she carried in one hand alongside a pie delicately balanced in the other. "I do need help," I said to her. But before I could explain what might be helpful, she yanked at my hand, entangling me with her grocery bags. I hardly moved off the ground, but I moved enough to knock her off balance and send her, her groceries, and her pie to join me on the ice. "Sorry," I said. "But I can't get up like that." Her smile faded and as she picked herself up she asked: "What do you mean you can't get up like that? Who would let you go outside if you can't get up?" We had attracted a small crowd at this point, and before I could respond a man came up behind me, grabbed me under my arms, and pulled me up. As I shook myself free, the woman pointed down and said "Look, you ruined my pie. You shouldn't go out in this weather."

II.

The following summer I was walking home from the subway when I tripped and fell in front of a café. The owner came rushing out with a glass of water and helped me to my feet.

"This heat!" he exclaimed. "It makes me dizzy. You are dizzy! Have some water. Would you like a cookie?" I didn't bother correcting his interpretation and thanked him for his help.

III.

Fast forward to January 2015. Once again I was out in "this weather," worried about how quickly my battery was draining as my scooter tried valiantly to plough through the snow of the unshoveled sidewalks. I was just a few blocks away from home when my scooter blew a fuse and abruptly died while trying to get up a particularly snowy curb cut. A man passed by and asked if I had someone I could call to help me. "I do," I said. "Great," he responded. "You're all set."

IV.

Someone I know is pregnant. "Congratulations" I said as we stand outside together. "We aren't sure if we are going to move ahead with the pregnancy," she said. "We don't have all the results back yet." A few weeks later, I received a text that declared what was once something not to celebrate is now a healthy baby girl.

The Tellings of Disability

The pie is ruined; you shouldn't be outside. The heat is dizzying; have a cookie. I have a phone; I am all set. Good news, the baby is healthy. Disability continually emerges and is re-made in relation with others; it is not mine to hold nor another's to claim. But, as I have marked in this dissertation, many of the tellings of disability emerge through the frames created by the biopolitical neoliberalization of disability relations. These frames function to render disability to be found in certain places, spaces, times, subjects and objects; disability can can loom as a possibility and its absence can be felt to open up a brighter future.

I have traced out the ways in which the biopolitics of disability, constituted within the contemporary neoliberalization of capitalist economies, enables some disabled bodies to live while others are left to die. By being compelled to either work to become legitimate disabled subjects or risk being excluded altogether, the contemporary production of disability is deeply entrenched in neoliberalized disability relations. I have argued that while ableism insidiously persists and continues to exclude and marginalize individuals through rendering disabled bodies as abnormal, neoliberal capacitation does not necessarily work to normalize disabled subjects. Instead, through the neoliberalization of disability relations, some disabled bodies and disabled subjects become valued as the abled-disabled. Therefore, neoliberal modes of capacitation and debilitation work alongside and also cross ableist categories to include enhanced and capacitated abled-disabled bodies and subjects.

Not limited to the capacitation of the abled-disabled, in this dissertation I also explored the ways in which practices of neoliberalization economize all aspects of life and financialize disability relations through both capacitating and debilitating disability. I did so by charting the social, political, economic, and cultural value of the difference of disability across various entangled sites that marked disability as multiple, contradictory, and ambivalent. In these different spaces, places, times, subjects and objects, I found that the neoliberalization of disability relations produces the social, political, and cultural conditions for the economization and individualization of disability. In sum, disability emerges as a problem to be solved, whether by way of the future-oriented promises and enhancements of biocapitalist technoscience, through processes of self-care, or through the good feelings of inclusion. These promises, processes, and feelings were explored in my dissertation to mark the ways by which the very social, material,

cultural, political, and economic practices and discourses by which disability comes to function is often erased or elided.

In Chapter 2, I explored how the wheelchair became both a marker of disability and also how the wheelchair is entangled in the emergence of neoliberalism. I argued that the way in which the International Symbol of Access and the wheelchair marks inclusion for disabled people is continuously mobilized in contradictory and ambivalent ways in contemporary neoliberal social relations. I noted that the ISA can be the source of disability pride, or a helpful sign to navigate around barriers, but it also offers a glimpse into the ways disability rights arose alongside the integration and capacitation of certain kinds of disabled people into neoliberalized capitalist social relations and how that integration and capacitation is caught up in the circulation of happy affects. The collective ease of good feelings of these happy affects of inclusion comes at the expense of the killjoy, at the expense of the "benefit scrounging scum" and at the expense of all those who leak outside of the boundaries produced by the ISA. While accessibility and the rights disabled people have fought for are very important, the symbol functions to both include and capacitate disability and to exclude and debilitate disability in particular ways, all the while making us feel good about consuming accessibility and feel like once the ISA appears, we've taken care of the problem.

In Chapter 3, I built on this idea of taking care of the problem of disability by delving into the politics of neoliberal biocapitalism and its implications for disability. Noting that the technologies that improve the lives of disabled people are part and parcel of the socioeconomic and political context that also produces disability and debilitates certain populations, I critically assessed the ways in which neoliberalism, the life sciences, and disability movements function to materially and discursively produce disability. In marking the ways in which biocapitalist

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economies capacitated and debilitate disability, I argued that this framing challenges the "wounded attachment" that many disabled people and scholars have in reproducing disability as an oppressed identity and an aggrieved subject. I argued that by focusing on normal/abnormal, or abled/disabled rather than on gradations of debility and capacity, disabled people hang onto an understanding of themselves as being excluded in a way that is not productive for fighting the neoliberal conditions in which disabled people are situated. This is because, as I argued, disability's wounded attachments do not just foreclose the future, but they also obfuscate the present and risk misunderstanding the mobilizations of biocapitalism. Thus, I concluded by suggesting that we need to be attentive to the ways in which differential inclusion functions, who gets to have grievances, how neoliberal biocapitalism capitalizes on those grievances, and the ways in which disability activists and scholars are implicated in these productions.

I further trace out the politics of biocapitalism in Chapter 4, examining the discourses of "toxic fetuses." In that chapter, I marked the ways by which disability is made to be economically unviable through the mobilization of speculative futures that privileges individualized entrepreneurs who can be capacitated and made to overcome their debilitations so as to contribute to the present and future profitability of neoliberal biocapital. I emphasized the importance of reproducing disabled lives while remaining critical of neoliberal economies that produce disability as an individually economically quantifiable toxic condition.

In Chapter 5, I built on these speculative futures by turning my attention to how the withering of some disabled lives and the capacitation of others are a result of material and discursive processes that imagine the suffering disabled child as a life without a future. Building on Lee Edelman's (2004) critique of what he calls reproductive futurity that privileges the Child as the image of the future, I showed how neoliberal futurity underwrites the prevention of

disabled suffering. By looking across disparate discursive and material sites, I showed that as opposed to homogenizing actions and desires, neoliberal futurity is productive, informing economies that prevent life, end life, capacitate infantilized bodies, and re-invest a caring public in biocapitalism. I also showed that the suffering disabled child nonetheless re-inscribes the hope for a future without disability or, at least, a future in which disability no longer seems to be difference that matters. I showed that some disabled people flourish in the future precisely because their futures gain traction in neoliberal society and that these tractable futures demand that others have no future. I concluded that the fight is not an anti-social turn away from the future entirely, but a negative turn away from the future that is currently being served to us in the form of neoliberal biocapital that strives to foreclose the possibility of other worlds.

In Chapter 6 I began charting a path towards the possibility of other worlds. In building on the importance of "wounded attachments" as explored in Chapter 3 to question why it "is still not fashionable to be disabled" (Goodley, Hughes and Davis 2012, 1), I argued that this undesirability of disability stems in part from an ableist failure of imagination. I suggested that in order to practice disability differently, we must begin with heterotopic imaginations to reconfigure how disability emerges, with whom it emerges, and where. I argued that a heterotopic imagination takes intracorporeality seriously and forces us to reckon with the ways that disability is not just something that tragically appears in the world that we must tolerate or include, but rather that disability is an emergence of the world; that is, disability is a practice.

In Chapter 7, I addressed the ways in which dominant cultural discourses of disabled parenting, with a particular focus on disabled mothering, re-enforce disability as located in an individual body. I showed how neoliberal processes of capacitating disabled people as parents sustain and celebrate disability as an individual problem that can be overcome by an inclusive

society. Building on the good feelings of inclusion presented in Chapter 2, I showed how disabled people are hailed to feel good about being capacitated into ideal normative mothers through neoliberal forms of care. I concluded by showing how disabled mothering emerges intracorporeally within and between bodies. Such an approach to disability, I argued, contests the affective neoliberal forms of good feelings that re-enforce individualizing uptakes of disabled parenting. This is to place the emphasis on what we can create together without re-inscribing individual accounts of overcoming disability, or through evoking creative individual solutions in the face of austerity.

In Chapter 8, I examined how blood functions through modes of biocertification to co-produce race and disability in the US as a stable, biological property of an individual so as to be able to know and govern such social identities. I traced how with the rise of genomic research, this biologically-based stable-identification has become a form of "biosociality," pointing to the novel alliances between patients, scientists, politicians, doctors and biotech companies that give rise to new kinds of disability socialities. Building on Chapter 3, I argued that disability studies has largely left biology untouched as an active agent in the social production of disability and noted the ways in which disability as an intracorporeal emergence is both materially and socially "natureculture" all the way down to the molecules of the body. I suggested that the "facts" of blood could not be located in an individual disabled body. Instead, I point to a complex constellation of disability production. I concluded that disability cannot be mine alone, nor can it be someome else's. Rather disability is always already an incredibly complex entanglement that continuously alters our tellings of, and worlding-relations with, disability.

Disabled subjects teeter between being made to live or being left to die within the logic of neoliberalized biopolitics. Mapping out the power relations of the neoliberal material-discursive

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practices surrounding disability moves us away from positioning disability solely as a problem of exclusion to interrogating how worthiness as the basis of inclusion itself is both economically and socially produced within neoliberal biocapitalism. Focusing on the problematics of inclusion highlights the dangers that are interwoven with potential gains for disabled people becoming productive subjects. To move away from a neoliberal approach that includes only worthy disabled persons while also disrupting other ableist representations of disability as excessive, contaminated, helpless, deviant, tragic, and inferior, requires going beyond including more disabled people within the exploitative and individualized relations of neoliberalism. That is, challenging the undesirability of disability requires more than individualized access to education, employment, or social lives, but rather requires changing the conditions, practices, and discourses that surround and produce disability.

The Worlding-Relations with Disability

Disability is continuously and variously presented as a problem to be solved by the good feelings of inclusion, a problem to be solved by the wheelchair, a problem to be solved by biocapitalism, or charity, or living each day to the fullest, or employing people, or by embracing the promise of biosocial identity, or by having a healthy baby.

To read Barad through disability studies is to open possibilities of new tellings of disability, tellings that mark not disability as the problem, but rather the common-sense ways in which neoliberal relations inject themselves into our notions of the biological, of the future, and of what is possible. As such, the point is not to forge a disabled "we," but to forge a disability ethics that foregrounds the porosity of disability. It is an ethics that demands different practices of disability on the street, in the clinic, and with nonhuman others. It is an ethics that demands a shift in common-sense. Practicing disability differently, marking disability as an intracorporeal

emergence of the human and nonhuman demands that we give some things up in order to create

different promises, commitments, and futures.

Bibliography

Abberley, Paul. 1987. "The Concept of Oppression and the Development of a Social Theory of Disability." *Disability, Handicap & Society* 2 (1): 5–19. doi:10.1080/02674648766780021.

Abdelhadi, Abla. 2013. "Addressing the Criminalization of Disability from a Disability Justice Framework: Centring The Experiences of Disabled Queer Trans Indigenous and People of Colour." *The Feminist Wire,* November 21. Accessed on May 1, 2015. http://thefeministwire.com/2013/11/addressing-the-criminalization-of-disability-from-a-disability-justice-framework-centring-the-experiences-of-disabled-queer-trans-indigenous-and-people-of-colour/

Accessible Icon Project. 2013. "The Accessible Icon Project." Accessed May 1, 2013. http://www.accessibleicon.org/

Ahmed, Sara. 2004. *The Cultural Politics of Emotion.* Edinburgh: Edinburgh University Press.

———. 2007. *Queer Phenomenology: Orientations, Objects, Others.* Durham, NC: Duke University Press.

———. 2010. *The Promise of Happiness*. Durham, NC: Duke University Press.

Albo, Greg, Sam Gindin, and Leo Panitch. 2010. *In and Out of Crisis: The Global Financial Meltdown and Left Alternatives.* Oakland: PM Press.

Albo, Greg and Carlo Fanelli. 2014. *Austerity Against Democracy: An Authoritarian Phase of Neoliberalism?* Toronto: Socialist Interventions Pamphlet Series.

Alaimo, Stacy. 2010. *Bodily Natures: Science, Environment, and the Material Self.* Bloomington: Indiana University Press.

Alaimo, Stacy and Susan Hekman. 2008. "Introduction: Emerging Models of Materiality in Feminist Theory." In *Material Feminisms,* edited by Stacy Alaimo and Susan Heckman, 1–19. Bloomington: Indiana University Press.

Asch, Adrienne, and Michelle Fine. 1992. "Beyond pedestals: Revisiting the lives of women with disabilities." In *Disruptive voices: The possibilities of feminist research,* edited by Michelle Fine, 139–171. Ann Arbour: The University of Michigan Press.

Asch, Adrienne, Harilyn Rousso, and Taran Jefferies. 2001. "Beyond pedestals: The lives of girls and women with disabilities." In *Double jeopardy: addressing gender equity in special education,* edited by Harilyn Rousso and Michael L. Wehmeyer, 13–48. Albany: State University of New York Press.

Barad, Karen. 2007. *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning.* Durham, NC: Duke University Press.

———. 2008. "Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter." In *Material Feminisms,* edited by Stacy Alaimo and Susan Heckman, 120–156. Bloomington: Indiana University Press.

Barnartt, Sharon N. 2008. "Social Movement Diffusion? The Case of Disability Protests in the US and Canada." *Disability Studies Quarterly* 28 (1). http://dsq-sds.org/article/view/70/70

Barnes, Colin. 1997. "A Legacy of Oppression: a history of disability in western culture." In *Disability Studies: Past, Present and Future*, edited by Len Barton and Michael Oliver, 3–25. Leeds: The Disability Press.

Baynton, Douglas. 2001. "Disability and the Justification of Inequality in American History." In *The New Disability History: American Perspectives,* edited by Paul K Longmore and Lauri Umansky, 33–57. New York: New York University Press.

Bednarska, Dominka. 2009. "Rethinking Access." In *The Culture of Efficiency: Technology in Everyday Life*, edited by Sharon Kleinman, 158–169. USA: Peter Lang.

Bell, Chris. 2006. "Introducing White Disability Studies: A Modest Proposal." In *The Disability Studies Reader*, edited by Lennard Davis (2nd Edition), 275–282. New York: Routledge.

———. 2011. *Blackness and Disability: Critical Examinations and Cultural Interventions*. East Lansing: Michigan State University Press.

Ben-Moshe, Liat and J. W. Powell. 2007. "Sign of our times? Revis(it)ing the International Symbol of Access." *Disability and Society*, 22 (5): 489–505.

Berardi, Franco. 2011. *After the Future*. Oakland: AK Press

Berlant, Lauren. 1997. *The Queen of America Goes to Washington City: Essays on Sex and Citizenship.* Durham, NC: Duke University Press.

———. 2007. "Slow death (sovereignty, obesity, lateral agency)." *Critical Inquiry* 33 (4): 754–780.

———. 2010. "Cruel Optimism." In *The Affect Theory Reader,* edited by M. Gregg and G. Siegworth, 93–117. Durham, NC: Duke University Press.

———. 2011. *Cruel Optimism*. Durham, NC: Duke University Press.

Berlant, L., and D. Seitz. 2013. "Interview with Lauren Berlant." *Society and Space - Environment and Planning D*. Accessed March 29, 2015. http://societyandspace.com/2013/03/22/interview-with-lauren-berlant/

Berman, Jessica. 2014. "Toxic chemicals blamed for 'Silent Pandemic' of Brain Disorders in Children." *Voice of America*. February 15. Accessed January 30, 2015. http://www.voanews.com/content/toxic-chemicals-blamed-for-silent-pandemic-of-brain-disorders-in-children/1852000.html

Berube, Michael. 2013. "Disability, Democracy, and the New Genetics." In *The Disability Studies Reader,* edited by Lennard Davis, 100–114. New York: Routledge.

Birch, Kean and Vlad Mykhnenko. 2010. *The Rise and Fall of Neoliberalism: The Collapse of an Economic Order?* London: Zed Books.

Birch, Kean, and David Tyfield. 2013. "Theorizing the Bioeconomy Biovalue, Biocapital, Bioeconomics or . . . What?." *Science, Technology & Human Values* 38 (3): 299–327. doi:10.1177/0162243912442398.

Blackford, Karen A. 1993. "Erasing Mothers with Disabilities Through Canadian Family-Related Policy." *Disability, Handicap & Society* 8 (3): 281–294. doi:10.1080/02674649366780281.

Bliss, Eula. 2014. *On Immunity: An Innoculation.* Minneapolis: Greywolf Press.

Booth, Tim, and Wendy Booth. 1998. "The myth of the upside down family." In *Growing up with parents who have learning difficulties,* edited by Tim Booth and Wendy Booth, 146–168. London: Routledge.

Boucher, Norman, Patrick Fougeyrollas, and Charles Gaucher. 2003. "Development and Transformation of Advocacy in the Disability Movement of Quebec." In *Making Equality: History of Advocacy and Persons with Disabilities in Canada,* edited by Deborah Stienstra and Aileen Wight-Felske, 137–162. Concord, Ontario: Captus Press.

BBC [British Broadcasting Corporation]. 2014. "New Malden Deaths: Arrest after three children found dead." *BBC News,* April 23. Accessed March 29, 2015. http://www.bbc.com/news/uk-england-london-27122410

Brown, Lydia. 2015. "Undoing Racism & Anti-Blackness in Disability Justice." *Autistic Hoya,* April 14. Accessed May 15, 2015. http://www.autistichoya.com/2015/04/undoing-racism-anti-blackness-in.html

Brown, Wendy. 1993. "Wounded Attachments." *Political Theory* 21: 390–410.

———. 2005. *Edgework: Critical essays on knowledge and politics*. Princeton: Princeton University Press.

———. 2006. "American Nightmare Neoliberalism, Neoconservatism, and De-Democratization." *Political Theory* 34 (6): 690–714. doi:10.1177/0090591706293016

———. 2015. *Undoing the Demos: Neoliberalism's Stealth Revolution.* New York: Zone Books.

Butler, Judith. 1990. *Gender Trouble: Feminism and the Subversion of Identity*. New York: Routledge.

———. 1993. *Bodies That Matter: On the Discursive Limits of "Sex."* New York: Routledge.

Callon, Michael, and Vololona Rabeharisoa. 2007. "The Growing Engagement of Emergent Concerned Groups in Political and Economic Life: Lessons From the French Association of Neuromuscular Disease Patients." *Science, Technology & Human Values* 33 (2): 230–261.

Campbell, Fiona Kumari. 2009. *Contours of Ableism: The Production of Disability and Abledness*. New York: Palgrave Macmillan.

CBC [Canadian Broadcasting Corporation]. 2014a. "New list of missing, murdered aboriginal women gives families hope." *CBC News*. January 24. Accessed September 15, 2014. http://www.cbc.ca/news/canada/manitoba/new-list-of-missing-murdered-aboriginal-women-gives-families-hope-1.2510650

———. 2014b. "Disability Good for Business." *The National,* February 26. Accessed March 13, 2014. http://www.cbc.ca/player/News/TV+Shows/The+National/ID/2439758698/?page=2

———. 2014c. "21 year-old Ontarian, Paige Cunliffe, lives in a nursing home: 'This is not a home, it's an institution'." *The Current.* Sept. 8. Accessed September 8, 2014. http://www.cbc.ca/thecurrent/episode/2014/09/08/21-year-old-ontarian-living-in-a-nursing-home-this-is-not-a-home-its-an-institution-says-paige-cunli/

Chandler, Eliza. 2013. "Mapping difference: Critical Connections Between Crip and Diaspora Communities." *Critical Disability Discourse/Discours Critiques dans le Champ du Handicap* 5: 39–66.

Chen, Mel Y. 2011. "Toxic Animacies, Inanimate Affections." *GLQ: a Journal of Lesbian and Gay Studies* 17 (2): 265–286. doi:10.1215/10642684-1163400.

———. 2012. *Animacies: Biopolitics, Racial Mattering, and Queer Affect.* Durham, NC: Duke University Press.

Chouinard, Vera, and Valorie A Crooks. 2005. "'Because They have All the Power and I Have None': State Restructuring of Income and Employment Supports and Disabled Women's Lives in Ontario, Canada." *Disability & Society* 20 (1): 19–32. doi:10.1080/0968759042000283610.

Clare, Eli. 2001. "Stolen Bodies, Reclaimed Bodies: Disability and Queerness." *Public Culture* 13 (3): 359–365.

Clarke, A., J. Fishman, J. Fosket, L. Mamo, and J. Shim. 2003. "Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine." *American Sociological Review* 68 (April): 161–194.

Clifford, Stacy. 2012. "Making disability public in deliberative democracy." *Contemporary Political Theory* 11 (2): 211–228.

Club of Rome. 2015. "About the Club of Rome." Accessed March 1, 2015. http://www.clubofrome.org/?p=324

Cooper, Melinda. 2008. *Life as Surplus: Biotechnology and Capitalism in the Neoliberal Era.* Washington, DC: University of Washington Press.

Cross, Merry. 2013. "Demonised, impoverished and now forced into isolation: the fate of disabled people under austerity." *Disability & Society* 28 (5): 719–723.

Cure SMA. 2014. "We can see a future without SMA." Accessed November 1. http://www.curesma.org

Daily Mail. 2014. "Justin Bieber take a ride at Disneyland… in a wheelchair (after 'injuring his knee' during basketball game." *Daily Mail Online*. July 23. Accessed September 24, 2014. http://www.dailymail.co.uk/tvshowbiz/article-2703125/Justin-Bieber-takes-ride-Disneyland-wheelchair-injuring-knee-basketball-game.html

Davies, C. 2014. "No murder trial for mother who suffocated disabled children" *The Guardian,* 13 October. Accessed on December 5, 2014. http://www.theguardian.com/uk-news/2014/oct/13/no-murder-trial-mother-suffocated-disabled-children-tania-clarence

Davis, Lennard, J. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body.* New York: Verso.

Diamond v. Chakrabarty, 447 US 303. 1980.

Disney Parks. 2013. "Disney Parks Disability Access Service Card Fact Sheet*." Disney Parks Blog,* October 13. Accessed September 24, 2014. http://disneyparks.disney.go.com/blog/disney-parks-disability-access-service-card-fact-sheet/

Disney Parks. 2014. "Disney's VIP Tour Services." Accessed September 24, 2014. https://disneyworld.disney.go.com/events-tours/vip-tour-services/

Dolmage, Jay. 2012. "From Retrofit to Universal Design, From Collapse to Occupation: Neo-Liberal Spaces of Disability." Paper presented at the Society for Disability Studies 25th Annual Conference, Denver, Colorado. http://www.academia.edu/1244157/_From_Retrofit_to_Universal_Design_From_Collapse_to_Occupation_Neo-Liberal_Spaces_of_Disability_

———. 2013. "Disability Space-Time-Economy." Paper presented at the Canadian Disability Studies Association, Victoria, BC. http://disabilitycapitalism.wordpress.com/author/drjaydolmage/

Dowse, Leanne. 2009. "'Some People Are Never Going to Be Able to Do That'. Challenges for People with Intellectual Disability in the 21st Century." *Disability & Society* 24 (5): 571–584. doi:10.1080/09687590903010933.

Dumenil, Gerard, and Dominque Levy. 2005. "The Neoliberal (Counter-)Revolution." In *Neoliberalism: A Critical Reader,* edited by Alfredo Saad-Filho and Deborah Johnston, 9–19. London: Pluto Press.

Dumit, Joseph. 2012. *Drugs for Life: How Pharmaceutical Companies Define our Health.* Durham, NC: Duke University Press.

Durkheim, Emile. 1964. *The Division of Labour in Society.* New York: The Free Press.

Edelman, Lee. 2004. *No Future: Queer Theory and the Death Drive.* Durham, NC: Duke University Press.

Elliott, Carl. 2008. "Guinea-Pigging." *The New Yorker.* January 7. Accessed February 14, 2015. http://www.newyorker.com/magazine/2008/01/07/guinea-pigging

Engels, Fredreich. 1968. *The Condition of the Working Class in England.* Palo Alto: Stanford University Press.

Erevelles, Nirmala. 2011. "The color of violence: Reflections on gender, race, and disability in wartime." In *Feminist Disability Studies,* edited by Kim Q Hall, 117–135. Indiana: Indiana University Press.

———. 2014. "Thinking with Disability Studies." *Disability Studies Quarterly* 34 (2). http://dsq-sds.org/article/view/4248/3587

Erdreich, Sarah. 2015. "Parenting with Chronic Pain." *Slate,* January 2. Accessed January 15, 2015. http://www.slate.com/articles/life/family/2015/01/parenting_with_chronic_pain.single.html.

Evans, M. 2014. "Tragic mum will not face murder charges for killing her three disabled kids, court hears." *Express,* October 13. http://www.express.co.uk/news/uk/522136/Tragic-mum-will-not-face-murder-charges-for-killing-her-three-disabled-kids-court-hears Accessed on December 5, 2014.

Evans, S, and L de Souza. 2008. "Dealing with Chronic Pain: Giving Voice to the Experiences of Mothers with Chronic Pain and Their Children." *Qualitative Health Research* 18 (4): 489–500. doi:10.1177/1049732308315433.

Families of Spinal Muscular Atrophy [FSMA]. 2014. "Inaugural Southern California Cure SMA Gala of Hope." Accessed on December 5, 2014. http://www.fsma.org/Fundraising/EventsCalendar/index.cfm?id=8845&eventRedirect=1&type=1154.

Filax, Gloria and Dena Taylor. 2014. "Introduction." In *Disabled Mothers: Stories and Scholarship by and about Mothers with Disabilities*, edited by Gloria Filax and Dena Taylor, 1–18. Bradford: Demeter Press.

Fitzgerald, Larry. 2014. "One person can make a difference – A child changed me." *Wish Granted: 25 Stories of Strength and Resilience from America's Favorite Athlete,* edited by Make-A-Wish and Don Yaeger, 222-233. New York: Harper Collins

Ford, Norman M. 2002. *The Prenatal Person: Ethics from Conception to Birth.* UK: Blackwell.

Foucault, Michel. 1977. *Discipline and Punish: The Birth of the Prison.* Translated by Alan Sheridan. New York: Random House.

———. 1978. *The History of Sexuality Vol. 1: An Introduction.* Translated by Robert Hurley. New York: Pantheon Books

———. 1997a. "Polemics, Politics and Problematizations." In *Ethics, Subjectivity and Truth,* edited by Paul Rabinow, 111–119. New York: New Press.

———. 1997b. "What is Enlightenment?" In *Ethics, Subjectivity, and Truth*, edited by Paul Rabinow, 303–319. New York: New Press.

———. 1998. "Different Spaces." In *Aesthetics, Method, and Epistemology,* edited by James D. Faubion, 175–185. New York: New Press.

———. 2007. *Security, Territory, Population: Lectures at the Collège de France, 1977- 1978.* New York: Palgrave Macmillan.

———. 2008. *The Birth of Biopolitics: Lectures at the Collège de France, 1978-1979,* trans. Graham Burchell. New York: Picador.

Franklin, Kaliya, and Sue Marsh. 2011. "The Benefits Scandal: The Government Is Withdrawing the Support That Enables Disabled People to Work, While Simultaneously Arguing That More of Them Should Be Working." *Soundings*, 49: 43–56

Frederick, Angela. 2014. "Mothering While Disabled." *Contexts* 13 (4): 30–35. doi:10.1177/1536504214558214.

Freund, P. 2001. "Bodies, Disability and Spaces: The social model and disabling spatial organisations." *Disability & Society* 16 (5): 689–706.

Friedman, Milton. 2002. *Capitalism and Freedom.* Chicago: University of Chicago Press.

Fritsch, Kelly. 2010. "Intimate assemblages: Disability, intercorporeality, and the labour of attendant care." *Critical Disability Discourse/Discours Critiques dans le Champ du Handicap* 2.

———. 2013. "On the negative possibility of suffering: Adorno, feminist philosophy, and the transfigured crip to come." *Disability Studies Quarterly*, 33 (4). http://dsq-sds.org/article/view/3869/3408

Garland Thomson, Rosemarie. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

———. 2012. "The Case for Conserving Disability." *Journal of Bioethical Inquiry*, 9 (3): 339–355. doi:10.1007/s11673-012-9380-0

Gerber, David A. 2003. "Disabled Veterans, the State, and the Experience of Disability in Western Societies, 1914-1950." *Journal of Social History* 36 (4): 899–916.

Gibson, Barbara E. 2006. "Disability, connectivity and transgressing the autonomous body." *Journal of Medical Humanities* 27 (3): 187–196. doi: 10.1007/s10912-006-9017-6.

Gleeson, Brendan. 1999. *Geographies of Disability.* London: Routledge.

Goodley, Dan. 2014. *Dis/Ability Studies: Theorising Disablism and Ableism.* New York: Routledge.

Goodley, Dan, and Katherine Runswick-Cole. 2014. "Becoming Dishuman: Thinking About the Human Through Dis/Ability." *Discourse: Studies in the Cultural Politics of Education,* December: 1–15. doi:10.1080/01596306.2014.930021.

Goodley, Dan, Bill Hughes and Lennard Davis. 2012. "Introducing Disability and Social Theory." In *Disability and Social Theory: New Developments and Directions,* edited by Dan Goodley, Bill Hughes, Lennard Davis, 1–14. New York: Palgrave Macmillan.

Goering, Sara. 2008. "'You Say You're Happy, but…': Contested Quality of Life Judgments in Bioethics and Disability Studies." *Journal of Bioethical Inquiry* 5 (2-3): 125–135. doi:10.1007/s11673-007-9076-z

Gordon, Andrea. 2014. "Doctors fear kids' brain disorders tied to industrial chemicals." *The Toronto Star.* February 14. Accessed January 30, 2015. http://www.thestar.com/life/2014/02/14/doctors_fear_kids_brain_disorders_tied_to_industrial_chemicals.html

Gorman, Rachel. 2013. "Mad Nation? Thinking through Race, Class, and Mad Identity Politics." In *Mad Matters: A Critical Reader in Canadian Mad Studies,* edited by Brenda A LeFrançois, Robert Menzies, and Geoffrey Reaume, 269–280. Toronto: Canadian Scholars' Press.

Grandjean, Philippe and Philip J Landrigan. 2014. "Neurobehavioural effects of developmental toxicity." *Lancet Neurol* 13: 330–38. doi:10.1016/S1474-4422(13)70278-3.

———. 2006. "Developmental Neurotoxicity of Industrial Chemicals." *The Lancet* 368: 2167–78. doi:10.1016/S0140-6736(06)69665-7.

Green, David. 2012. "Incapacity Benefits: Death of recipients." *Department for Work and Pensions.* 9 July. Accessed May 20, 2015. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/223050/incap_decd_recips_0712.pdf

Groce, Nora. 2002. *From Charity to Disability Rights: Global Initiatives of Rehabilitation International, 1922-2002.* New York: Rehabilitation International.

Grue, Lars, and Kristin Tafjord Lærum. 2002. "'Doing Motherhood': Some Experiences of Mothers with Physical Disabilities." *Disability & Society* 17 (6): 671–83. doi:10.1080/0968759022000010443.

Guillot, Toni. 2014. "Blind woman told to look for work 'because she can cross road with help of her guide dog." *The Gazette.* September 19. http://www.gazettelive.co.uk/news/teesside-news/blind-woman-told-look-work-7797745

Hall, Stuart. 2003. "New Labour's Double-Shuffle." *Soundings*, 24: 10–24.

Haller, Beth. 1994. "The misfit and muscular dystrophy." *Journal of Popular Film and Television* 21 (4): 141–149.

Hamblin, James. 2014. "The Toxins that Threaten our Brains" *The Atlantic.* March 18.
http://www.theatlantic.com/features/archive/2014/03/the-toxins-that-threaten-our-brains/284466/

Hamraie, A. 2013. "Designing Collective Access: A Feminist Disability Theory of Universal Design." *Disability Studies Quarterly* 33 (4).
http://dsq-sds.org/article/view/3871/3411#endnoteref04

Hansen, Helena, Philippe Bourgois, and Ernest Drucker. 2014. "Pathologizing Poverty: New Forms of Diagnosis, Disability, and Structural Stigma Under Welfare Reform." *Social Science & Medicine* 103 (February): 76–83. doi:10.1016/j.socscimed.2013.06.033.

Haraway, Donna. 1991. *Simians, Cyborgs, and Women. The Reinvention of Nature.* New York: Routledge.

———. 1997. *Modest_Witness@Second_Millennium.FemaleMan_Meets_OncoMouse.* New York: Routledge.

Harvard School of Public Health. 2014. "Growing number of chemicals linked with brain disorders in children." February 14. Accessed January 30, 2015.
http://www.hsph.harvard.edu/news/press-releases/chemicals-linked-with-brain-disorders-in-children/

Harvey, David. 2005. *A Brief History of Neoliberalism.* Oxford: Oxford University Press.

Hayek, Freidrich von. 1976/1944. *The Road to Serfdom.* Chicago: University of Chicago Press.

Hays, Sharon. 1996. *The Cultural Contradictions of Motherhood.* New Haven: Yale University Press.

Hayward, Sally. 2009. "The Canadian Legal System, the Robert Latimer Case, and the Rhetorical Construction of (Dis)ability: 'Bodies that Matter?'" *Developmental Disabilities Bulletin* 37: 187–201.

Healy, Jack. 2014. "Legal Use of Marijuann Clashes with Job Rules" *New York Times.* September 7. http://www.nytimes.com/2014/09/08/us/legal-use-of-marijuana-clashes-with-workplace-drug-testing.html?_r=1

Helmreich, Stefan. 2008. "Species of Biocapital." *Science as Culture* 17 (4): 463–478. doi:10.1080/09505430802519256.

Hengehold, Laura. 2007. *The Body Problematic: Political Imagination in Kant and Foucault.* Pennsylvania: The Pennsylvania State University Press.

Hershey, L. 1993. "From Poster Child to Protester." Accessed December 5, 2014. http://www.independentliving.org/docs4/hershey93.html

Hershey, L. 2003. "Other Obnoxious Comments Made by Jerry Lewis." http://www.cripcommentary.com/jlquotes.html Accessed December 5, 2014.

Higgins, W. 1982. "To Him that Hath: The Welfare State." In *Australian Welfare History: Critical Essays,* edited by R. Kennedy, 199–224. Melbourne: Macmillan.

Hilgartner, Stephen. 2007. "Making the Bioeconomy Measurable: Politics of an Emerging Anticipatory Machinery." *BioSocieties* 2 (3): 382–386. doi:10.1017/S1745855207005819.

Hing, Julianne. 2014. "Race, Disability, and the School-to-Prison Pipeline." *Colorlines, News for Action.* May 13. Accessed September 15, 2014. http://colorlines.com/archives/2014/05/race_disability_and_the_school_to_prison_pipeline.html

Hoogsteyns, Maartje, and Hilje van der Horst. 2013. "Wearing the Arm (or Not). Reconceptualising Notions of in- and Exclusion in Disability Studies." *Scandinavian Journal of Disability Research* 15 (1): 58–69. doi:10.1080/15017419.2012.679687.

Hubbard, Ruth. 2013. "Abortion and Disability: Who Should and Should Not Inhabit the World?" In *The Disability Studies Reader,* edited by Lennard Davis, 74–86. New York: Routledge.

Hughes, Bill. 2009. "Disability Activisms: Social Model Stalwarts and Biological Citizens." *Disability & Society* 24 (6): 677–688. doi:10.1080/09687590903160118.

Hughes, Bill, L. McKie, D. Hopkins, and Nick Watson. 2005. "Love Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care." *Sociology*, 39 (2): 259–275.

James, J. C. 2011. "Gwendolyn Brooks, World War II, and the Politics of Rehabilitation." In *Feminist Disability Studies,* edited by K. Q. Hall, 136–158. Bloomington: Indiana University Press.

Jameson, Fredric. 1994. *The Seeds of Time.* New York: Columbia University Press.

Jasanoff, Sheila. 2004. "Ordering Knowledge, Ordering Society." In *States of Knowledge: The Co-Production of Science and Social Order,* edited by Sheila Jasanoff, 11–45. New York: Routledge.

Johnson, Mary. 1992. "A Test of Wills: Jerry Lewis, Jerry's Orphans, and the Telethon." *The Disability Rag.* September. http://www.raggededgemagazine.com/archive/jerry92.htm

Jordan, Michael. 2014. "Introduction." *Wish Granted: 25 Stories of Strength and Resilience from America's Favorite Athlete,* edited by Make-A-Wish and Don Yaeger, 12-31. New York: HarperCollins.

Kafer, Alison. 2013. *Feminist, Queer, Crip.* Bloomington: Indiana University Press.

Kant, Immanuel. 1998. *Critique of Pure Reason.* Translated and edited by Paul Gyer and Allen W. Wood. New York: Cambridge University Press.

Karlberg, Kristen. 2011. "Shaping Babies: No Not THAT Kind! Can I Try Again?" In *Gendered Bodies: Feminist Perspectives,* edited by Judith Lorber and Lisa Jean Moore, 36–47. New York: Oxford University Press.

———. 2010. "Am I Good Enough for My Family: Fetal Genetic Bodies and Prenatal Genetic Testing." *The Body Reader: Essential Social and Cultural Readings*, edited by Lisa Jean Moore and Mary Kosut, 66–79. New York: New York University Press.

Kelly, Christine. 2014. "Re/Moving Care From the Ontario Direct Funding Program: Altering Conversations Among Disability and Feminist Scholars." *Social Politics: International Studies in Gender, State & Society* 21 (1): 124–147. doi:10.1093/sp/jxt017.

Kemp, Evan Jr. 1981. Aiding the Disabled: No Pity Please. *New York Times.* September 3. http://www.nytimes.com/1981/09/03/opinion/aiding-the-disabled-no-pity-please.html

Kitchin, Rob, and Robert Wilton. 2003. "Disability Activism and the Politics of Scale." *The Canadian Geographer* 47 (2): 97–115.

Kolarova, K. 2012. "Affective Politics of Disability Shame in the Times of Neoliberal Exceptionalism." In *Import-Export-Transport. Queer theory, Queer Critique and Activism in Motion,* edited by S. Mesquita, M. K. Wiedlack, & K. Lasthofer, 261–279. Wien: Zaglossus.

———. 2011. "How Sam Became a Father, Became a Citizen: Scripts of Neoliberal Inclusion of Disability." In *Hegemony and Heteronormativity: Revisiting the "Political" in Queer Politics*, edited by M. do Mar Castro Varela, N. Dhawan, and A. Engel, 121–142. Burlington, VT: Ashgate Publishing.

Kurtz, H. 2001. "Jerry's Kidding, Edited Out." *Washington Post*, September 3. C1.

Kuttai, Heather. 2010. *Maternity Rolls: Pregnancy, Childbirth and Disability*. Halifax: Fernwood.

Lamm, Nomy. 2015. "This is Disability Justice." *the body is not an apology*, February 6. Accessed May 15, 2015. http://thebodyisnotanapology.com/magazine/this-is-disability-justice/

Landecker, Hannah. 2011. "Food as exposure: Nutritional epigenetics and the new metabolism." *BioSocieties* 6 (2): 167–194.

Lazzarato, Maurizio. 2009. "Neoliberalism in Action: Inequality, Insecurity and the Reconstitution of the Social." *Theory, Culture & Society*, 26 (6): 109–133. doi: 10.1177/0263276409350283

Lemke, Thomas. 2002. "Genetic testing, eugenics and risk." *Critical Public Health* 12 (3): 283–290.

———. 2011. *Biopolitics: An Advanced Introduction.* NY: New York University Press.

———. 2015. "New Materialisms: Foucault and the 'Government of Things.'" *Theory, Culture & Society* 32 (4): 3-25. doi:10.1177/0263276413519340

———. 2015a. "Patient Organizations as Biosocial Communities? Conceptual Clarifications and Critical remarks." In *The Public Shaping of Medical Research. Patient Associations, Health Movements and Biomedicine,* edited by P. Wehling, W. Viehoover, and Sophia Koenen, 191–207. London and New York: Routledge,

Lewis, Jerry. 1990. "If I had Muscular Dystrophy." *Parade Magazine.* September 2.

Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity.* New York: New York University Press.

Longmore, Paul. 2013. "Heaven's Special Child": The Making of Poster Children." In *The Disability Studies Reader*, edited by Lennard Davis, 34–41. Chicago: Routledge.

MWF [Make-A-Wish Foundation of America]. 2013. "The 2013 Annual Report." Accessed November 10, 2014. http://fy13annualreport.wish.org/our-year/

———. 2014. "Our Mission." Accessed November 10, 2014. http://wish.org/about-us/our-story/our-mission

———. 2014a. "Wish Impact and Facts" Accessed November 10, 2014. http://wish.org/wishes/wish-impact

———. 2014b. "How it all started." Accessed November 10, 2014. http://wish.org/about-us/our-story/how-it-started)

———. 2014c. "Working with Us." Retrieved from: http://wish.org/about-us/employment-and-internships/working-with-us)

Malacrida, Claudia. 2007. "Negotiating the Dependency/Nurturance Tightrope: Dilemmas of Motherhood and Disability*." *Canadian Review of Sociology/Revue Canadienne De Sociologie* 44 (4). 469–493. doi:10.1111/j.1755-618X.2007.tb01353.x.

———. 2009. "Performing Motherhood in a Disablist World: Dilemmas of Motherhood, Femininity and Disability." *International Journal of Qualitative Studies in Education* 22 (1): 99–117. doi:10.1080/09518390802581927.

Martin, Aryn. 2008. "The Chimera of Liberal Individualism: How Cells Became Selves in Human Clinical Genetics." *Osiris* 22 (1): 205–222.

———. 2010. "Microchimerism in the Mother(Land): Blurring the Borders of Body and Nation." *Body & Society* 16 (3): 23–50.

Marx, Karl. 1990. *Capital: A Critique of Political Economy, Volume 1*. Translated by Ben Fowkes. New York: Penguin Books.

Mattlin, Ben. 2007. "No Longer One of 'Jerry's Kids.'" *The Washington Post.* September 3. Accessed November 15, 2014. http://www.washingtonpost.com/wpdyn/content/article/2007/08/31/AR2007083101273.html

McCoy, Tracey Harrington. 2014. "In Disney Crackdown, Disabled Kids are the Collateral Damage." *Newsweek*. April 22. Accessed September 15, 2014. http://www.newsweek.com/disney-crackdown-disabled-kids-are-collateral-damage-10959

McKenzie, J. 2014. "Pope Francis in impromptu plea for peace: 'Please stop!'" *Haaretz*. http://www.haaretz.com/news/world/1.607404

McKeever, Patricia, Jan Angus, Karen Lee-Miller, and Denise Reid. 2003. "'It's More of a Production': Accomplishing Mothering Using a Mobility Device." *Disability & Society* 18 (2): 179–197. doi:10.1080/0968759032000052824.

McMahon, M. 1995. *Engendering Motherhood: Identity and Self-transformation in Women's Lives*. New York: The Guilford Press.

McRuer, Robert. 2006. *Crip Theory: Cultural signs of queerness and disability*. New York: NYU Press.

———. 2008. "Bad Education: Crip Representation and the Limits of Tolerance." Accessed November 1, 2014. http://disabilities.temple.edu/media/ds/mcruerTranscript2008.shtml

———. 2012. "The Crip's Speech in an Age of Austerity: Composing Disability Transnationally." Paper presented at the University of Toronto, Canada.

Michalko, Rod. 1999. *The Two in One: Walking with Smokie, Walking with Blindness.* Philadelphia: Temple University Press.

Milonakis, D and B. Fine. 2009. *From Political Economy to Economics: Method, the Social and Historical in the Evolution of Economic Theory.* New York: Routledge.

Minaki, Christina. 2014. "Scrutinizing and Resisting Oppressive Assumptions about Disabled Parents." In *Disabled Mothers: Stories and Scholarship by and about Mothers with Disabilities*. Edited by Gloria Filax and Dena Taylor, 31–48. Bradford: Demeter Press.

Mingus, Mia. 2010a. "Changing the Framework: Disability Justice." *RESIST Newsletter*. November/December. Accessed May 15, 2013. http://www.resistinc.org/sites/default/files/NovDec10NL_sm.pdf

———. 2010b. "Reflections On An Opening: Disability Justice and Creating Collective Access in Detriot" *INCITE!Blog*, August 23. Accessed May 1, 2015. https://inciteblog.wordpress.com/2010/08/23/reflections-from-detroit-reflections-on-an-opening-disability-justice-and-creating-collective-access-in-detroit/

Mingus, Mia and Greg Macdougall. 2013. "Beyond Access: Mia Mingus on Disability Justice" *The Icarus Project,* December 11. Accessed May 1, 2015. http://theicarusproject.net/disability/video-interview-wmia-mingus-on-disability-justice

Mingus, Mia and Heather Laine Talley. 2013. "Feminists We Love: Mia Mingus" *The Feminist Wire,* November 22. Accessed May 1, 2015. http://thefeministwire.com/2013/11/feminists-we-love-mia-mingus/

Mirowski, Philip. 2013. *Never Let a Serious Crisis Go to Waste: How Neoliberalism Survived the Financial Meltdown.* New York: Verso.

Mitchell, David T. 2014. "Gay Pasts and Disability Future(s) Tense." *Journal of Literary & Cultural Disability Studies* 8 (1): 1–16. doi:10.1353/jlc.2014.0000.

Mitchell, David and Sharon Snyder. 2003. "The eugenic Atlantic: Race, disability, and the making of an international eugenic science, 1800-1945." *Disability and Society*, 18 (7): 843–864.

———. 2010. "Disability as Multitude: Re-Working Non-Productive Labor Power." *Journal of Literary & Cultural Disability Studies* 4 (2): 179–194. doi:10.3828/jlcds.2010.14.

Mol, Annemarie. 2002. *The body multiple: Ontology in medical practice.* Durham, NC: Duke University Press.

Mollow, Anna. 2012. "Is Sex Disability?" In *Sex and Disability,* edited by Robert McRuer and Anna Mollow, 285–312. Durham, NC: Duke University Press.

Morini, Cristina, and Andrea Fumagalli. 2010. "Life Put to Work: Towards a Life Theory of Value." *Ephemera: Theory and Politics in Organization* 10 (January): 234–52.

Morris, J. 2001. Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights. *Hypatia: A Journal of Feminist Philosophy,* 16 (4): 1–16.

Mostert, Mark P. 2002. "Useless Eaters: Disability as Genocidal Marker in Nazi Germany." *The Journal of Special Education* 36 (3): 157–170.

Muñoz, J.E. 2009. *Cruising Utopia: The Then and There of Queer Futurity*. New York: NYU Press.

Murphy, Michelle. 2006. *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers.* Durham, NC: Duke University Press.

———. 2011. "Distributed Reproduction." In *Corpus: Bodies of Knowledge,* edited by Paisley Currah and Monica Casper, 21–38. New York: Palgrave Macmillan.

———. 2013. "The Girl: Mergers of Feminism and Finance in Neoliberal Times." *The Scholar and Feminist Online*. 11.2. Accessed on February 27, 2014. http://sfonline.barnard.edu/gender-justice-and-neoliberal-transformations/the-girl-mergers-of-feminism-and-finance-in-neoliberal-times/

MDA [Muscular Dystrophy Association]. 2014. "MDA Labor Day Telethon History." http://mda.org/about/telethon-history

———. 2014b. "MDA National Goodwill Ambassador Program." http://www.youtube.com/watch?v=495Hbex2atM

NCD [National Council on Disability]. 2012. *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children.* http://www.ncd.gov/publications/2012/Sep272012/

Nielsen, Kim E. 2012. *A Disability History of the United States*. Boston: Beacon Press.

Noske, Barbara. 1989. *Humans and Other Animals: Beyond the Boundaries of Anthropology.* London: Pluto Press.

Oliver, Michael. 2009. *Understanding Disability: From Theory to Practice*. New York: Palgrave Macmillan.

O'Donovan, Maeve. 2012. "The Practical and Theoretical Challenges of Mothering with Disabilities: A Feminist Standpoint Analysis." In *Philosophical Inquiries into Pregnancy, Childbirth, and Mother: Maternal Subjects,* edited by Sheila Lintott and Maureen Sander-Staudt, 93–106. New York: Routledge.

O'Toole, C.J., and T. Doe. 2002. "Sexuality and disabled parents with disabled children." *Sexuality and Disability* 20 (1): 89–102.

Palmeri, Tara. 2013. "Rich Manhattan moms hire handicapped tour guides so kids can cut lines as Disney World." *New York Post.* May 14. Accessed September 25, 2014. http://nypost.com/2013/05/14/rich-manhattan-moms-hire-handicapped-tour-guides-so-kids-can-cut-lines-at-disney-world/

Panitch, Leo and Sam Gindin. 2012. *The Making of Global Capitalism: The Political Economy of American Empire.* London: Verso.

Peachman, Rachel Rabkin. 2014. "Parenting through Chronic Physical Pain." *The Atlantic*, January 6. Accessed January 15, 2015. http://www.theatlantic.com/health/archive/2014/01/parenting-through-chronic-physical-pain/282543/?single_page=true

Peck, Jamie. 2008. "Remaking Lasissez-Faire." *Progress in Human Geography*, 32 (1): 3–43.

———. 2010. *Constructions of Neoliberal Reason.* Oxford: Oxford University Press.

Peck, Jamie and Adam Tickell. 2002. "Neoliberalizing Space." *Antipode* 34: 380–404.

Pelka, Fred. 2012. *What we have done: An oral history of the disability rights movement.* Amherst: University of Massachusetts Press.

Peters, Yvonne. 2003. "From Charity to Equality: Canadians with Disabilities Take Their Rightful Place in Canada's Constitution." In *Making Equality: History of Advocacy and Persons with Disabilities in Canada,* edited by Deborah Stienstra and Aileen Wight-Felske, 119–136. Concord, Ontario: Captus Press.

Petryna, Adriana. 2002. *Life Exposed: Biological Citizens after Chernobyl.* Princeton: Princeton University Press.

Phillips, Cassandra. 2003. "Steering Your Own Ship: The Growth of Individual Advocacy within the Canadian Association of Independent Living Centres." In *Making Equality: History of Advocacy and Persons with Disabilities in Canada,* edited by Deborah Stienstra and Aileen Wight-Felske, 197–220.Concord, Ontario: Captus Press.

Plehwe, D., and B. Walpen. 2006. "Between network and complex organization: The making of neoliberal knowledge and hegemony." In *Neoliberal hegemony: A global critique,* edited by D. Plehwe, B. Walpen, and G. Neunhoffer, 27–50. London: Routledge.

Powell, Justin, and Liat Ben-Moshe. 2009. "The icons of access: From exclusion to inclusion." *stimulus respond*, 5: 91–96. Accessed May 1, 2013. http://issuu.com/stimulusrespond/docs/icon

Prilleltensky, Ora. 2004. "My Child Is Not My Carer: Mothers with Physical Disabilities and the Well-Being of Children." *Disability & Society* 19 (3): 209–223. doi:10.1080/0968759042000204185.

Prilleltensky, Ora. 2003. "A Ramp to Motherhood: the Experiences of Mothers with Physical Disabilities." *Sexuality and Disability* 21 (1): 21–47. doi:10.1023/A:1023558808891.

Puar, Jasbir K. 2009. "Prognosis Time: Towards a Geopolitics of Affect, Debility and Capacity." *Women & Performance: a Journal of Feminist Theory* 19 (2): 161–72. doi:10.1080/07407700903034147.

———. 2011. "Coda: The Cost of Getting Better Suicide, Sensation, Switchpoints." *GLQ: A Journal of Lesbian and Gay Studies* 18 (1): 149–158.

———. 2012. "'I Would Rather Be a Cyborg Than a Goddess': Becoming-Intersectional in Assemblage Theory." *Philosophia* 2 (2): 49–66.

Rabinow, Paul. 1996. "Artificiality and Enlightenment: From Sociobiology to Biosociality" *Essays in the Anthropology of Reason*, 91–111. Princeton, New Jersey: Princeton University Press.

Rapp Emily. 2013. *The Still Point of the Turning World.* New York: Penguin Press.

———. 2014a. "'Dragon Mother' Emily Rapp: A New Baby Doesn't, and Shouldn't. Replace What's Lost." *New York Times.* Accessed January 5, 2015. http://parenting.blogs.nytimes.com/2014/03/13/dragon-mother-emily-rapp-a-new-baby-doesnt-and-shouldnt-replace-whats-lost/?_r=0)

———. 2014b. "The End of Winter: Reflections on Advanced Maternal Age." Accessed January 5, 2015. http://www.rolereboot.org/family/details/2014-03-end-winter-reflections-advanced-maternal-age/

———. 2014c. "What the Living Do." *Brain, Child: The Magazine of Thinking Mothers.* Accessed January 5, 2015. http://www.brainchildmag.com/tag/emily-rapp/

Rapp, Ranya. 2000. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America.* New York: Routledge.

Reardon, Jenny. 2001. "The Human Genome Diversity Project a Case Study in Coproduction." *Social Studies of Science* 31 (3): 357–88. doi:10.1177/030631201031003002.

———. 2005. *Race to the Finish: Identity and Governance in an Age of Genomics.* Princeton, New Jersey: Princeton University Press.

Rehabilitation International. 1978. "The international symbol of access assembly resolution." Baguio, January 22-23. Accessed May 1, 2013. http://www.riglobal.org/wp-content/uploads/2010/08/symbolofaccess.doc

Rehabilitation International. 2013. "Symbol of Access." Accessed May 1, 2013. http://www.riglobal.org/symbol-of-access/

Ricks, Delthia. 2014. "Scientists name 6 more toxins affecting developing brains" *Newsday* Feb 14. Accessed January 30, 2015. http://www.newsday.com/news/health/scientists-name-6-more-toxins-affecting-developing-brains-1.7084963

Ruddick, Sara. 1989. *Maternal Thinking*. Boston: Beacon Press.

Russell, Marta, and Ravi Malhotra. 2002. "Capitalism and Disability." *Socialist Register* 38: 212–228.

Samuels, Ellen. 2014. *Fantasies of Identification: Disability, Gender, Race*. New York: NYU Press.

Sapey, B., Stewart, J., & Donaldson, G. 2005. "Increases in wheelchair use and perceptions of disablement." *Disability & Society*, 20 (5): 489–505. doi:10.1080/09687590500156162

Saad-Filho, Alfredo, and Deborah Johnston. 2005. "Introduction." In *Neoliberalism: A Critical Reader,* edited by Alfredo Saad-Filho and Deborah Johnston, 1–6. London: Pluto Press.

Saxton, Marsha. 2013. "Disability Rights and Selective Abortion." In *The Disability Studies Reader,* edited by Lennard Davis, 87–90. New York: Routledge.

Schierow, Linda-Jo. 2009. "Toxic Substances Control Act (TSCA): Implementation and New Challenges." *Congressional Research Service Report for Congress.* July 28. Accessed January 20, 2015. https://www.acs.org/content/dam/acsorg/policy/acsonthehill/briefings/toxicitytesting/crs-rl34118.pdf

Schweik, Susan M. 2009. *The ugly laws: Disability in public.* New York: NYU Press.

Serlin, David. 2015. "Constructing Autonomy: Smart Homes for Disabled Veterans and the Politics of Normative Citizenship." *Critical Military Studies*, February: 1–9. doi:10.1080/23337486.2015.1005392.

Shakespeare, Tom. 2006. *Disability Rights and Wrongs.* New York: Routledge.

Shapiro, Joseph P. 1993. *No pity: People with disabilities forging a new civil rights movement.* New York: Random House.

Shildrick, Margrit. 1997. *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)Ethics.* New York: Routledge.

———. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality.* New York: Palgrave-Macmillan.

———. 2010. "Some Reflections on the Socio-Cultural and Bioscientific Limits of Bodily Integrity." *Body & Society* 16 (3): 11–22.

Silvers, Anita. 1995. "Reconciling equality to difference: Caring (f)or justice for people with disabilities." *Hypatia* 10 (1): 30–55.

Sins Invalid. 2014. "Sins Invalid Statement on Police Violence." *Sins Invalid Blog.* September 4. Accessed September 4, 2014. http://sinsinvalid.org/blog/sins-invalid-statement-on-police-violence

———. 2015. "About Us" *Sins Invalid.* Accessed May 15, 2015. http://sinsinvalid.org/mission.html

Smit, Chris R. 2013. "Disability Things: A Technological Ontology." Paper presented at the Society for Disability Studies Conference, Orlando, Florida. Accessed August 1, 2013. http://media.virbcdn.com/files/6e/15a827c30f9c9dca-DisabilityThingsATechnologicalOntology.pdf

Smit, C. R. 2003. "'Please Call Now, Before It's Too Late': Spectacle Discourse in the Jerry Lewis Muscular Dystrophy Telethon." *The Journal of Popular Culture*, 36 (4): 687–703.

Smith, S. E. 2013. "Yet Another Disabled Child Killed by Family." *Xojane.* June 19. Accessed September 14, 2014. http://www.xojane.com/issues/yet-another-disabled-child-killed-by-family.

Smith, Thomas. 2013. "Guest Assistance Card Program Update for Walt Disney World Resort, Disneyland Resort." *Disney Parks Blog,* October 4. Accessed September 24, 2014. http://disneyparks.disney.go.com/blog/2013/10/guest-assistance-card-program-update-for-walt-disney-world-resort-disneyland-resort/

Smith, V. 2014. "Mother who suffocated disabled children 'to end their suffering' won't face murder trial." *Mirror*. October 13. Accessed November 18, 2014. http://www.mirror.co.uk/news/uk-news/depressed-mother-who-suffocated-disabled-4429274

Snyder, Sharon L., and David T. Mitchell. 2006. *Cultural locations of disability*. Chicago: University of Chicago Press.

Soldatic, Karen. 2011. "Appointment Time: Disability and Neoliberal Workfare Temporalities." *Critical Sociology*. doi:10.1177/0896920511430168.

Sothern, Matthew. 2007. "You could truly be yourself if you just weren't you: sexuality, disabled body space, and the (neo)liberal politics of self-help." *Environment and Planning D: Society and Space*, 25 (1): 144–159. doi:10.1068/d1704

Spencer, Ruth. 2014. "Model Danielle Sheypuk: 'People with disabilities are consumers of fashion.'" *The Guardian.* February 14. Accessed February 26, 2014. http://www.theguardian.com/fashion/2014/feb/14/model-wheelchair-new-york-fashion-week

Springer, Simon. 2012. "Neoliberalism as Discourse: Between Foucauldian Political Economy and Marxian Poststructuralism." *Critical Discourse Studies* 9 (2): 133–147. doi:10.1080/17405904.2012.656375.

Standing, Guy. 1999. *Global Labour Flexibility: Seeking Distributive Justice*. London: MacMillan.

Stedman Jones, Daniel. 2012. *Masters of the Universe: Hayek, Friedman and the Birth of Neoliberal Politics.* Princeton, New Jersey: Princeton University Press.

Storey, Robert. 2002. "Don't Work Too Hard: Health and Safety and Worker's Compensation in Canada." In *Health, Illness and Health Care in Canada,* edited by B. Singh Bolaria and Harley D Dickinson, 388-411. Toronto: Nelson Thomson Learning.

Stiker, Henri Jacques. 1999. *A History of Disability*. Translated by William Sayers. Ann Arbor: University of Michigan Press.

Sunder Rajan, Kaushik. 2007. *Biocapital: The Constitution of Postgenomic Life.* Durham, NC: Duke University Press.

———. 2012. "Introduction: The Capitalization of Life and the Liveliness of Capital." In *Lively Capital: Biotechnologies, Ethics, and Governance in Global Markets*, edited by Kaushik Sunder Rajan, 1-44. Durham, NC: Duke University Press.

TallBear, Kim. 2013. *Native American DNA: Tribal Belonging and the False Promise of Genetic Science*. Minneapolis: University of Minnesota Press.

Taussig, Karen-Sue, Ranya Rapp, and Deborah Heath. 2003. "Flexible Eugenics: Technologies of the Self in the Age of Genetics." In *Genetic Nature/Culture: Anthropology and Culture Beyond the Two-Culture Divide*, edited by Alan Good-man, Deborah Heath, and M. Susan Lindee, 58–76. Berkeley: University of California Press.

Taylor, Sunny. 2004. "The right not to work: Power and disability." *Monthly Review* 55(10). Accessed May 1, 2011. http://monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/

Thomas, Carol. 1997. "The baby and the bathwater: Disabled women and motherhood in social context." *Sociology of Health and Illness* 19 (5): 622–643.

Through the Looking Glass. 2006. "Visible, Diverse, and United: A Report of the Bay Area Parents with Disabilities and Deaf Parents Task Force." October 30. Accessed December 1, 2014. http://www.lookingglass.org/announcements/67-news/100-report-task-force-on-bayarea-parents-with-disabilities-and-deaf-parents

Tikell, Adam and Jamie Peck. 2003. "Making Global Rules: Globalization or Neoliberalization?" In *Remaking the Global Economy*, edited by Jamie Peck and Henry Wai-chung Yeung, 163–181. London: Sage.

Titchkosky, Tanya. 2003. "Governing embodiment: Technologies of constituting citizens with disabilities." *Canadian Journal of Sociology/Cahiers canadiens de sociologie* 28 (4): 517–542.

———. 2011. *The Question of Access: Disability, Space, Meaning*. Toronto: University of Toronto Press.

Titchkosky, Tanya and Rod Michalko. 2009. "Introduction." In *Rethinking Normalcy: A Disability Studies Reader,* edited by Tanya Titchkosky and Rod Michalko, 1–14. Toronto: Canadian Scholars Press.

Track, Laura. 2014. *Able Mothers: The intersection of parenting, disability and the law.* Vancouver: West Coast Leaf.

Tremain, Shelley. 2001. "On the Government of Disability." *Social Theory and Practice* 27 (4): 617–636.

———. 2002. "On the Subject of Impairment." In *Disability/ Postmodernity: Embodying Disability Theory,* edited by Mairian Corker and Tom Shakespeare, 32–47. New York: Continuum.

———. 2008. "The Biopolitics of Bioethics and Disability." *Journal of Bioethical Inquiry,* 5 (2-3): 101–106. doi:10.1007/s11673-008-9105-6

Toronto Sun. 2014. "Wheelchair-bound Justin Bieber upsets fans as Disneyland." July 23. Accessed September 15, 2014. http://www.torontosun.com/2014/07/23/wheelchair-bound-justin-bieber-upsets-fans-at-disneyland

Tremblay, Mary. 1996. "Going back to Civvy Street: A historical account of the impact of the Everest and Jennings wheelchair for Canadian World War II veterans with spinal cord injury." *Disability & Society* 11(2): 149–170.

UPIAS. 1976. *Fundamental Principles of Disability.* London: Union of the Physically Impaired Against Segregation.

Ventura, Patricia. 2012. *Neoliberal Culture: Living with American Neoliberalism.* Burlington, Burlington,Vermont: Ashgate.

Van Waeyenberge, Elisa. 2010. "Tightening the Web: The World Bank and Enforced Policy Reform." In *The Rise and Fall of Neoliberalism – The Collapse of an Economic Order,* edited by Kean Birch and Vlad Mykhnenko, 94–111. New York: Zed Books.

Vosko, Leah. 2006. *Precarious Employment: Understanding Labour Market Insecurity in Canada.* Montreal: McGill-Queen's University Press.

Waldby, Catherine, and Robert Mitchell. 2006. *Tissue economies: Blood, organs, and cell lines in late capitalism.* Durham, NC: Duke University Press.

Walton, D. 1997. *Appeal to Pity: Argumentum ad Misericordiam.* SUNY Press.

Webb, A. 2013. "I Measure Every Single Thing My Child Does." *Slate*. July 9. Accessed January 5, 2015. http://www.slate.com/articles/technology/data_mine_1/2013/07/data_driven_parenting_tracking_baby_sleep_eating_and_pooping_on_spreadsheets.html

Weintraub, Karen. 2014. "Researchers warn of chemical impacts on children." *USA Today*. February 14. Accessed January 30, 2015. http://www.usatoday.com/story/news/nation/2014/02/14/chemicals-adhd-autism/5494649/

Weiss, Gail. 1999. *Body Images: Embodiment as Intercorporeality.* New York: Routledge.

White, F.R. 2013. "No Fat Future? The Uses of Anti-Social Queer Theory for Fat Activism." In *Queer Futures: Reconsidering Ethics, Activism, and the Political,* edited by Elahe Haschemi Yekani, Eveline Kilian and Beatrice Michaelis, 21–36. Burlington, Vermont: Ashgate.

Wiener, J. 2011. "The End of the Jerry Lewis Telethon – It's About Time." *The Nation.* Accessed November 17, 2014. http://www.thenation.com/blog/163119/end-jerry-lewis-telethon-its-about-time

Wilkes, D. 2014. "'I am finding it so difficult to kill my child': After smothering her two disabled twin sons, the letter mother wrote to husband before she also killed their older sister" *The DailyMail.* November 17. Accessed November 17, 2014. http://www.dailymail.co.uk/news/article-2834550/Investment-banker-s-wife-smothered-three-disabled-nappy-husband-South-Africa-eldest-daughter-birthday.html

Williams, Raymond. 1978. *Marxism and Literature*. Oxford: Oxford University Press.

Williamson, Bess. 2012. "The People's Sidewalks" *Boom: A Journal of California.* 2(1) Accessed March 29, 2015. http://www.boomcalifornia.com/2012/06/the-peoples-sidewalks/

Wilton, Robert, and Stephanie Schuer. 2006. "Towards Socio-Spatial Inclusion? Disabled People, Neoliberalism and the Contemporary Labour Market." *Area* 38 (2): 186–195.

Winter, Katy. 2014. "Breaking down barriers: Russian designers present catwalk collections on disabled models at Moscow Fashion Week." *Dailymail*. March 31. Accessed April 7, 2014. http://www.dailymail.co.uk/femail/article-2593426/Breaking-barriers-Russian-designers-present-catwalk-collections-disabled-models-Moscow-Fashion-Week.html

Woerner, Amanda. 2014. "Number of chemicals linked to autism and other disorders doubled in the past years, study shows" *Fox News*. Accessed January 30 2015. http://www.foxnews.com/health/2014/02/15/number-chemicals-linked-to-autism-and-other-disorders-doubled-in-past-7-years/

Woods, Brian, and Nick Watson. 2003a. "A short history of powered wheelchairs." *Assistive Technology* 15 (2): 164–180.

Woods, Brian, and Nick Watson. 2003b. *Power to Independence: A Historical Glimpse at the Interactions between Powered Wheelchairs and the Physically Disabled Students Program at Berkeley*. Paper presented to the Inaugural Conference of the Disability Studies Association. Disability Studies: Theory, Policy and Practice, Lancaster University. http://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2003/papers/woods_watson2003.pdf

Young, Iris Marion. 1997. "Asymmetrical reciprocity: On moral respect, wonder, and enlarged thought." *Constellations* 3 (3): 340–363.

Young, Saundra. 2014. "Putting the next generation of brain in danger" *CNN*. February 17. Accessed February 28, 2014. http://www.cnn.com/2014/02/14/health/chemicals-children-brains/

Zames Fleischer, Doris, and Frieda Zames. 2011. *The Disability Rights Movement: From Charity to Confrontation.* Philadelphia: Temple University Press.

Zitzelsberger, Hilde. 2005. "(In)Visibility: Accounts of Embodiment of Women with Physical Disabilities and Differences." *Disability & Society* 20 (4): 389–403. doi:10.1080/09687590500086492.

Zola, Irving Kenneth. 1982. *Missing pieces: A chronicle of living with a disability*. Philadelphia: Temple University Press.