# Disablement, Diversity, Deviation: Disability in an Age of Environmental Risk

by

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A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
English

Waterloo, Ontario, Canada, 2016

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I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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#### Abstract

This dissertation brings disability studies and postcolonial studies into dialogue with discourse surrounding risk in the environmental humanities. The central question that it investigates is how critics can reframe and reinterpret existing threat registers to accept and celebrate disability and embodied difference without passively accepting the social policies that produce disabiling conditions. It examines the literary and rhetorical strategies of contemporary cultural works that one, promote a disability politics that aims for greater recognition of how our environmental surroundings affect human health and ability, but also two, put forward a disability politics that objects to devaluing disabled bodies by stigmatizing them as unnatural. Some of the major works under discussion in this dissertation include Marie Clements's *Burning Vision* (2003), Indra Sinha's *Animal's People* (2007), Gerardine Wurzburg's *Wretches & Jabberers* (2010) and Corinne Duyvis's *On the Edge of Gone* (2016).

The first section of this dissertation focuses on disability, illness, industry, and environmental health to consider how critics can discuss disability and environmental health in conjunction without returning to a medical model in which the term 'disability' often designates how closely bodies visibly conform or deviate from definitions of the normal body. It shows how inadequate medical care, heavily polluted environments, and negative social attitudes might be understood as barriers to access that create disability. The second section of this dissertation focuses on disability, neurological difference, and 'ecological othering' as it considers how autistic artists and writers offer an alternative to the belief that their communicative practices are unnatural. This section argues that metaphors linking ecological devastation to changes in human neurology promote fear, and suggests that exploring the parallels between understandings of

neurological diversity and understandings of biological diversity would allow for a more nuanced means of pursuing efforts to link disability rights and environmental justice.

An important aspect of this project involves a critique of the impetus to celebrate the promise of technology for solving social issues, as it brings critiques of the technological fix approach to environmentalism into conversation with critiques of the medical cure as a technofix for disability. With the introduction of concept of *critical ecologies of embodiment*, a concept that unites these two critiques, this dissertation offers insight into how disability studies scholars and environmental justice scholars might further collaborate.

## Acknowledgments

I would like to thank everyone who has supported me during the intellectually stimulating and emotionally challenging process of writing of this dissertation. During my time at the University of Waterloo, Dr. Jay Dolmage has been an incredibly dedicated and encouraging supervisor, whose guidance and support has been integral to the successful completion of this project. Jay is always generous with his time and thoughtful with his feedback. I am very thankful to have had the opportunity to work with such an accomplished and accountable disability studies scholar and teacher. Jay, I cannot thank you enough. I would like to extend a warm thank you to Dr. Heather Smyth for her early encouragement of my scholarship during her graduate course, and for her confidence in this project. I am grateful for the insight that she provided to my dissertation as an expert in postcolonial studies. I would also like to extend a sincere thank you to Dr. Andrew McMurry for his dedication to my committee, as his expertise in environmental criticism was of central importance to this project. Thank you to Dr. Kathleen Rybczynski, from the Department of Economics, for joining my committee and for providing generous and helpful feedback. Finally, I would like to thank Dr. Nicole Markotić of the University of Windsor for reading my work and travelling to the University of Waterloo for my examination. I am very grateful for her thoughtful questions, comments, and suggestions.

As a PhD candidate at the University of Waterloo, I have had the opportunity to study with many excellent scholars and teachers whose guidance and direction shaped my research program; I am very thankful for the opportunities afforded to me by the inspiring and collegial faculty in the Department of English. I would specifically like to thank Dr. Aimée Morrison and Dr. Randy Harris, who both served as graduate coordinators during my PhD. I would also like to thank Margaret Ulbrick, Tina Davidson, and the rest of the administrative staff for their tireless

support of graduate students in the Department. Before coming to the University of Waterloo, I studied at Queen's University and the University of Ottawa. I am thankful for the excellent mentorship that I received at these institutions as well, particularly from Dr. Molly Wallace and Dr. Sylvia Söderlind. I am grateful for the incredible support from, and fascinating conversations with, all graduate students that I had the good fortune to meet and befriend along the way, including Débora Antunes, Lacey Beer, Natalee Blagden, Betsy Brey, Lauren Burr, Adam Cilevitz, Keely Cronin, Stephen Fernandez, Kim Garwood, Michael Hancock, Naj Khatami, Shannon Maguire, Phil Miletic, Tommy Mayberry, Jaime McGrane, Ciara O'Shea, Quinn Powell, Dani Stock, Elise Vist, Emma Vossen, Steve Wilcox, and many, many others.

I am also very grateful to the wonderful people at the University of Waterloo Writing

Centre, including Clare Bermingham and Dr. Nadine Fladd, who helped me to develop an

effective writing schedule. My time at Waterloo was also enriched by my interactions with my

undergraduate students. I am thankful, both for the opportunity to have been an instructor at the

University of Waterloo, and for the students themselves, who were motivated and passionate
individuals from a variety of programs who brought to my courses their own disciplinary

knowledge, critical perspectives, and strategies for social change. Along the way, I also
benefitted from the support of the members of the Canadian Disability Studies Association, who
first encountered these chapters as conference papers. I am also extremely thankful for my
Ontario Graduate Scholarship, and for my Joseph-Armand Bombardier Doctoral Scholarship
from the Social Sciences and Humanities Research Council that made this research possible.

I would also like to extend a special thanks to the Bloomfield family in Guelph, and specifically to my friend Andrew Bloomfield, who created the Bridges-Over-Barriers

Communication Initiative. His important advocacy for communication rights and individualized

housing options has increased my knowledge of the specific challenges facing many Ontarians with disabilities. Thank you for the excellent conversations, and for sharing your book collection with me. A major thank you is also in order for my closest friends, including Aasma Alam, Haider Khawaja, Duke Patrick Sonsing, and Megan Stanford-Jones. Finally, I would like to thank both my immediate family and my large extended family for their love and support. I would especially like to thank my long-time partner and occasional science advisor, Adam Potter, for supporting my decision to return to graduate school for my PhD, and for his efforts to relocate to Waterloo. I am also grateful for the continued support of my parents, with whom I was able to have many interesting and thoughtful conversations about my research. My mother, Diana Gibbons, and my father, Michael Gibbons, have fostered my passion for reading, writing, and research through their own intellectual curiosity; their genuine interest in my project was invaluable. My brother, Christopher Gibbons, a talented painter, accomplished athlete, and the best Super Mario 64 player I have yet to meet, helped me to relax and stay motivated. Thank you for all the hikes in the woods, Chris.

To Christopher Gibbons

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# An Introduction to the Problem of Environmental Inaccessibility: Contemporary Issues in Disability Studies, Ecocritical Studies, and Postcolonial Studies

On July 31, 2014, members of the Grassy Narrows First Nation and their allies marched to Queen's Park in Toronto to call for Ontario Premier Kathleen Wynne to address mercury contamination in the Wabigoon River, in Kenora, Ontario. Many people from Grassy Narrows have been adversely affected by methyl mercury released into the river by a paper mill in the 1970s, which continues to affect the water that they drink and the fish that they consume (Willow 73-74). Many of the residents of Grassy Narrows are now disabled as a result of the health consequences of Minamata disease, or mercury poisoning. As a Waterloo resident, I was nearby and able to join as a supporter in the march on that day. In my daily life, however, I am often confronted with a different conversation surrounding mercury contamination. In 1998, British physician Andrew Wakefield published a research paper in The Lancet medical journal that posited a link between autism and the Measles, Mumps, Rubella (MMR) vaccine. While the paper has since been retracted, many people, including significant political figures, believe that autism is a form of mercury poisoning that can result from vaccinating children. My brother is autistic, and I am consequently very familiar with the ongoing public debates surrounding the safety of the MMR vaccine. I am very much in support of researchers, policy makers, and other stakeholders who are spreading the message that scientific research has repeatedly shown that there is no link between autism and vaccination. I am even more supportive of autistic selfadvocates who point out that fear and stigma surrounding autism fuels fears surrounding vaccination. My dissertation is in part inspired by the unusual place that I find myself in, as I

advocate at times for the recognition of environmental concerns, and at other times for their reevaluation, but always with respect to the rights of people with disabilities.

My dissertation project aims to bring these two sites of disability resistance together by examining contemporary global literature that one, promotes a disability politics that aims for greater recognition of how our environmental surroundings affect human health and ability, but also two, puts forward a disability politics that objects to devaluing disabled bodies by stigmatizing them as unnatural. I am interested in the language that we use to talk about disability, and the stories that we tell about, through, and from disability. In the following chapters, I examine a selection of texts that can inform cultural understandings of the interaction between disability and ecological risk in order to investigate the intersections and tensions amongst the fields of disability studies, postcolonial studies, and ecocritical studies within the humanities. My main research goal is to consider the representational strategies of narratives that transform an idea of disability as a risk to be feared into an investigation of the risks that people with disabilities face. I ask, how do creative works suggest possibilities for celebrating human variation while maintaining a strong critique of disabling global politics? What kinds of narrative strategies allow writers and artists to engage the material difficulties of living in a globalized world without problematically positioning disabled bodies as inferior bodies, or as signs of social and environmental degradation? My answer to these questions has led me to develop the concept of critical ecologies of embodiment, and I contribute to the meaning of this concept through four chapters. However, before exploring the critical origins of this term, I would like to outline the three fields that my dissertation draws on in order to better situate this critical intervention.

## **Disability Studies**

Disability studies is an interdisciplinary field of scholarship that seeks to understand, frame, and reshape cultural understandings of disability. Disability studies in the western academy emerged in conjunction with the work of activists in North America and Europe in the 1970s (Shapiro 11). Medical sociologist Irving Zola began to publish a newsletter which became *Disability Studies* Quarterly (DSQ) in 1980, and in 1986, a section of the Western Social Science Association formed a separate association called The Society for Disability Studies (Ferguson and Nusbaum 70). Disability studies positions itself against a medical model in which disability is a deficit rooted in an individual person (Davis; Garland-Thomson). This is not to say that disability studies is anti-medicine or anti-medical interventions; in fact, many disability studies scholars advocate for greater access to medical treatment and life-saving operations for people whose lives are often represented by mainstream media as not worth living. However, scholars in disability studies are critical of the suggestion that disability is a purely medical problem in need of a cure. A significant body of research in disability studies works within an alternative to the medical model of disability called the social model of disability. The social model differentiates between disability as a cultural experience and impairment as a bodily experience. As it recognizes that people with disabilities constitute a marginalized group, the social model understands disability to be a social and political experience, and so emphasizes the disabling impact of built environments and social stigma (Pfeiffer). It understands impairment to refer to a physical difference, such as the loss of a limb or the loss of some of its functionality. An impairment is not understood to be disabling in itself; it is only disabling in a social context. For example, wheelchair users are understood to be disabled by environments that are only navigable by stairs. The social model was foundational to the establishment of disability studies in the academy, and continues to inform much of the scholarship in the field today.

Other scholars, however, critique the social model for its strict distinction between disability and impairment by using poststructuralist theory. These scholars suggest how other modes of understanding disability might open up the generative possibilities of bodily difference. Mairian Corker and Tom Shakespeare, in the introduction to their edited collection, Disability/Postmodernity (2002), discuss the merits of poststructuralist approaches to disability studies. They caution, however, that postmodernism's deconstruction of the individual as an autonomous agent, "makes for a tension-ridden relationship with versions of the social model that see only 'society,' or which stress the agency of disabled people in achieving their own liberation" (3). Despite these concerns, Corker and Shakespeare ultimately contend that the social model, like the medical model before it, creates a meta-historical narrative that leaves out important dimensions of disabled people's lives (15). The challenge, they argue, is to make full use of a "new theoretical toolbox" without losing an audience amongst disabled people themselves (15). Shelley Tremain, who is featured in this collection, exposes the realist ontology that informs understandings of impairment within the social model, arguing that definitions are not transhistorical or objective (34). My own work draws upon Tremain's insights by looking at one, contexts in which pain remains even when social attitudes and built environments change, and two, examining groups who do not recognize themselves as having clear impairments.

One example that indicates how definitions of impairment are not transhistorical or objective consists of the changing attitudes surrounding differences in sexual orientation. While homosexuality was pathologized by the original *Diagnostic and Statistical Manual of Mental Disorders*, many societies now largely recognize same-sex attraction as a significant part of

human diversity, and not as a medical condition in need of treatment. Other disabled people, such as members of Deaf culture or intersex people, may not experience pain and may not define themselves as having impairments. Those who capitalize Deaf often view themselves as a linguistic minority, while intersex people may view society's narrow understanding of two sexes as a greater problem than their physical bodies that resist this clear categorization. The social model, informed by identity politics, creates a distinction between disability and impairment that is similar to the distinction that feminists created between gender and sex (Shakespeare and Corker 3). Therefore, we might see the intervention that a postmodern model of disability makes as analogous to Judith Butler's intervention in queer theory, as Butler interrogates the distinction between sex and gender, and the fixity of one's sex (xxxii). Iris Marion Young explains that, "while the social model of disability destabilizes the assumption that the 'problem' with some people has to do with the attributes of their bodies and functions, it nevertheless continues to presume a certain fixity to these bodies..." (xii). In other words, the term 'impairment' may call up a template of the human form to which certain individuals do not adhere; a postmodern disability studies dispenses with the template altogether. Interestingly, many of the delays that took place in adopting poststructuralist methodologies in disability studies have also been observed within the discipline of ecocriticism.

#### **Environmental Criticism**

Scholars working in environmental criticism, or ecocriticism, similarly employ poststructuralist approaches, challenging, for example, the dichotomy between nature and culture. Environmental criticism is a form of scholarship that takes environmental threat seriously, and looks at human relationships with the non-human world in literature and culture. One of the founders of

ecocriticism is scholar William Rueckert, who published the essay "Literature and Ecology: An Experiment in Ecocriticism" in 1978. However, scholars working in this field were also influenced by earlier works from the 1960s, such as Rachel Carson's Silent Spring (1962), which began with a fable that warned of how dichlorodiphenyltrichloroethane, or DDT, would damage the environment. Similarly, literary critic Leo Marx's *The Machine in the Garden: Technology* and the Pastoral Ideal in America (1964), which examines representations of industry in American literature, was an important influence (Cohen 11). As with disability studies, environmental criticism has strong activist roots, arising from the environmental movement during the civil rights era in the United States. Environmental criticism began with studies of nature writing in environmental works. In The Environmental Imagination: Thoreau, Nature Writing, and the Formation of American Culture (1995), influential literary critic Lawrence Buell set out criteria for what would be considered an "environmentally oriented work" (7-8). Buell himself and other scholars later expanded this definition, and acknowledged a multiplicity of methodologies that often involved considering the exploration of ecological issues even in works that were not specifically environmentally oriented. Ecocriticism was formalized with the creation of the Association for the Study of Literature and the Environment, which was established in 1992 (Cohen 13). The association has since achieved international reach, with groups in Germany, India, Japan, Korea, Taiwan, and the United Kingdom.

While disability studies objects to normalizing and instrumental views of the human body, environmental criticism objects to ways of knowing that position nature as passively subservient to human interests. Ursula K. Heise explains that ecocritics were initially nervous that engagement with poststructuralist theory might make the reality of environmental degradation appear less real and less immediately present (512). However, environmental critics

have turned to poststructuralist theory in order to challenge the binary between nature and culture that creates the impression that nature resides in a paradisiacal space outside of culture, that nature is a place people can visit. Environmental criticism has also cultivated intersections with feminism, critical race studies, and Marxist theory, as scholars increasingly assume an environmental justice lens to examining literature. Intersections with disability studies are beginning to emerge as well. Many writings in ecocriticism by scholars who seek to make present the materiality of environmental degradation while working within a poststructuralist model that distinguishes between nature and culture will turn to the relationship between bodies and environments to articulate the dangers that we face, and to communicate how such dangers are unevenly distributed.

In ecocritic Rob Nixon's monograph *Slow Violence*: *The Environmentalism of the Poor* (2011), he argues that the world's poorest populations experience the slow violence of environmental degradation most acutely. Nixon defines slow violence as "a violence that occurs gradually and out of sight, a violence of delayed destruction that is dispersed across time and space, an attritional violence that is not typically viewed as violence at all" (2). He argues that contemporary society associates violence with immediacy and "sensational visibility" (2). Addressing the near invisibility of slow violence in the form of toxic drift, acidifying oceans, and radioactive aftermaths of war requires new representational strategies (2). Nixon's argument hinges upon recognition that the world's poorest populations experience slow violence in the greatest degrees as victims of invisibility and collective amnesia. His term 'amnesia' refers to

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<sup>&</sup>lt;sup>1</sup> In Heise's history of ecocriticism, she notes that, "from the turn of the millennium, environmental-justice criticism increasingly influenced the field by drawing attention to social and racial inequalities in both access to natural resources and exposure to technological and ecological risk," and she references the work of Joan Martinez Alier; and Joni Adamson, Mei Mei Evans, and Rachel Stein (508).

<sup>&</sup>lt;sup>2</sup> Nixon refers to the journalistic slogan, "if it bleeds, it leads" to show how sensational violence receives more coverage than slow violence: "As a corollary, if it's bloodless, slow-motion violence, the story is more likely to be buried, particularly if it's relayed by people whose witnessing authority is culturally discounted" (16).

how people who experience prolonged violence and who live in deplorable conditions are forgotten, as their stories fade out of mainstream media (7). The use of the term 'amnesia' to characterize the ways that society selectively forgets about the predicament of particular people or places over time is a clear example of how disability metaphors pervade language; amnesia is a cognitive disability that Nixon uses as a metaphor to signify the violence of social neglect. This use of amnesia, coupled with the implication that disability itself might be a form of violence against the body, suggests the need for a critical disability studies approach to understanding the relationship between bodies and environments. Nixon's work, however, is crucial because he emphasizes how populations in the Global South are subject to a resurgent imperialism advanced by neoliberal economic policies that result in an uneven distribution of threat.

#### **Postcolonial Studies**

Populations in the Global South are also largely subjected to more disabling experiences because of this uneven distribution of threat. In a 2010 special issue of the *Journal of Literary & Cultural Disability Studies*, Clare Barker and Stuart Murray address the relative inattention to experiences of disability outside of North America and Europe within research in the humanities. They explore how the fields of disability studies and postcolonial studies might better inform each other. Postcolonial studies is a field of scholarship that examines the damaging legacies of colonization. An influential theorist whose works contributed to the development of the field was the Algerian psychiatrist Frantz Fanon, whose book *The Wretched of the Earth* (1961) investigates the dehumanizing effects of colonialism. Within literary studies, Nigerian novelist and literary critic Chinua Achebe's essay "An Image of Africa: Racism in *Heart of Darkness*" (1975) contributed to the development of postcolonial methodologies. Achebe examines Joseph

Conrad's literary work from a critical perspective, arguing that the novel's images of African people that had been praised for their aesthetic merit are racist, and that the novel's uncritical canonization perpetuates this racism. Literary theorist Edward Said's *Orientalism* (1978) assumed a similar project, showing how scholarship and literature about the Middle East and Asia on the part of Europeans was filled with assumptions about Eastern cultures as unscientific, childlike, barbaric, and exotic; Said's work shows how the West draws upon the East to define itself through oppositions that aim to justify western superiority. However, Said moved toward a poststructuralist perspective by clarifying that his intention was not to present authoritative truths about the Middle East that stand in opposition to Western stereotypes, arguing, "never has there been such a thing as a pure, or unconditional, Orient" (23). A poststructuralist and self-reflective approach to postcolonial studies was furthered by Gayatri Spivak, who examines to what extent postcolonial academics themselves are inadvertently complicit in the postcolonial project in her essay, "Can the Subaltern Speak?" (1988). On this point, it is worth noting that the 'post' in postcolonial is a prefix that scholars working within the field often protest, and the discipline is often refigured as anti-colonial studies or neocolonial studies to recognize that the consequences of colonialism are not yet situated in the past.

Postcolonial studies has a similar contentious relationship to science that disability studies and environmental criticism share. Entire colonies were used as experimental laboratories in which people of colour were dehumanized, and yet, science was eventually able to show that race is a social construction, with no biological basis. Many postcolonial novels feature characters with disabilities, whose bodies reveal the material effects of living amidst such colonial violence. Barker and Murray argue that the tension between disability studies and postcolonial studies in the humanities and in literary studies specifically has often been one of

materiality and metaphor. They contend that scholars of postcolonial literature often examine disability metaphorically without interrogating how representations speak to lived experiences and concerns. Traditionally, many scholars have read characters with disabilities in literature as symbolic of the postcolonial nation in development. Disability studies scholars, in contrast, have been known to uncritically export theories from the west to other locations (Barker and Murray 219). For example, while significant work in disability studies interrogates the binary between disability and normalcy, in many global contexts, having a disability may be understood as a normal state; citizens with disabilities may constitute the majority of the population in some locales (Barker; Barker and Murray; Carrigan). Although many studies of disability representation in literature and popular culture continue to focus on western texts and media, many critics have begun to examine the materiality of disability in postcolonial texts by questioning or expanding upon metaphorical readings of disability. Other scholars explore the significance of the interplay between metaphor and materiality in these works. While not all of the texts that I discuss in my dissertation necessarily fall under the rubric of postcolonial literature, I draw on theoretical insights from postcolonial studies for all of my analyses. I also contribute to postcolonial studies by considering the representation of disability in global texts, and specifically how these instances of disability often result from the health effects resulting from environmental racism.

### **Introducing Critical Ecologies of Embodiment**

Addressing the perception that disability signifies suffering and that disabled bodies are closer to death, disability studies scholar Robert McRuer expresses concern that the common approbation that everyone who lives long enough will become disabled invokes fear as opposed to

identification in his monograph Crip Theory: Cultural Signs of Queerness and Disability (2006). He asks what it would mean to "welcome the disability to come, to desire it?" (207). Conscious of the difficulties that this question presents in an era of advanced capitalism, in which global bodies can refer to corporations that function as legally autonomous agents, McRuer asks, "in such terrible times, is it even possible to ask the question this way?" (207). Considering the ecological contexts of disabling pain, I add the following questions to McRuer's list: What might it mean to "welcome the disability to come" even as we, as disability studies scholars and scholars in the environmental humanities, recognize that our unsustainable practices are creating disabling environments? How can we critique these practices while resisting the tendency to point toward disabled bodies as the undesirable outcomes of social injustice or environmental degradation? How can we celebrate disability as diversity without justifying the disproportionate experiences of painful disability throughout the globe? I argue that investigating the interplay of disability and illness as materiality and disability and illness as metaphor in creative works by disabled authors and their allies about communal experiences of bodily difference is one strategy. In the following chapters, I will be focusing on four main works, which are Marie Clements's Burning Vision, a play that dramatizes the violence of Canada's history; Indra Sinha's, *Animal's People*, a novel about corporate eco-crime and the aftermath of disaster; Gerardine Wurzburg's Wretches & Jabberers, a documentary on the lives of people who type to talk, and Corinne Duyvis's On the Edge of Gone, a science fiction novel that welcomes disability into the future. I contend that the reading strategy that I undertake allows for a crucial recognition of both the cultural and the aesthetic insight that emerges from chronicling experiences of disability and illness. Such readings can allow for clear attention to the agency of

individuals whose bodies are sometimes held up as signs of injustice; in other words, these readings can look at how individuals are not just signs, but are subjects capable of signifying.

Certainly, one of the risks of acknowledging the relationship between environments and health is reasserting a medical model that disability studies has rightly worked to challenge. However, following Stacy Alaimo, who works at the intersection of environmental studies and disability studies, I argue that broadening understandings of access would help unite disability studies scholarship and environmental studies scholarship. Rather than returning to a medical model in which the term disability often designates how closely bodies visibly conform or deviate from definitions of the normal body, I argue that we can consider how barriers to access, when framed as inadequate medical care, heavily polluted environments, and social attitudes, create disability. New paradigms of accessibility need to attend to how, as Alaimo argues, "materiality, at a less perceptible level – that of pharmaceuticals, xenobiotic chemicals, air pollution, etc. – affects human health and ability" (12). Throughout this dissertation, I argue that if we attend to how human influences upon the environment adversely affect human wellbeing, while at the same time remembering that even a seemingly innocuous term like health is also ideological, perhaps 'welcoming the disability to come' can involve recognizing our inherent vulnerability as the environments we are shaping are becoming less habitable for everyone (207).

One of my contentions in this work is that disabled people are often interpreted as signs of the worsening conditions of ecological and social environments, as embodied symbols of larger forms of suffering. In many cultural artifacts, disability symbolizes the declining health of an environment. In *Disability Rhetoric* (2014), Jay Dolmage explains that one myth surrounding disability is the myth that it is a symptom of the human abuse of nature. He notes that, "as with the idea that disability is a punishment for an individual or social evil, disability is often used to

reflect, even more 'causally,' humankind's degradation and neglect of the natural world and the environment" (Dolmage 36). Symbolic interpretations of disabled characters as evidence of the declining health of an environment suggest how contemporary culture tends to stigmatize disabled people, projecting contemporary anxieties onto bodies that we abject. However, some environmental justice activists might argue that understanding disabilities as symptoms of environmental degradation is imperative. Using disability to measure environmental degradation would seem to give credence to the argument that our decisions concerning the environments that we inhabit have material effects, and can result in extremely painful embodied experiences. While using disability as an indicator of environmental degradation may appear sound, its more insidious eugenic implications are more apparent when we consider whether an indicator of environmental health would be the elimination of disability.

Although medical technologies have been implemented to reduce the presence of specific disabilities in some areas, the often unintended side effects of technological advances can yield new kinds of (sometimes painful) embodiments. Researchers may celebrate the invention of certain pharmaceuticals that will alleviate pain, only to discover that they affect human health and ability in different ways.<sup>3</sup> As scholars like Rosemarie Garland-Thomson argue, even when we know that disability will affect anyone who lives long enough, we are often instructed to consider disability as "an exceptional and escapable calamity rather than as what is perhaps the

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<sup>&</sup>lt;sup>3</sup> A useful example here would be the drug Thalidomide, which women took as a treatment for morning sickness in the late 1950s. One might make the argument that the affect that thalidomide had upon fetal development demonstrates the unnaturalness of disability. However, one could also argue that the manner in which disability naturally follows invention demonstrates how disability is universal and natural (Garland Thomson 1568). Of course, this is not to suggest that companies should be less cautious about the effects of pharmaceutical drugs. When writing about the relationship between Thalidomide activism and disability studies, Thomas Abrams notes that the community has embraced a narrative of suffering in order to create recognition of the significance of their voices in debates concerning the drug's future use (27). Abrams distinguishes between active and passive victimhood to suggest that the activism of Thalidomiders – a term that those affected have chosen themselves – is compatible with other activist efforts in disability studies (28). This is one example of how disability often follows new technological and medical advances, and is unlikely to disappear from human futures, as much as we tend to imagine it away.

most universal of human experiences" ("Feminist Disability Studies" 1568). In another context, with the completion of the Human Genome Project, the public is taught to read disabilities as errors in the master text of one's genetic code (Wilson). One of the challenges for scholars researching how environmental factors can affect human health and ability is acknowledging these factors while retaining a focus on the importance of disability acceptance, an acceptance that involves deconstructing traditional definitions of disability that view the body as a problem. In this dissertation, I bring disability studies and postcolonial studies together in conversation with discourse surrounding risk in the environmental humanities to consider how we might rethink and decentre existing threat registers to accept disability without passively accepting the social policies that produce disabling conditions. An important aspect of this project involves a critique of the impetus to celebrate the promise of technology for social issues, by bringing critiques of the technological fix approach to environmentalism in dialogue with critiques of the medical cure as a techno-fix for disability that aims to erase the promise of bodily difference.<sup>4</sup>

In disability studies, when we differentiate the social model of disability from the medical model of disability, we often use the term "environment" to refer to physical or built environments. As a field, we draw attention to the disabling attributes of buildings, campuses, and cities, as well as the enabling potential of inclusive, or universal, design. In our scholarship, "environment" often refers to the social environments that we cultivate through our attitudes and approaches to disability (See Davis; Garland-Thomson; Pfeiffer). However, some work in recent years has placed an emphasis on what we might call, for now, "natural" environments - the kinds of environments that Nixon refers to when he looks at the relationship between environments and

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<sup>&</sup>lt;sup>4</sup> Physicist Alvin Weinberg coined the term "technological fix". He advocated creating and implementing technological solutions for large scale problems because he believed that it was easier and more effective to change technology than to change human behaviour (Stunkel and Sarsar 81-82). The term has since acquired a more negative connotation.

human health. <sup>5</sup> Some scholarship examines the relationship between disability and environmental activism. For example, scholars Eli Clare, a poet and essayist, and Sunaura Taylor, a painter whose work critiques the treatment of non-human animals, are both disability activists and environmental activists. Other scholarship specifically employs a disability studies lens to examine how exposure to environmental problems in specific localities affects human health and ability. Gregor Wolbring and Verlyn Leopatra have shown that the impact of environmental risks on people with disabilities receives less critical attention than the impact of risks on other communities (68). They argue that further scholarship on the implications of environmental challenges like climate change, energy scarcity, and water sanitation for people with disabilities is needed. Furthermore, research communities need scholarship that approaches such environmental challenges from the lens of disability studies, as opposed to scholarship based on a medical model that focuses on individual deficits as the site of disability.

A disability studies perspective on environmental challenges would be able to sustain a critique of disabling corporate practices by complicating arguments that health and sustainable living consists of a series of personal choices concerning physical exercise and nutritional consumption. Jonathan M. Metzl, co-editor of the collection *Against Health: How Health Became the New Morality* (2010), draws attention to the stigma directed toward people who are understood to be refusing to make healthy life choices (1-2). Metzl and Kirkland, along with the authors published in their collection, clarify that they are not against attempts to alleviate human suffering, but against the ideological assumptions that underpin definitions of health. Ecocritic and disability studies scholar Sarah Jaquette Ray similarly complicates correlations between health and morality by suggesting that we redirect critique away from individual behaviour and

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<sup>&</sup>lt;sup>5</sup> I use the term "natural" environment here to show that I am referring not to interactions in built spaces, but to the interactions amongst people, animals, nonhuman organic life, chemical toxicants, etc. Below, I draw on critical discussions to show how the terms 'nature' and 'natural' have often been deployed in exclusionary ways.

toward, "the institutions that constrain individual choice" and "the cultural and socioeconomic contexts in which we all eat" (5). I use the term 'health' in this introduction and throughout this dissertation, but rather than positioning health as an individual or moral responsibility, I wish to emphasize how human well-being is connected to place and social identity. On that note, I argue that a disability studies perspective on environmental challenges would also be able to focus on place, remaining critical of technological and medical solutions that purport to cure disability by showing how human vulnerability is not rooted in static individual deficits, but is contingent upon the spaces that we inhabit. A disability lens on environmental issues would be able to redefine what have been defined as 'problems', by focusing on environmental accessibility as an ongoing process as opposed to a single technological solution for what the medical model identifies as the problem of disability.

Scholars like Stacy Alaimo and Mel Chen have commenced a critical dialogue between disability studies and the environmental humanities by showing how the painful disabilities that result from metal poisoning and exposure to toxins deserve greater consideration than they have previously been given. Chen combines theory and autobiography to examine her own experience of mercury toxicity, as she "engage[s] toxicity as a *condition*, one that is too complex to imagine as a property of one or another individual group or something that could itself be so easily bounded" (196). The connection between environments and human health is one that Alaimo similarly pursues in *Bodily Natures: Science, Environment, and the Material Self* (2010), in which she engages both scholarly movements in environmental criticism and disability studies to argue for a continuum of sensitivity to the environment. Alaimo explains that while disability studies scholars offer important insights into how our built environments, in the form of architecture and social attitudes, influence definitions of disability, her own focus is on the

connection between disability and natural environments. Specifically, Alaimo examines the narratives of individuals with multiple chemical sensitivity, or MCS. She introduces the term 'transcorporeality' to contest humanist understandings of the individual as separate and autonomous from the environment that he or she inhabits; as disabilities like MCS indicate, bodily ability is often connected to place, as exposure to chemicals that are concentrated in our environments affects human health. Alaimo explains that, "imagining human corporeality as trans-corporeality, in which the human is always intermeshed with the more-than-human world, underlines the extent to which the substance of the human is ultimately inseparable from 'the environment'" (2). The prefix 'trans' acknowledges movement across bodies and, "the often unpredictable and unwanted actions of human bodies, non-human creatures, ecological systems, chemical agents, and other actors" (2). As Alaimo examines connections between environments and human health, she argues that we can understand MCS as an environmental illness.

In Alaimo and Nixon's critical works on environmental degradation, they often discuss both disability and illness. The extent to which disability and illness are interrelated has been subject to debate within disability studies. Early scholarship tends to express a clear distinction between disability and illness (Amundson 106). This distinction has been important to scholars because it has often been imperative to emphasize that disability does not always involve physical pain. One of the benefits of differentiating disability from illness is that it facilitates communicating to those outside the disability rights movement that disability does not necessarily entail suffering, and that many disabled people do not have any pressing health concerns. Differentiating disability and illness has also helped disability activists and scholars critique what Rosemarie Garland-Thomson calls the sentimental visual rhetoric of disability ("Seeing the Disabled"). Describing how charities use images of disabled children, or 'poster

children,' to garner financial support, Garland-Thomson argues that sentimental images diminish their subjects to "evoke pity, inspiration, and frequent contributions" (341). Explaining to popular audiences that inclusion and accessibility are more appropriate responses to disability than pity and charity often involves emphasizing that disability is a normal experience rather than a tragic one, and so disability memoirs are often differentiated from illness memoirs. The distinction between disability and disease has been particularly important for autistic advocates, who critique how many charity organizations refer to autism as a disease with a cure as a means of garnering support. However, scholars such as Susan Wendell, who discusses chronic illness, have pointed out that there is fluidity between disability and illness. If the advantage of differentiating between disability and illness is that it helps people to understand that people with disabilities can experience superb quality of life, the disadvantage of creating a strict binary between the two is the erasure of the voices of people with painful disabilities.

Like Wendell, disability theorist Tobin Siebers similarly acknowledges that disability and illness can overlap. He points out that when we as scholars theorize the body, it is important for us to remember that many bodies continuously experience pain:

Susan Wendell, for example, makes the case that changes in the built environment will not improve the situation of some people with painful disabilities. The reality of certain bodies is a fact, while harsh, that must be recognized (45). If the field is to advance, disability studies needs to account for both the negative and positive valences of disability, to resist the negative by advocating the positive and to resist the positive by acknowledging the negative - while never forgetting that its reason for being is to speak about, for, and with disabled people. (Siebers 5)

While arguing that celebrations of disability and embodied difference are crucial, Siebers also argues that embodiment is complex and often painful. He argues that recognizing the reality of pain should not threaten the empowerment and identity positivity that is so central to the work of disability studies. He also cautions that while individuals may embrace their identities as people with disabilities, they may not be as accepting of other disabilities that they acquire later; for example, a woman who is proud of her deafness will most likely not feel the same way about receiving a cancer diagnosis (4). Similarly, Julie Livingston, in her study of debility in Botswana, notes that the demographics of disability are difficult to chart because of, among other challenges, definitional fluidity; she asks, for example, "how stiff should a leg be before the person is considered to be disabled?" (36). Nirmala Erevelles makes a different but related point when she argues, despite her belief in the transgressive potential of celebrating disability, that people may be hesitant to embrace a disability identity when such an identity is "acquired under the oppressive conditions of poverty, economic exploitation, police brutality, neocolonial violence, and a lack of access to health care and education..." (130). She expresses concern that the argument that disability is a universal condition implicitly assumes "that the acquisition of a disabled identity always occurs outside of historical, social, and economic contexts" (130). <sup>6</sup> The cautions that Erevelles, Livingston, and Siebers all offer in their disability studies scholarship are also useful for considering painful disabilities and illnesses acquired through industrial work, chemical poisoning, or radioactive exposure when these complex embodiments are connected to environments and policies toward them.

<sup>&</sup>lt;sup>6</sup> Erevelles's caveat to Garland-Thomson's point regarding the lack of universality surrounding the conditions under which disability is acquired is applicable to the Thalidomide case as well. Considering how disability can result from unequal power relations is a good reminder that accepting difference does not mean accepting the conditions under which such difference was acquired.

Erevelles, Siebers, and Wendell, whose work illustrates the fluidity between illness and disability as categories, and who emphasize that people with disabilities experience pain and suffering, still resist a discourse that would suggest that people with disabilities are only defined by their suffering. Symbolizing suffering with disability can position disabled people as objects rather than subjects in their own right, particularly when people with disabilities are not themselves in control of these representations. Clare Barker, in her work on the representation of disabled children in postcolonial fiction, contends that the use of poster children concerns both disability rights activists and anti-colonial thinkers. She argues that, "media representations of global trauma capitalize on this formation of the child's docile or fragile body, emphasizing its susceptibility to disablement in order to heighten the urgency of western intervention..." (11). The rhetorical purpose of these images is not to encourage an inquiry into the conditions in which the children live, or into how international relations in a globalized world have shaped these conditions, but rather to compel viewers to attempt to rescue these photographic subjects through monetary aid. My related concern throughout this dissertation is how individuals living in disabling environments, who are exposed to radiation, chemicals, and other hazardous materials, become signs of ill health and lose agency over their own representation. The literary and cultural works that I discuss address this issue of representation, and it is because of this material lack of representation surrounding disability by people with disabilities that I merge discussions of fiction with non-fiction, and, accordingly, merge approaches from literary studies and rhetorical studies throughout this dissertation. One of the consequences of this loss of representation is that the disappearance of disabled people from an environment can become a sign of that environment's improved health, or its return to a natural state.

One of the tensions between disability studies and environmentalism that a discussion of the environmental causes of painful disabilities raises is the use of the term 'natural,' which often has a positive connotation in mainstream environmentalism, in contrast to its more insidious connotation in disability studies, as a field that examines how individuals have been categorized, classified, exhibited, and institutionalized because their bodies or cognitive processes have been deemed 'unnatural'. Many ecocritics address this issue surrounding the term 'natural' by referring to how individuals have attempted to justify discrimination and exclusion based on race, gender, and sexuality by insisting that certain social identities are unnatural. Timothy Clark notes that in our moment of environmental crisis, calls to respect nature and protect the natural world are occurring at the same time as intense and justified resistance against calls to uphold 'human nature,' a concept that has historically been used to support eugenic projects (75). He explains that the word 'nature' has problematic connotations in many political debates:

To say that something is "natural" or is "naturally" x or y is to use a word that seems to validate itself as a matter of course, "naturally." One crucial but dubious function of the concept of nature has been to lend seemingly unchallengeable foundations to very contestable political claims. Western history has been plagued by kinds of dogmatic politics in which some appeal to nature or what is natural for a human being was central, as, for instance, in assertions about hierarchy, ethnicity, or about some same-sex relationships ('it's not natural"). (75)

As Clark illustrates here, turning to the biological to claim that something is 'unnatural' is a means of deploying the term as a verbal panacea designed to put an end to behaviours and practices that a society views as unacceptable. Donna Haraway and Anne-Lise François have also made this point in their critiques of how environmental discourse problematically draws on

such terms as 'natural' and 'pure' to oppose advances in biotechnology. François is critical of the development of GMOS, but she argues that the popular trend of calling these products "Frankenfoods" betrays, "a dangerous fetishization of purity and biological essence fueling the resistance to these newer technologies" (50). Similarly, Haraway, "cannot help but hear in the biotechnology debates the unintended tones of fear of the alien and suspicion of the mixed...a mystification of kind and purity akin to the doctrines of white racial hegemony and U.S. national integrity and purpose that so permeate North American culture and history" (qtd. in François).

One could argue that these meanings can be easily differentiated. We could argue that the material world that we share with nonhuman actors is one meaning of the term nature, while a set of defining characteristics or properties is another meaning. However, in many cases, overlap occurs. These differences in meaning have not precluded the exclusion of certain bodies under the guise of upholding the natural. Ray argues that mainstream environmentalism has contributed to the exclusion of individuals with disabilities, explaining that "the figure of the disabled body is the quintessential symbol of humanity's alienation from nature," as the historical role environmentalism played in constructing the disabled body continues to justify exclusions today (6). Ray's argument addresses an American context, describing the incommensurability between the self-reliance of wilderness adventurers and the interdependence that a disability studies perspective calls for. However, throughout this dissertation I argue that the concept of ecological othering that Ray discusses in relation to specific nineteenth century discourses in the United States can be extended beyond these national and temporal borders. As well, while Ray predominantly focuses on physical disabilities, I argue that individuals with neurological differences have also been subjected to practices of othering that are similarly grounded in sentiments borrowed from mainstream environmental movements. My scholarship is very much

indebted to the important intersections between disability studies and the environmental humanities that Ray continues to spearhead.

# **Methodological Notes**

My dissertation explores the three fields that I have outlined above, and consequently utilizes methodologies from literary studies, cultural studies, and rhetorical studies. My texts under discussion include both fiction and non-fiction, and they span across a variety of genres, including plays, novels, documentaries, memoirs, and poetry. In order to investigate multiple strategies for drawing attention to the relationship between bodies and environment, I blend multiple approaches. As a disability studies project, my dissertation draws on the foundational work of French philosopher Michel Foucault. Rosemarie Garland-Thomson, who introduced disability studies from the social science to the humanities, extends Foucault's analyses to consider disability. She explains that Foucault's account of the historical conditions that led to the classification of healthy and pathological bodies as a means of "disciplining all bodies in the name of improvement" led to the concept of the norm, which serves to measure and regulate all bodies (Extraordinary Bodies 39). Philosopher Shelley Tremain's edited collection, Foucault and the Government of Disability (2005), features the writings of many scholars who show how Foucault's theories allow for nuanced understandings of disability and the particular challenges that disabled people face. I draw on Foucault's account of how, within the space of the clinic, the medical gaze sees and knows truth because medical experience "is made up, as one entity, of those who unmask and before whom one unmasks," as I explore the politics surrounding both medical and humanist efforts to unmask the environmental truths of embodiment (110). I use

Foucault's writings to inform my understanding of authorship, but I also bring his insights into dialogue with postcolonial literary critics who examine the value that we place on literature.

Specifically, I draw on postcolonial literary critic Srinivas Aravamudan, who problematizes the relationship between literary production and empathy. Aravamudan specifically considers how the writings of Olaudah Equiano, an eighteenth century slave, have been fetishized when compared to the less aesthetically pleasing and more grammatically fraught writings of Sierra Leoneans writing during the same time period. He writes:

It is true that eighteenth century racialists deemed slaves irrational by pointing to their illiteracy, yet why should the act of literate – idealized as literary – persuasion be privileged as *an end in itself* (to the extent that it is conflated with the a priori definition of humanity) if not for the fact that we believe, perhaps too much as literary critics, in the transformative power of literature and are all too willing to demonstrate literature *as* the sign of humanity? (270).

Aravamudan cautions that while the rhetorical enterprise of showing how former slaves were capable of writing literature played a significant role in encouraging the public to recognize the humanity of people whose very personhood was systematically denied, this strategy should not be an end in itself. I consider Aravamudan's insights to be extremely important to disability studies because disability scholars and activists often depend upon similar rhetorical strategies, showing, in particular, how individuals with intellectual disabilities are vastly more capable writers than we would believe. However, while it is important to take these writings into account and make corresponding changes to educational practices that allow individuals with different learning styles to thrive, we must also recognize that arguments that hinge upon unrealized intelligence may inadvertently create distinctions between disabled people who can advocate for

themselves and those who may not speak verbally or write grammatically correct sentences. I draw on Aravamudan, then, for two purposes: one, to explain my reasoning for including both fictional and non-fictional writings about disability, as I argue that comparing them helps to generate a fuller picture of the issues that I wish to explore, and secondly, to explore how many of the writers that I discuss deploy literary strategies for drawing attention to disability politics while also demonstrating awareness of the fact that these strategies are often fetishized.

In addition to drawing on Michel Foucault and Srinivas Aravamudan for the methodology that I undertake, I also engage with risk theorists, and particularly German sociologist Ulrich Beck, whose insights inform the writings of Alaimo, Heise, Nixon, and Ray. While Beck praises the work of Michel Foucault and Mary Douglas for having demonstrated that risk is part of a struggle to "redefine state and scientific power," he critiques how they position risk as a dependable ally of the powerful, as opposed to an unreliable ally (79). Beck's theory of world risk society describes the current period as one of reflexive or hyper-modernity in which risks proliferate "not because of [society's] omissions and defeats but because of its triumphs" (36). He characterizes the contemporary era as one that cannot avert risk by acquiring more knowledge; risk society results from the production of more knowledge in a world that operates like a laboratory in which "application precedes research" (36). I use Beck's insights to demonstrate the rhetorical nature of scientific knowledge, amid a proliferation of expert discourses, and I use his concept of 'staging risk' to examine the strategies that writers use to communicate risk. However, Beck argues that the experience of living in this laboratory of crisis is unifying as global threats shape global risk communities, necessitating the creation of new cosmopolitan outlooks as "risk-based difference increasingly overlays, aggravates, or replaces the old class division as the original and intrinsic form of inequality" (142). While I make use of

Beck's analyses of hyper-modernity, I am critical of his cosmopolitan turn to global unity; I do not adopt his cosmopolitan hypothesis because, in my view, this hypothesis does not present a strong enough critique of the workings of capitalism or neo-colonialism.<sup>7</sup>

While the writings of Aravamudan, Beck, and Foucault best illustrate my methodologies in this dissertation, my critical project aims to continue the work of Alaimo, Nixon, and Ray, who all, to varying degrees, explore the intersections amongst the three fields that inform my dissertation. In the following section, I outline the content of my chapters, as well as the corresponding methodologies that I employ.

# **Establishing Critical Ecologies of Embodiment**

My dissertation is divided into two parts, the first of which investigates disability, illness, and industry through an examination of communal experiences of mass disablement. My second section focuses on neurological difference and environmentalism, as it examines communal experiences of being cast as ecological others. In many ways, my first section celebrates the important work that has already been accomplished in environmental criticism in terms of

<sup>&</sup>lt;sup>7</sup> While Beck acknowledges that world risk society presents the possibility for a new beginning, he calls for a radical redefinition of the relations of production. He expresses confidence in the development of an alliance between sustainability and capitalism that will avert both ecological and financial crisis. Beck's vision of green capitalism depends upon the action of non-governmental organizations and responsible consumers. He describes the emergence of a new non-legislative force in the form of an alliance of consumers who can exercise subpolitics, which he defines as the practice of decoupling politics from government (95).

Beck's primary example of subpolitics is a boycott against Shell initiated by Greenpeace in 1995. Shell was going to dispose of a scrapped oil tanker, the Brent Sparr, by sinking it into the Atlantic. Consumers created a boycott against Shell and filled their tanks at other location instead. Under pressure, Shell disposed of the oil rig on land instead. Beck suggests that this incident revealed that, "the post-traditional world only appears to be dominated by individualization....Status or class consciousness, belief in progress or decline, all of this could be replaced by the humanity-wide project of saving the global environment" (97). He also suggests the emergence of a new type of politics, as "citizens are discovering that the act of purchasing functions as a vote that they can always use in a political way" (97). Beck's theory assumes that it is possible to respond to ecological threat and minimize it in a meaningful way through an economic system based on continual growth, in which we vote with our purchases. My critique here is that as Beck posits the replacement of class-consciousness through a shared project, he suggests that citizens can influence corporations through the act of purchasing. I would argue that the claim that citizens can always vote with their dollars rings ominous when one considers that those who have the most purchasing power have the greatest representation through such a system. As well, the purchases of individuals who have limited income may not always reflect their political values.

thinking about environmental health and bodily health in conjunction. We urgently need environmental criticism of many different varieties, and the trajectory of this section of my dissertation aims to move disability studies toward adopting ecocritical approaches.

In my first chapter, "Staging Slow Violence: The Temporalities of Disabling Illness," I establish how an approach to critical ecologies requires acknowledging the presence of disabling environments, which involves rethinking understandings of the environment with which disability studies scholarship often engages. I provide a literary interpretive analysis of Métis-Dene writer Marie Clements's portrayal of the disabling illnesses experienced by the Dene people in the Northwest Territories in her play Burning Vision (2003). I explore, as well, the historical and contemporary contexts of her work, including the Dene communal history, If Only We Had Known (2005). In her play, Clements represents the experiences of individuals who carried the uranium ore used in the atomic bomb that was dropped on Hiroshima. She juxtaposes the immediacy of the attack upon Hiroshima with the violence slowly inflicted upon the Dene ore carriers and poor miners who developed cancers from unsafe exposure, despite the fact that scientists of the time knew about the dangers of uranium mining. My theoretical approach to considering the impact of technological development upon bodies and landscapes draws on Nixon's concept of slow violence. Specifically, the questions that guide this chapter concern the connections between slow disaster and political representation in Canadian literature. In a review of Nixon's work, legal scholar Dayna Nadine Scott argues that his descriptions of communities in the Global South map onto descriptions of Indigenous activists in the Global North (482). I consider how Scott's insights might inform readings of literary works, as I ask how postcolonial writers in Canada, like writers in the Global South, employ strategies for making slow violence visible. In this chapter, I argue that the expansive historical scope and instances of dramatic irony in Clements's play form a representational strategy for addressing the calculated amnesia that characterizes relationships toward Canada's marginalized populations.<sup>8</sup>

The high rates of cancer experienced by people in Déline suggest the importance of a nuanced examination of the relationship between debilitating illnesses and place. I examine this relationship between the play's characters and the environment with reference to the material feminism of Stacy Alaimo. Alaimo is careful to avoid reinscribing a medical model of disability. Her work speaks to Nixon's environmental concerns, but her disability studies lens provides insight into how understanding disability as violence against the body might reinforce stigma. With respect to a model of disability that values deviation, Alaimo does caution that many people who are sensitive to chemicals would insist, "not all deviations in this world of toxicants and xenobiotic chemicals should be embraced" (139). Her development of the concept of an openness to deviation, which draws on the work of Ladelle McWhorter, involves placing everyone on a continuum of sensitivity to the environment. She advocates "tak[ing] the ontoepistemological condition of chemically reactive people seriously by making the world more accessible for them," which would require drastically changing global political and economic practices (139). Along with using Alaimo and Nixon's work to read Clements's play, however, I also consider how Burning Vision offers new questions with regards to slow violence and transcorporeality, and their potential for guiding a transformation from the ethics of apology to the practice of access. I argue that the engagement of Indigenous writers with the slow progression of environmental disaster, practices of silencing, and collective amnesia offers insight into creating strategies for social and environmental change.

<sup>&</sup>lt;sup>8</sup> I use the term 'amnesia' throughout this dissertation to signal that I am drawing on Nixon's concept. Although, as I noted earlier, the metaphorical use of disability to suggest a calculated forgetting is an example of how disability metaphors pervade language, I use this term to indicate how my project builds upon Nixon's important work.

Chapter Two, "Novel Embodiments: Deviation, Disability, and Industrial Disaster" builds upon my discussion of disability and industrial development, examining narrative strategies for representing slow violence that avoid stigmatizing the disabled body. I turn to Indra Sinha's novel Animal's People (2007), and its fictional representation of the Bhopal Disaster. Here, I use the novel to explore the tension between a model of disability that celebrates human variation, and the material experiences of bodily difference originating from chemical poisoning. The Bhopal Disaster of 1984 is one of Nixon's primary examples of the prolonged impact of slow violence. Chemicals continue to affect residents because corporate amalgamation made Union Carbide disappear as a corporate body, and consequently, citizens do not have access to medical care or a clean environment. Although Dow Chemical Corporation now owns Union Carbide, it has refused to assume responsibility for Bhopal. Sinha's protagonist, Animal, walks on his hands and feet because chemical poisoning has affected his spinal growth. Nixon argues that Animal's posture "embodies a crushing, neoliberal, transnational economic relationship and also marks him as a literal 'lowlife', a social and anatomical other whose physical form externalizes the unhurried metastases coursing through the community" (56). He writes:

A novel narrated by a human animal – "a beastly boy" (*Animal's* 9) – bent out of shape by his foreign load simultaneously questions other forms of mutability, not least the plasticity of ownership, how foreign corporate practices inside India can be owned (for short-term profit) and disowned (for long-term consequences to environmental and human health). (57)

As Nixon emphasizes how irresponsible corporate practices have shaped Animal, he reads his disability as a metaphor for India and the effects of foreign corporate practices within the country (57). As Barker and Murray argue, the tension between disability studies and postcolonial studies

has often been one of materiality and metaphor, or, of reading disability as symbolic of the postcolonial nation in development versus reading disability as a material experience (219). I do not wish to contest Nixon's reading, or to suggest that metaphorical readings of disability are necessarily incompatible with disability studies readings. Instead, I wish to emphasize how Animal's rejection of interpretive readings of his body by journalists, doctors, and imagined readers or "Eyes" reveal the limitations of humanist representations of disability that invoke suffering by referencing an essential shape to which individuals should conform.

While Animal can be read as symbolic, his story also draws attention to how ideologies shape understandings of disability. I argue that Sinha's novel destabilizes traditional understandings of the body while also drawing attention to pain. As Barker argues, representations of global trauma depend upon the docile body of the child to "emphasiz[e] its susceptibility to disablement in order to heighten the sense of humanitarian crisis and to insist on the urgency of western intervention..." (11). While Sinha's novel does show how people living in areas of mass disablement do experience great pain, it also highlights how Animal's body has been used to create a narrative of suffering in which his life can *only* signify injustice. Within a medical model of disability, Animal's spine requires correction and an operation would ensure that this need is met. However, after surgery he would need to use a wheelchair or crutches in a city not designed for them, which would further disable Animal by preventing him from accessing familiar places. The inaccessibility of Khaufpur indicates how disablement is a process rather than a static condition; disability is not located within Animal's body, but imposed upon him. Animal's acceptance of the shape his own body has taken, however, does not signify a passive acceptance of the situation within Khaufpur. The novel is critical of exported solutions, as it shifts its focus away from Animal's body and toward neo-colonial corporate practices. In

keeping with this shift, I also examine the community of Khaufpur depicted in *Animal's People*, which has not received as much attention in other analyses of disability in the novel.

In the second section of my dissertation, I examine how disability studies methodologies and insights can inform the environmental humanities by drawing attention to how certain bodies have been cast as outside of nature. This section explores the concept of neurodiversity, which Ari Ne'eman defines as "the idea that the paradigm of acceptance extended toward racial, religious and other similar differences should apply to neurology as well" (Qtd. in Broderick and Ne'eman 470). Chapter Three, "Documenting Global Connections: Autistic Self Advocacy and its Reframing of Awareness Discourse," moves from discussions of disability and industry to disability and neurological divergence, as I investigate the proliferation of expert discourse surrounding autism. This chapter concentrates on how developing critical ecologies of embodiment involves listening to the voices of disabled subjects. The focal point of this chapter is the documentary Wretches & Jabberers (2010), directed by Gerardine Wurzburg and starring Larry Bissonnette and Tracy Thresher, which positions autistic individuals as experts in their own right. This film chronicles the travels of Larry Bissonnette and Tracy Thresher to meet with other advocates using facilitated communication in Sri Lanka, Japan, and Finland. Many organizations suggest that rising diagnoses of autism constitute a health crisis, when one could also frame the crisis, as Wretches & Jabberers does, as one of accommodations, services, and attitudes toward communication. Ari Ne'eman, founder of the Autistic Self-Advocacy Network, and researcher Alicia Broderick clarify that autistic people may not have any health problems. They argue that positioning autism as a health crisis "draws upon a medicalized discourse in which people who have labels of autism are constituted not as neurologically different, nor even as disabled, but rather as diseased, not healthy, or as ill" (468). Tracing the characterization of

autism as a global health crisis, my third chapter builds upon my discussion of the connections between bodies and environments that are central to instances of painful chemical poisoning and radiation exposure by examining the ways in which autism is understood as resulting from our unsustainable environmental practices. In part, this is a way of pushing Alaimo's discussion of an openness to deviation further by considering how disability acceptance can be pursued alongside environmental advocacy when individuals with disabilities object to research that presents the body as a sign of environmental injustice.

As I show how this film reframes the struggles associated with rising diagnoses of autism, suggesting that social acceptance and new understandings of terms like 'communication' and 'intelligence' constitute greater priorities than medical cures or behavioural interventions, I also explore its relationship to other writings by autistic self-advocates. Many self-advocates challenge assumptions that autistic people are incapable of representing themselves through language, often by employing literary and rhetorical devices that they have been deemed incapable of using. However, they also complicate associations between language and empathy. Erin Manning, who argues that autistic perception productively destabilizes established modes of thinking, explains that language is a "double-edged sword" for advocates who want to deemphasize language, but also understand that language has been held up as central to inclusion (162). As Manning points out, efforts to help individuals use language "rel[y] on the idea that language as the model of human-to-human interaction is the passport to a life worth living" (163). The question of empathy and its relationship to language has particular resonance in autism communities because of the popularity of Simon Baron-Cohen's concept of mindblindness, or the idea that autistic individuals lack a theory of mind and are consequently unable to perceive or understand the emotions of other people. As a result of the popularity of

this theory, in the popular and clinical imaginations, autistic individuals are denied the ability to empathize, an ability which has been so strongly linked to reading and writing literature. I argue that while it is important to recognize the intelligence of autistic writers, readers should also look at how autistic writers themselves focus on how it is not sufficient enough to stop with the realization that autistic people are better writers than people once believed; instead, individuals need to rethink how they value communication. In this chapter, I focus on examples of cultural production that point toward the generative possibilities of other ways of knowing that have been discounted as defective forms of communication. I conclude with an explanation of how the film and other works that I discuss move away from a western medical model, and away from a model of disability that focuses solely on rights; instead, they focus on the development of networks of understanding and support, beginning an international dialogue on acceptance.

In Chapter Four, "Alternative Futurities: Neurological Difference and Environmental Diversity," I explain how developing critical ecologies requires attending to the rhetorical aspects of risk in scientific discourse. Taking neurological difference as my subject once more, I examine how many people have understood autism as a condition hosted by individuals, in the way that bodies are understood to host diseases. In other words, autism is understood as a barrier behind which lies a 'normal' child (Sinclair). Stuart Murray considers the impact that this "autism-inside-the-person" model has had upon awareness efforts and approaches to treatment (*Representing Autism* 30). Many theories, like the theory that autism was a form of mercury poisoning, fostered the belief that autism is an unnatural deviation in need of cure when "all serious research into autism acknowledges that it is a lifelong condition that is built into the fabric of the person who has it" and "as such, it cannot be cured" (*Autism* 89-90). While the belief that a cure for autism is desirable has been contested by many activists and academics,

despite growing acceptance of neurological difference, many parties continue to discuss autism as an epidemic. My main object text in this chapter is *On the Edge of Gone* by Corinne Duyvis, a science fiction novel that imagines autism as part of a desirable future even as it portrays an increasingly precarious future, from an environmental standpoint. In addition to Duyvis's work, I discuss the writings of other autistic adults who present an alternative to the belief that autism is unnatural. I argue that rather than reading autism as a sign of environmental degradation, readers can move to an exploration of neurological diversity as a significant form of biological diversity.

In this chapter, I draw on the work of Ray, who explains that mainstream environmentalism has contributed to the exclusion of individuals with disabilities in American culture, arguing that, "the figure of the disabled body is the quintessential symbol of humanity's alienation from nature," and that, "historically, environmentalism played a significant role in constructing the disabled body, a historical legacy that continues to shape the corporeal bases for its various forms of exclusion" (6). I argue that Ray's concept, although developed to describe an American context, is also useful for considering how the language of risk and threat surrounding autism is bolstered by a belief that its development is unnatural and represents the toxic effects of contemporary diets and products developed by multinational biotechnology companies. The texts that I use to construct my argument in this chapter include newspaper and magazine articles, blog posts from autistic individuals, caregivers, researchers, and materials from autism organizations. I do not engage with the scientific question of whether or to what extent autism has environmental causes; rather, I focus on the knowledge translation of research linking autism and environmental factors into the popular imagination. My chapter investigates the narrative strategies and rhetorical devices used in multiple forms of media. I consider how metaphors linking ecological devastation to the changing condition of human neurology can be problematic,

and I show how the interpretation of hypotheses that there are links between environmental toxins and autism tend to be expressed using language and imagery designed to evoke fear. The materials that I discuss advance a medical model that frames autism not as neurological diversity, but as an unnatural deviation, a defective neurology, or an illness to be cured. I argue that autistic individuals are positioned as ecological others when autism is held up as an example of the toxicity of contemporary society, and I emphasize the importance of pursuing efforts to link disability rights and environmental justice in a more nuanced way.

In my conclusion to this dissertation, "Toward Critical Ecologies of Embodiment:

Concluding Remarks," I reiterate how my texts show other ways of knowing, thinking, and being in the world that respond to the ways that disability, as McRuer reminds us, appears within discourse as a risk to be feared. I argue that my texts question both the stigma associated with disability and illness, and the collective amnesia that renders the lives of people with disabilities precarious. I emphasize that creative works that engage disability and ecology show how bridging environmental justice and disability does not necessitate a reintroduction of the medical model, but instead suggests the need for deeper investigations into the risks that individuals with disabilities face in contexts specific to place. In addition to reiterating how my chosen works contribute to a more expansive understanding of access, I also consider how they offer productive new metaphors for imagining disability.

## **Chapter One**

Staging Slow Violence: The Temporalities of Disabling Illness

### 1. Embodiment and Slow Violence

As of the March 2016 issue of the Bulletin of the Atomic Scientists, the time setting of the Doomsday Clock housed in the University of Chicago's Harris School of Public Policy Studies is three minutes to midnight. A group known as the Chicago scientists created the Bulletin and its well-recognized symbolic clock face after their involvement in the Manhattan Project during the Second World War persuaded them of the dangers of nuclear weaponry and the urgency of communicating these dangers to the larger public. Martyl Langsdorf, an artist who was married to one of the scientists, designed the first cover of the Bulletin in 1947. Her design featured the face of a clock that has since acquired the name of The Doomsday Clock. The initial setting of seven minutes to midnight on the clock was a design choice. However, when the Soviet Union began conducting nuclear tests in 1949, the scientists decided to advance the clock further; the new setting was three minutes to midnight (Smith 26). Scientists from the Bulletin continue to meet bi-annually to assess the threats facing humanity and the imminence of catastrophe. More than 60 years later, despite gaining and losing time as it has moved both further from midnight and closer to it, the reading of the clock is now set at three minutes to midnight once again.

The Doomsday Clock appears in many artifacts of western popular culture, from the film Dr. Strangelove or: How I Learned to Stop Worrying and Love the Bomb (1964) to rock songs by Iron Maiden and the Smashing Pumpkins. It features prominently in Alan Moore's limited

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<sup>&</sup>lt;sup>9</sup> The Bulletin of the Atomic Scientists maintains a timeline that lists the dates when the scientists moved the minute hand forward or backward, as well as short excerpts from the accompanying issues that indicate which threats had either intensified or subsided. The clock was closest to midnight in 1953, when it was advanced to 11:58 after the United States and the Soviet Union both tested thermonuclear weapons. The furthest setting from midnight was seventeen minutes away, when the Cold War officially ended in 1991 and the United States and the Soviet Union signed the Strategic Arms Reduction Treaty (Bulletin of the Atomic Scientists).

series *Watchmen* (1986-1987), in which the clock is often disguised as a smiley face with a blood splatter serving as the minute hand. Douglas Wolk connects the recurring visual rhetoric of the clock to the overarching metaphor of the comic, which he defines as, "nuclear eschatology: a blinding and unstoppable disaster that's perpetually descending, a clock perched at a few minutes to midnight" (244). But three years after the release of the *Watchmen* series, in 1989, the real Doomsday Clock took on a new face. An image of earth is embossed on the new clock, emphasizing the global nature of the dangers that we face. While midnight on the original clock symbolized nuclear annihilation, now, the movement of the clock also indicates the growing threat of climate change. Some scholars suggest that with this symbolic shift, the clock has lost its rhetorical force. Molly Wallace notes that "when what the Clock measures is no longer only nuclear, but also chemical, biological, and atmospheric, the speeds are varied and the ends less sure" (16). Analyzing the clock as a symbol of securitization, Juha A. Vuori writes:

During the cold war, it was as though the whole of humanity was moving across a minefield where a misstep could have led to nuclear annihilation, in a matter of hours, if not even minutes. When the possibility of such rapid destruction is compared to the slowness of degradation brought about by global climate change, it seems that the threshold of doom and the pace at which it can approach have changed in respect to the most prominent of catastrophes that constitute contemporary (mainly Western) threat registers. (207)

As Vuori acknowledges here, our sense of urgency falters when we shift registers from considering the immediate destruction of nuclear annihilation, the primary fear of western civilians during the Cold War who faced the promise of mutually assured destruction, to the slow progression of climate change and environmental degradation more generally. Vuori's concerns

invite us to question whether a clockface with the minute hand perched at midnight effectively communicates the urgency of environmental catastrophe.

Concerns surrounding the clock as a shifting signifier are consistent with the concerns of contemporary ecocritics, who are interested in both reconceptualizing disaster, and in attending to the persuasive narrative strategies that would need to attend such a reconceptualization. In this chapter, I engage with theoretical reconceptualizations of the temporalities of risk, threat, and violence to consider the significance of the body in these discourses. I establish how a central aspect of the concept of critical ecologies of embodiment that I introduce in this dissertation is the acknowledgment of the presence of disabling environments. This is an acknowledgment that, as I noted in my introduction, involves expanding definitions of 'environment' within the field of disability studies. Throughout this dissertation, I explore how contemporary activist-oriented works explore disabling environments during three cultural moments. I begin with texts surrounding the legacy of the Second World War, nuclear technology, and disabling illnesses; move to a discussion of disability and the industrial, chemical, and agricultural technologies of the Green Revolution; and conclude with a discussion of the discourse surrounding autism and contemporary environmental concerns in the early twenty-first century. While the representations of disability and industry that I will examine in the first section of my dissertation begin at different historical moments, with the first centred on 1945 and the second centered on 1984, both chapters share a concern with recalibrating the timeline of disaster and in that sense, the issues that they explore persist into the present.

As I consider how a disability studies perspective might approach the Doomsday Clock and related threat registers from 1945 onward, one of my contentions is that disabled people are often interpreted as signs of the worsening conditions of our ecological and social environments,

or as symbols of suffering that individuals can read like they would read as the minute hand on the face of the clock approaching midnight. In this chapter, I examine the representation of illness and industrial production in Marie Clements's *Burning Vision* (2003), returning to the motif of a ticking clock to consider how the play explores the temporalities of disaster. I discuss literary strategies for mobilizing powerful stories of illness and disability to communicate urgency and for maintaining a critical focus on how disabling conditions are shaped.

One of the ways that ecocritics are already working to reconceptualize the timeline of disaster is by showing how what we have imagined to be an impending apocalypse may already be here, even if it is progressing slowly. For example, Andrew McMurry argues that we are beyond any hope of recovery, positioning himself against calm proponents of the techno-fix who believe that, "what man has unleashed, he can, so to speak, re-leash", as well as those who hope that massive changes in global economic and political policy can curb inevitable destruction (para. 28). Our belief in hope, he argues, is informed by our limited temporal perspective; continually assured by our guardians that everything will be okay in the end, we grow up believing that humanity will always survive with the earth because we cannot fathom the alternative (para. 13). Rob Nixon suggests that the problem of addressing ecological destruction stems in part from this limited temporal perspective. Drawing on Johan Galtung's 'structural violence,' Nixon offers the concept of 'slow violence,' which I discussed in my introduction, to address this issue of temporality. The time of environmental degradation and

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<sup>&</sup>lt;sup>10</sup> In an introduction to a special issue of *The Journal of Ecocriticism* in 2012, McMurry and William Major argue that imagining the alternative is sometimes even discouraged within ecocriticism. Describing an initially promising call for papers for a conference that ended with an approbation to avoid the rhetoric of 'catastrophic urgency,' McMurry and William Major argue that, "the very thing that in the last 20 years has prompted many humanists to question humanism – i.e., the 'catastrophic urgency' of our environmental movement – is dismissed out of hand, as if serious scholars shall have no truck and trade with planetary catastrophe in its full horror" (3).

<sup>&</sup>lt;sup>11</sup> Nixon acknowledges Galtung as an influence, but he notes that despite the continued relevance of structural violence to many contemporary writers, Galtung formulated the concept over 40 years ago and it is very structuralist. He differentiates his own theory from Galtung's by explaining the significance of his focus on speed:

the gradual speed of disaster that Nixon and McMurry both emphasize in their critical writings reveal the limitations of the instruments that we use to take stock of the threats facing humanity and the planet that we inhabit. Nixon's work, which explicitly contrasts the sensational violence of western media with the slow progression of toxicity in communities where environmental risks are conveniently exported, provides insight into how an image of a clock hovering at a few minutes to midnight reflects the fears of the Global North in particular. The clock and its rhetorical purpose will be of ongoing significance to this chapter, as I discuss the implications of Nixon's move toward using the body and health as indicators of environmental suffering, and how a disability studies perspective might recognize and engage with his concerns.

In taking up the concept of slow violence, Nixon necessarily enters into a discussion of health and ability as he examines the representational strategies of written works that show how environmental problems affect human health. Nixon argues that precision warfare, and specifically the use of depleted uranium munitions in the Gulf War, calls us to ask: "What is a war casualty?" (200). Clarifying the question, he asks: "After an official victory has been declared, how do we track the persistence of unofficial hostilities in the cellular domain, the untidy, attritional lethality that moves through the tissue, blood, and bones of combatants and noncombatants alike, moving through as well the living body of the land itself?" (Nixon 200). While Nixon's proposed positioning of individuals who have been exposed to the radioactive aftermaths of war as war casualties might prompt greater accountability, we can also ask, what are the implications of adding people to the body count when we know, as I established in the introduction to this work, that people problematically associate disability with death, and that

In contrast to the static connotations of structural violence, I have sought, through the notion of slow violence, to foreground questions of time, movement, and change, however gradual. The explicitly temporal emphasis of slow violence allows us to keep front and center the representational challenges and imaginative dilemmas posed not just by imperceptible violence but by imperceptible change whereby violence is decoupled from its original cause by the workings of time. (11)

many societies foster the idea that living with illness or disability is a fate worse than death?<sup>12</sup> As well, an approach that considers what Nixon terms the "unofficial hostilities in the cellular domain" would need to acknowledge how military metaphors for discussing illness can stigmatize or place fault on the individual (200).<sup>13</sup> While attention to how our social and political structures have made our environments more hazardous and more disabiling is important, what are the implications of understanding prolonged bodily states as forms of violence? To echo and expand upon a question from my introduction, how can we celebrate disability while also acknowledging the experiences of painful disability for people who might acquire disability through working in industry, through exposure to toxic gases, radioactive materials, and other substances?<sup>14</sup> And, at the level of cultural representation, what kinds of exclusions are created when disabled bodies are used to represent social and environmental degradation? In my next section, I investigate these questions by turning to literature to consider the significance of Nixon's concept of slow violence and Sarah Jaquette Ray's outlining of the process of ecological othering in a postcolonial Canadian context.

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<sup>&</sup>lt;sup>12</sup> With respect to The Gulf War, Nixon argues that the United States military needs to assume greater accountability for the lives lost in the aftermath of the conflict. He writes, "The calculus of any conflict needs to acknowledge such casualties, even if they cannot be quantified. Such casualties may suffer slow invisible deaths that don't fit the news cycle at Fox or CNN, but they are war casualties nonetheless" (201).

<sup>13</sup> Susan Sontag argues that the war metaphors surrounding illness that describe individuals as fighting battles can

<sup>&</sup>lt;sup>13</sup> Susan Sontag argues that the war metaphors surrounding illness that describe individuals as fighting battles can have detrimental effects in *Illness as Metaphor and AIDS and its Metaphors*. She explains that she observed, "again and again, that the metaphoric trappings that deform the experience of having cancer have very real consequences: they inhibit people from seeking treatment early enough, or from making a greater effort to get competent treatment" (102). Perhaps, however, an issue that has received less attention is the use of the vocabulary surrounding disability and illness to describe war. In Nixon's work, he describes how the use of words such as "surgical" with respect to military strikes serve to mask the protracted health effects of precision warfare.

<sup>&</sup>lt;sup>14</sup> Nirmala Erevelles explores a similar question in *Disability and Global Difference*, in which she considers the disabling impact of structural violence. She asks, "How is disability celebrated if its very existence is inextricably linked to the violence of social/economic conditions of capitalism?" (Erevelles 17). My questions regarding disability and slow violence are related, but focus specifically on the relationship between disability and natural environments.

## 2. Slow Violence, Disability, and Indigeneity

Scholars in Canada have addressed how national mythologies that elevate nature as something to be both revered and feared have influenced our perceptions of disability. Catherine Frazee's review of the short documentary "Taking Mercy," produced by Canada's Global Television Network, shows how cultural understandings of what is natural influence our perceptions of whose bodies matter and whose bodies deserve a place in our national body. Frazee's review describes how the film portrays Robert Latimer, the Saskatchewan canola farmer who took the life of his disabled daughter Tracy. The opening frame shows Latimer surveying the land as it sets up a dichotomy between the law of nature and the existing law of a nation (Global). Naming her quarrel as one with "the clichés and platitudes that foster and condone a very particular homicidal impulse," Frazee states, "it is a preposterous notion that Tracy's life did not conform to the law of nature that Robert somehow epitomizes" (para.8). Maria Truchan-Tataryn also suggests that support for Latimer is bound up in our cultural myths. In her study of the representation of disability in Canadian literature, she considers why Canadians support Robert Latimer despite their pride in the Canadian Charter of Rights and Freedoms, and asks to what extent this support might stem from the literary erasure of disability (191).

In a thematic study of Canadian literature, Margaret Atwood suggests that the central symbol for Canada is one of survival, a preoccupation accompanied by "an almost intolerable anxiety" (33). She notes that in early Canadian literature, the obstacles to survival are external ones, like the land and the climate, while later works often feature spiritual survival. She argues that when fear of the obstacle becomes the obstacle, then the individual might fear life itself: "when life itself becomes a threat to life, you have a moderately vicious circle. If a man feels he can only survive by amputating himself, turning himself into a cripple or a eunuch, what price

survival?" (33). <sup>15</sup> Many environmentalist discourses have worked to create a portrait of an "environmentalist body," or a body good for nature, which is a portrait that attributes environmental problems to individuals as opposed to social and economic forces that constrain action, shape environments, or lead to displacement (Ray 5). Many environmentalist discourses also assume this approach with respect to their consideration of Indigenous people, often presuming an essential closeness with nature, rather than addressing the ways that Indigenous communities often have interests in environmental protection because they bear the costs of environmental racism (Ray 85). In this work, I am not focused on access to an experience of transcendence in nature that allows for spiritual or individual development, although I acknowledge the importance of these topics with respect to many literary and cultural works. Rather, I am interested here in a form of access based on the idea that environmental destruction creates barriers to access, when we broaden the term to consider the disabling impact of social and economic policies that affect our lived environments.

In a recent review of Nixon's work, legal scholar Dayna Nadine Scott looks to his concept of "displacement without moving", or the loss of resources that renders a place uninhabitable (482). Nixon explains that we often understand the term displacement to mean the physical relocation of people and communities. However, he argues, an equally destructive form of displacement occurs when individuals must remain in an area that has been "stripped of the very characteristics that make it habitable" (19). Nixon's revised concept of a "stationary displacement" acknowledges the politics of mobility - that many individuals, even if they desired to leave their homes, would not have the freedom or the means to do so, primarily because of neoliberal policies (19). Scott argues that Nixon's descriptions of communities in the Global

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<sup>&</sup>lt;sup>15</sup> Atwood suggests that the Canadian poem "David" (1942) by Earle Birney is an example of the harsh depiction of nature and death in Canadian literature (55). For a comprehensive reading of "David" from a disability studies perspective, please see Nicole Markotić's article "Icarus, Gods, and the 'Lesson' of Disability."

South map onto descriptions of Indigenous activists in the Global North. She observes that the contamination of areas like the Mohawk nation of Akwesasne, where aluminum and automobiles are now manufactured, provide evidence that Indigenous communities in Canada and North America more broadly are clearly impacted by policies that Nixon outlines (482). Susana Deranger, an activist and member of the Athabasca Chipewyan First Nation, argues for a link between such approaches to Indigenous communities and earlier practices, pointing out that Canada engages in an unacknowledged continuation of the genocide of Indigenous populations in North America, from the use of small pox blankets as a form of bioterrorism to the "resource extraction and downstream pollution, poverty, racism, and lack of access to those things that most Canadians take for granted" ("Our Home on Native Land").

Connections between environmental protection and health are central to the Idle No More movement, which opposes the introduction of policies that threaten to make Canada uninhabitable for both Indigenous and non-Indigenous people. In November 2012, Indigenous activists held a meeting at Station 20 West in Saskatoon called "Idle No More" in opposition to the Conservative Party of Canada's introduction of Bill C-45. Bill C-45, also known as the Omnibus Bill, was introduced by Stephen Harper's government on October 18, 2012 with the title, "A second Act to implement certain provisions of the budget tabled in Parliament on March 29, 2012, and other measures" (CBC News). The bill received royal assent two months later in December, becoming *The Jobs and Growth Act*, 2012. Among many other changes, Bill C-45 amended the Navigable Waters Protection Act (NWPA). Its new name, the Navigable Protection Act (NPA), separates navigational concerns from environmental concerns, and thus significantly weakens the protection of Canada's waterways ("Ecojustice"). While the Idle No More movement was created in response to Bill C-45, its purview has expanded beyond opposing one

piece of legislation in order to address land claims, a lack of resources, and funding for education and housing. It has also extended beyond Indigenous communities in Canada, as Idle No More activists stand in solidarity with many international Indigenous movements.

As Idle No More has been at the forefront of environmental and anti-colonial activism in Canada, the movement takes a nuanced approach to health. While many approaches to health tend to present disease itself as an invader or enemy, Indigenous approaches to health are often explicitly political, linking the poor health of communities to the violence of colonialism. The concerns addressed by Idle No More's manifesto clearly reflect that First Nations peoples are being displaced without moving in the manner that Nixon articulates:

Some of the poorest First Nations communities (such as Attawapiskat) have mines or other developments on their lands but do not get a share of the profit. The taking of resources has left many lands and waters poisoned – the animals and plants are dying in many areas in Canada. We cannot live without the water. ("The Manifesto")

The text of "The Manifesto" shows how First Nations communities in Canada are at the forefront of an activism that emphasizes central connections between natural environments and human health. 16 As an acknowledgment of the centrality of these topics to Indigenous literature and activism, this chapter seeks to explore connections between environmental activism and disability rights by first turning to Indigenous displacement in Canada, although the scope of this dissertation extends beyond Canada. Since Scott's review of Nixon appears in the context of a legal journal, her focus is on implicating law itself in the perpetuation of slow violence. While

the term "natural environment," I am attempting to indicate that I am not referring to the built environment or to attitudes, but to the places that human beings share with nonhuman organic life. However, the term "nature" is a contested term within ecocriticism because many scholars working in the field argue against the binary known as the

nature-culture divide.

<sup>&</sup>lt;sup>16</sup> Again, I use "natural environment" as opposed to simply "environment" because in disability studies the term environment is often used to signify the built environment or the environments shaped by human attitudes. By using

Scott's questions surrounding the practical application of Nixon's theories are essential, here, I draw upon Scott's review to bring the discussion of slow violence back to the literary, but with new questions. The questions that guide this chapter concern the connections between slow disaster and political representation in literature, as well as the implications for thinking about slow violence as a violence that is perpetrated against the body. How do Indigenous writers in Canada, like writers in the Global South, employ strategies for making slow violence visible? What genres do they employ? How might they complicate the concept of slow violence, or the recent and related figuration of the trans-corporeal advanced by Alaimo, which emphasizes the interconnection between individuals and their environments? And how might they provide further insight into these theoretical projects? While answering all of these questions is beyond the scope of this project, I open up a dialogue on this topic by addressing the specific literary strategies employed by Métis-Dene writer Marie Clements in *Burning Vision*.

Nixon focuses on non-fiction and the novel, but he expresses concern that some novels about slow violence suffer from a drama deficit, resorting to sentimentality and moralizing as opposed to arresting spectacle and narrative tension (52). With a concern like "drama deficit", and a penchant for "arresting spectacle," the terms of his analysis suggest the potential for an analysis of a play.<sup>17</sup> In this chapter, I examine the script of Marie Clements's *Burning Vision*, a

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Although Nixon's work focuses on fiction, and my analysis focuses on drama, it is also worth noting that many visual artists work to address our limited temporal perspectives in science fiction-like installations that project the risks that we face now into the future to imagine the consequences. For example, European artist Isaac Cordal creates miniature sculptures which he arranges on city streets and other public places, establishing what he refers to as "cement eclipses". Cordal critiques contemporary capitalism by imagining the devastation of its aftermath. He refers to his installation, "Follow the leaders" as "a cultural reflection on our own inertia as a social mass" (Cordal). One installation from this series that social media users refer to as "Politicians discussing global warming" depicts a deliberating council of miniature statues submerged up to their necks in a puddle of water. On his website, he describes the process of creating cement eclipses, noting that, "with the master touch of a stage director, the figures are placed in locations that quickly open doors to other worlds" (Cordal). His works attempt to make what many activists and ecocritics believe to be our inevitable future come to life in the present. These works are placed on city streets where citizens can easily stumble upon them, and so their unexpected presence works to shake up the complacency of the everyday. The David Suzuki Foundation's Tideline Project works toward a similar objective.

production that traces connections between the Dene community of Déline located near Port Radium on the eastern shore of Great Bear Lake in the Northwest Territories, and the Japanese victims of the bombings of Hiroshima and Nagasaki during the Second World War. 18 I argue that the expansive historical scope of Clements's play and its instances of dramatic irony serve as representational strategies for addressing the prolonged trauma and the calculated amnesia that characterizes relationships toward Canada's marginalized populations. Moreover, I suggest the potential for using this play to consider the ways in which contexts specific to place might be further considered as disability studies forges connections with environmental studies.

However, I want to heed the caution given by other scholars that although connections between Indigenous activism and environmental justice movements may appear obvious, the tensions between these allegiances need to be considered too. Marc Woons clarifies that equating Idle No More with the environmental movement is problematic because Indigenous claims to sovereignty and self-determination are inclusive of environmental protection but not bound by it. While he acknowledges that Indigenous nationalists and environmentalists share, "a common enemy in the unsustainable development brought on by global economic forces supported by the world's powerful industrialized states," and that there have been many successful instances of cooperation, he also cautions that not all environmentalists are interested in Indigenous nationhood (147). For example, he notes that some "environmentalists fight hard to stop Indigenous people from whaling, despite its extreme cultural significance and Indigenous claims that their practices are sustainable" (174). Similarly, Ray argues that to equate Indigenous people with environmentalism reinforces a harmful stereotype. While Ray insists that Indigenous

Guerrilla street artists attached barnacles and shells to fabric panels that they draped over street poles in Vancouver to create tidelines and give the impression that the city had been flooded (Spring Advertising).

<sup>&</sup>lt;sup>18</sup> My analysis centres on the published text of the play, as a live performance was not staged while I was working on this research. When discussing the play as a performance, I reference commentaries from directors who have staged this play in Canada.

people are "disproportionately exposed to the environmental problems of our day, from nuclear waste dumping and uranium mine tailings to disappearing glaciers and rising sea levels," she notes that environmental racism can be acknowledged without reasserting an essentialist closeness to nature that many Native people would find very limiting (84). She explains:

Native communities do have a vested interest in addressing environmental issues, but not because of an essential 'closeness to land' that mainstream environmentalism ascribes them. Reserved tribal lands contain the majority of US natural resources and have been primary sites of nuclear weapons testing and nuclear waste dumping. Native American communities have borne the costs of the state's policies of environmental racism in ways that would suggest a natural alliance between environmentalists and Native Americans. Despite these realities, mainstream environmentalism has often relied on the symbol of the Indian as an emblem of *healthy*-human nature relations. Thus, the movement obscures Indigenous issues and Native American environmental concerns even as it uses the Indian as a symbol for its own agendas. (85).

It is in this sense that Indigenous people in North America have been cast as what Ray names the "ecological other," a term that designates how individuals are positioned as the site of environmental problems. This term, which focuses on individuals, masks the social and economic forces that constrain action and that shape environments (5).

While Ray focuses on the position of Indigenous peoples within American culture, it is important to note that Canadian culture has also cast Indigenous people as outsiders, often through equating Indigeneity and disability. Disability studies scholars Siobhan Senier and Clare Barker argue that, "from Canada to Australia and New Zealand, colonial discourses have pathologized indigenous bodies – and, by extension, pathologized indigenous communities and

nations" (127). As Cameron Greensmith illustrates, in Canada, disability has been used as a mark to delegitimize the political concerns of Indigenous activists. Greensmith notes the importance of building connections between disability studies and Indigenous studies by investigating how Canadian culture, by way of the media, has pathologized Indigenous identities. Greensmith explains how, "by producing Indigenous peoples as disruptive, abnormal, and pathologized due to their protesting, settlers can continue to understand themselves as rightful owners of Indigenous territory" (22). Illustrating how ableist disability tropes have been used to suggest that Indigenous people are irrational and childlike, he shows how these tropes work politically to maintain the integrity of a settler Canadian identity.

Ray's contention that Indigenous peoples are most directly exposed to the environmental problems of our day is true of Canada as well. In James Daschuk's *Clearing the Plains:*Disease, Politics of Starvation, and the Loss of Aboriginal Life, he shows how the health of many Native communities today stems from very early policies and practices. He traces how the ecological changes brought about by Canadian settlers from the 17<sup>th</sup> century to the 20th century created disease among Canada's many Aboriginal communities. Dolmage also argues that practices toward Indigenous people have been disabling; he explains that the Immigration Act of 1952 allowed the Canadian government to exclude immigrants due to "climatic suitability," which "solidified the sense that only certain, sanctioned races were biologically matched to the Canadian environment, even as settlers were drastically altering the very same environment in ways that were making it toxic to peoples who had actually been living on this land for generations" (4). Although Canadians may wish to distinguish their country's treatment of Indigenous people from the treatment of Indigenous people internationally, scholars have shown that Canada's environmental policies have resulted in the 'stationary displacement' of

Indigenous people from many communities. To echo Barker and Senier's assessment of settler colonialism on a global scale, in Canada, "we might say that while settler colonialism has constructed indigenous people as ill or disabled discursively, it has also produced indigenous illness and disability materially" (129). Canadian disability studies scholar Heather Norris makes this claim as well, but she also points out that since the point of European contact, western understandings of disability have influenced and entangled perceptions of disability in Indigenous societies in North America. She points out that research into multiple Indigenous cultures suggests that many languages do not have the words crippled, disabled, and handicapped (68). Explaining that disability within the Navajo culture equalled disharmony within the universe, Norris argues that, "colonization was and is the ultimate disruptions of mind-body-spirit harmony, revealing a different understanding of the cause of disability, in stark opposition to the victim-blaming stance of the Eurocentric worldview construction of disability" (68). A resurgence of Indigenous worldviews, she concludes, could allow for a resurgence of a concept of disability that places greater focus on interdependence (56-57).

My focus in the remainder of this chapter, then, is on engaging McRuer's question of what it would mean "to welcome the disability to come" in relation to painful disabilities and illnesses acquired through disproportionate exposure to environmental change (208). In the section that follows, I will explore the intertwined concerns of literary representation and political advocacy that Rob Nixon explores with respect to Canada, and specifically the representation of Canada in Clements's play. The objective of this investigation is to consider how both questions of colonialism and ecological devastation that are central to our lived environments can be examined with a disability studies lens as opposed to a traditional medical model. Other scholars have explored the ecocritical dimensions of Clements's work (Gray;

Smith). Nelson Gray notes that perhaps some have hesitated because of concerns that "the very mention of nature and ecology in the writings of a Métis artist like Clements might perpetuate colonial stereotypes or raise the spectre, characterized by Shepard Krech, of one of their offshoots 'the Ecological Indian'" (194). However, he argues that to ignore the eco-centric tradition of Clements's works would "perpetuate another kind of colonialism, one based on anthropocentric assumptions endemic in Western thought" (Gray 194). I would like to echo posthumanist geographer Juanita Sundberg, in establishing my argument throughout this dissertation that postcolonial literature offers possibilities for thinking through connections and tensions between disability studies and environmental criticism. Sundberg notes that her own excitement about the possibilities of posthumanist theory and its criticism of anthropocentric thought is tempered by posthumanism's lack of engagement with thinkers, communities, and cultures that already operate outside of dualistic Eurocentric paradigms. She writes, "Indeed, the literature [of posthumanism] continuously refers to the foundational ontological split between nature and culture as if it is universal ...this literature repeatedly references such dualisms as if they are universal foundations of thought, which only serves to perpetuate their presumed universality" (35). In turning to Indigenous literature to explore the allegiances and tensions between disability studies and environmentalism, and in drawing on many posthumanist theorists like Stacy Alaimo, I do not wish to suggest that the insights of scholars in the western academy should explicate established ideas within Indigenous communities to those communities. Rather, I hope to draw on this body of knowledge to argue for its centrality in thinking through the body as commensurate with its environment in a deeper way.

# 3. Burning Vision and the Temporalities of Violence

Marie Clements's play Burning Vision takes the form of four movements that cross chronological and geographical boundaries. The movements of the play correspond to the four elements: air, earth, water, and fire (Smith 144). The action of the play largely takes place in the form of cross cultural dialogues that similarly cut across the various eras represented in the work, from the prophecy or burning vision of the Dene medicine man in the 1880s that foretold the bombing of Hiroshima and Nagasaki, to the aftermath of World War Two. In the late 1880s, a Dene Medicine man had a dream that material found in the area that was to become Port Radium would be used for destructive purposes; he saw that people living far away were burning, and he described these people as looking just like the Dene (Gilday 109; Blondin 79). Dene people have interpreted these people from the Dene Medicine Man's vision as Japanese people, who were victims of nuclear bombing during the Second World War. Once the mine at Port Radium was opened, many of the Dene people were employed as miners and ore carriers. The play, centered on the burning vision of the character known as The Dene See-er, dramatizes the role of the Dene ore carriers at Port Radium, who unknowingly transported the ore that was used to manufacture weapons of mass destruction, as well as losses of the Dene widows who mourn the deaths of their husbands to cancer. It also captures the devastating repercussions of these events on the health of the community of Port Radium in relation to people, animals, and the nonhuman environment. Interrelated stories include the discovery of uranium at Port Radium by the Labine brothers<sup>19</sup>; the plight of the American test dummy Fat Man, named after the atomic bomb dropped on Nagasaki, and his encounter with Little Boy, a Native child named after the bomb

<sup>&</sup>lt;sup>19</sup> Victor Beyonnie, a former chief of Déline, clarifies that his father discovered the rock at Port Radium before the Labine brothers: "There was a whiteman who worked in Port Radium. My father found a good rock so he gave it to him and the whiteman said it's a worthless rock. Three years later they said Labine found the rock. Labine, he is the one they said found Port Radium money" (Déline Uranium Team 25).

dropped on Hiroshima who personifies "the darkest uranium found at the center of the earth" ("Characters"); the persecution of the radio announcer Tokyo Rose; and the meeting of Koji, the Japanese fisherman with Rose, a Métis woman. The play juxtaposes the immediacy of the attacks against Japan and the violence slowly inflicted against the Dene ore carriers, poor miners, and radium painters, who suffered even though the historical record indicates that scientists at the time knew about the dangers of Uranium mining (Blow; Déline Uranium Team). At a crucial moment in the play, the character Rose states, "The Widow says there is no word in Dene, for radioactive," revealing the lack of knowledge that the Dene were provided with regarding the risks of the mining operation (Clements 112).

Burning Vision, like many of Clements's plays, explores the perils and possibilities of cultural encounters, and does so by eroding temporal barriers; often her performances allow for the interaction of characters despite historical and geographic distance. An adaptation of Euripides's Trojan Woman, her Age of Iron (1993) fuses the mythology of the Trojan War with the lives of Indigenous people on Vancouver's streets. Copper Thunderbird (2007), a play that explores the talents of Aboriginal Canadian artist Norval Morrisseau, trifurcates his identity into characters referred to as "The Old Man," "The Young Man," and the "The Boy," who can converse, criticize, and comfort one another. Her collaborative multi-media project with documentary photographer Rita Leistner, The Edward Curtis Project (2013), includes a drama that captures the complicated relationship that Native journalist Angeline has with The North American Indian (1907), a book length collection of photographs by Edward Curtis subtitled The Vanishing Indian; while Angeline is uncomfortable with the practice of ethnography and the impending extinction that the title of the work implies, she is captivated by the photographs themselves. While the photography exhibition created in conjunction with Clements's play

captures images of Aboriginal people in both traditional dress and contemporary clothes to serve as a counter-narrative to Curtis's project, Clements's drama affords Angeline and Edward Curtis the opportunity to meet. Throughout the play, characters from the past and present not only have the opportunity to meet each other, but also often merge into one another, and sometimes become the other, as though they are part of a dream. *Burning Vision* similarly features such impossible encounters and attachments, as it juxtaposes slow and sensational violence to compare the trauma and hardship experienced by the community of Déline to that experienced by the citizens of Hiroshima and Nagasaki in World War Two and its aftermath.

In this play, motifs of speed signal the alarming pace of technological development and its accompanying catastrophes. The first movement, beginning with an atomic detonation, is entitled "The Frequency of Discovery". The many short dialogues and movements between characters create a sense of urgency, culminating in a final movement featuring the ominous sound of a Geiger counter clicking to indicate increased radiation levels and clocks ticking to indicate the passage of time. Wallace characterizes Clements's play as an exemplary text for thinking through the "paradoxical temporalities" of Beck's risk society, as it "telescopes time and space in order to highlight the legacies of uranium mining in Canada's Northwest

Territories" with the final act "syncopated by the ominous "tick tick tick" of a clock, "click click click" of a Geiger counter, and "beat beat beat" of a human heart" (25). Define Gilbert similarly suggests that Clements's play stages a longer, broader, history of the events surrounding the bombing of Hiroshima, even as the play itself functions as an interpretation of the Dene medicine

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<sup>&</sup>lt;sup>20</sup> As previously discussed in the introduction to this work, Beck argues that we live in a period of hyper-modernity or reflexive modernity, as opposed to a period of postmodernity. In his theory of world risk society, Beck argues that risks have resulted from the triumphs of contemporary society, as opposed to its defeats (55). For example, global warming is the result of successful industrialization. One of the differences that Beck identifies between the modern period and the hyper-modern period is that the world itself has become a laboratory, in which "testing *follows* the application, production *precedes* research" (emphasis in the original 36). He contends that contemporary risks cannot be contained in the same manner as the risks that people faced during earlier historical periods.

man's vision, in which Clements "bookend[s] the action with evocations of an atomic blast so that the story is compressed, metaphorically, into the explosive instant between the bomb's impact, and the deadly silence that follows its roar" (200). As Robin C. Whittaker, who characterizes Clements's play as a chronotopic dramaturgy, argues, "the play reevaluates notions of historical and cultural responsibility across times and spaces" (131). As critics have pointed out, Burning Vision's engagement with time is distinctive when compared to many other works that portray the events surrounding World War Two. This engagement with time allows the audience members to come to understand connections between well-known historical events and lesser known events that are often left out of the historical archive. Clements's play draws attention to these archival exclusions. Many of Burning Vision's readers and audience members may learn of some historical events informing the play for the first time. For example, some readers and audience members may be unfamiliar with Canada's involvement in the creation of the atomic bombs deployed against Japan during the Second World War. However, while some historical references may be unfamiliar to audience members, the play is filled with many instances of dramatic irony. Contemporary readers or viewers can anticipate what will happen to the play's characters as the story progresses, as their knowledge, and particularly their knowledge of the dangers of handling uranium ore, exceeds that of the characters.

Dramatic irony helps audience members becomes attuned to the larger, structural connections between the events of the past and the violence that continues into the present.

Nixon explains that in the long arc between the emergence of slow violence and its delayed effects, the causes disappear from view, and become difficult to remember (7). The repeated concerns that echo over a multitude of perspectives in this play are resounding and make

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<sup>&</sup>lt;sup>21</sup> Whittaker combines Mikhail Bakhtin's concept of the chronotope and Ric Knowles's "alternative dramaturgy of space and time" to posit that *Burning Vision* is a chronotopic dramaturgy (132).

invisible violence present through repetition. Character responses to the discovery at Port Radium serve as instances of dramatic irony that undercut narratives of triumph and discovery. As the song "I saw the light" plays in the first movement, Gilbert Labine announces with pride that he and his brother will discover the radium for radiation treatments (Clements 25). Later in the play, Rose echoes this sense of purpose, explaining that men are taking ore out of the mines to cure cancer. A contemporary audience that understands both that the miners are supplying the materials to manufacture the atomic bomb, and that these miners might develop cancer because of their exposure to uranium ore, is placed on an imaginative trajectory that reveals the persistence of past mistakes and injustices into the present, as well as the uninterrupted workings of the power relations that influence who will be most at risk. Little Boy, the Native child who personifies the atomic bomb, disrupts the progress suggested by characters in the first movement with his ominous warning: "The real monster is the light of the discoveries" (Clements 41). The Widow's story and her interaction with characters from an earlier time similarly disrupts a traditional progress narrative, as her story highlights the connections between uranium mining, the making and detonating of the bomb, and the slow death of her husband. As Rose, at the end of the play, considers that The Widow is concerned about the word cancer, the play circles back to the discovery in the first movement and the warnings from the Dene that the characters Brother Labine 1 and Brother Labine 2 ignore.

Burning Vision also dramatizes the dangers of exposure through a character named Frances, referred to as "The Radium Painter." Frances is an American dial painter working in the 1930s. In the historical notes overlaid upon a map of Port Radium that preface the written text of the play, the entry for 1925-1930 reads, "Radium watch-dial painters, all women, were encouraged by their employers to lick their paint brushes to give them a sharp point for better

application of the luminous paint. The ingestion of radium resulted in severe anemia, 'radium' jaw and bone cancer" (Clements). 22 When Frances visits a character known as "The Miner" while he is at work, she brings her paintbox in hopes of giving it back so that others will not have to experience her pain (73). Throughout the play, the stage directions indicate the moments during which the Gieiger counter becomes louder, with one direction describing its clicking as "aggressive" (111). The sounds of the clock and the Geiger counter heighten around Frances when she becomes conscious of her own precarious health. Frances addresses the ticking clocks, signaled in her speech by her refrain, "tick...tick...", imploring them to slow down. Addressing the clock face, she states, "Time can be ugly but your face is beautiful. I made you beautiful and what will you do for me? Could you slow down for me" (110). Her plea to the clocks highlights how her role making hours legible on clock faces has led to a loss of her own time, as she develops cancer as a result of her time spent painting. This transfer is also apparent when The Miner, Frances's fiancé, sees the progression of her cancer. The stage directions note, "Half [Frances's] face is missing and her beautiful hair is completely gone" (117). Throughout this movement, the stage directions indicate that The Miner's health is also worsening as his coughing becomes more frequent.

I will continue my discussion of the play's representation of Frances and the significance of her time spent painting clocks with reference to the Doomsday Clock in the next section of this chapter, but here, I would note that the impact of radiation on the bodies of Frances and the miner illustrate the play's engagement with the slow violence associated with waging war. In some ways, it may seem contradictory to suggest that a play so concerned with speed would also be concerned with the slow impact of dispersed violence. However, because the motif of speed is

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<sup>&</sup>lt;sup>22</sup> Claudia Clark describes the American dial painters as some of the first victims of radium poisoning in *Radium Girls, Women, and Industrial Health Reform: 1910-1935*.

connected to the pace of technological development, the play is in many ways about the chaos that results from the refusal of officials and institutions to take the time to remember and learn from the past. Annie Smith, who staged *Burning Vision* in Northern Alberta, set the action of the play in a medicine wheel stage circled by a compass dial that moved counter clockwise.<sup>23</sup> In *Canadian Theatre Review*, Smith explains that clockwise movement following the sun represents life and growth. Her own belief that *Burning Vision* proceeds through cycles of destruction rather than cycles of growth influenced her decision to set the movement counter clockwise. Other decisions in staging emphasize the play's potential for representing how destructive effects are unevenly distributed. Many characters in the play are double cast. For example, in the premier performance of the play, actor Kevin Loring played both the Dene Ore Carrier and Gilbert Labine. The fact that actors visibly perform multiple characters points to how individuals are often scripted into particular roles and places in society based on such social identities as ethnicity, class, and gender, and that these roles affect the extent to which the slow violence of environmental degradation influences the lived realities of their day-to-day lives.

The voice of Gilbert, or "Brother Labine 1" in particular, shows how the poor and disempowered are subject to material risks from which characters like Gilbert can more easily detach themselves. As the character Gilbert expresses his own disregard for the words of experts, his phrasing suggests the enduring nature of his own implication in the perpetuation of slow violence: "The particles just keep embedding and decaying everything that's touched them," (111). "As if they could send a bunch of so called 'experts' up here and convince me that this uranium is like a goddamn grenade going off," he tells the audience (110). He continues: "These

<sup>&</sup>lt;sup>23</sup> Smith explains that she decided to stage *Burning Vision* in response to a debate in 2008 surrounding the building of nuclear power plants to provide power for the tar sands in Peace River, believing that the play, "might bring some historical perspective to this debate, bringing to light the devastation unleashed by the willful ignorance and greed of a previous era, and reminding us that these same attributes could prove equally harmful today" (143).

goddamn assholes say they got proof that other uranium miners in Europe are dead from cancers, that those radium painters died of cancers. That uranium is like shrapnel" (111). The similes that compare uranium to grenades and shrapnel evoke violent imagery that lend slow violence the force of explosive immediacy. The reports of the deaths of European miners alluded to in the play are real reports featured in Peter Blow's 1999 documentary, A Village of Widows, which concerns the impact of uranium mining on the Dene community. 24 The film chronicles the journey of the Dene delegation to Japan on the 53<sup>rd</sup> anniversary of the bombing of Hiroshima to apologize for their unintentional involvement in the making of the bomb. In communication theorist Peter van Wyck's examination of the Canadian involvement in the creation of the atomic bomb in Highway of the Atom, he considers how the Dene apologized despite their own lack of knowledge of the destructive intended use of the materials that they were involved in transporting. He notes, "I have come to think that the Dene's response to their slow-motion, retroactive disaster was irreducibly ethical, for they had nothing to give" (van Wyck 47). This apology, when considered alongside the concerns of the collective amnesia that slow violence fosters, is significant because of its assumption of accountability for the trauma of nuclear war, even while individuals in Déline awaited justice.

The Dene apology that van Wyck describes as he frames the predicament of people living in Déline as a slow-moving disaster in its own right is useful for considering the ways that apology appears in this play, as the sincerity of official apologies are understandably suspect.

One of the most incriminating takes on apology and its reparative claims is offered by the character Round Rose. Round Rose is an older version of the Radio broadcaster Tokyo Rose - a character based on the historical broadcaster who was arrested for treason against the United

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<sup>&</sup>lt;sup>24</sup> Since the publication of *Burning Vision*, another documentary exploring the history of uranium mining in Déline has been released. David Henningson's *Somba* Ke: *The Money Place* (2006) explores the division of the community surrounding contemporary mining operations in the Northwest Territories.

States due to the content of her broadcasts to allied forces during the Second World War. Listing injustices from residential schools to Japanese internment, she questions the extent to which apologies are genuine: "You have to know when to be sorry. You can't really be sorry for something you don't want to remember can you. Selective memory isn't it? Let's be honest, you can't even apologize for the shit you did yesterday never mind 50 years ago" (Clements 100). In her full monologue, Round Rose clearly captures the emptiness that characterizes an apology for injustice that is ongoing. Reading *Burning Vision* in conjunction with Jane Stewart's "Statement of Reconciliation," David R. Gaertner argues that for Clements, the word "sorry", "no longer facilitates healing and reconciliation, but simply allows the perpetrators to continue their harmful narratives under the pretence of regret and contrition" (100). Jane Stewart, Canada's Minister of Indian Affairs and Northern Development (now Aboriginal Affairs and Northern Development) in 1998, offered this official statement while unveiling "Gathering Strength: Canada's Aboriginal Action Plan." The problem with Stewart's statement that many critics identified was its recognition of pain and trauma without the direct assumption of responsibility for that trauma on behalf of Canada (Gaertner 100). Gaertner explains that Stewart's "Statement of Reconciliation," like apologies to Aboriginal Canadians from churches that often employ the passive voice to avoid assuming direct responsibility, strategically avoids accountability (97). What Round Rose's statement in the play makes apparent is that apologies are issued even in the face of "the shit you did yesterday," in the face of ongoing injustice (100). In what follows, I consider: How might the critiques of apology that Clements, Gaertner, and van Wyck offer point toward an expanded practice of access that moves beyond the discourse of official apologies? As well, how does the representation of bodies and communities in pain that Clements offers differ from predominant ways of representing the injuries and illnesses brought on by the events surrounding the Second World War? To consider this question, I read Clements's play in conjunction with scholarship on the representation of the travels of a group of Japanese women known as the Hiroshima Maidens to the United States. By comparing the representation that Clements offers with discursive celebrations of medicine as a techno-fix for the body, I suggest that *Burning Vision* figures illness and disablement as processes as opposed to problems rooted in the body.

## 4. Bodies and Geographies in Burning Vision

In this final section, I examine the representation of human connections to non-human environments in Burning Vision with reference to the material feminism of Stacy Alaimo and her work in bringing disability studies and environmental studies into conversation to create an expanded notion of access. While I have been using the work of Alaimo and Nixon to read Clements's play, I also think that considering a text like *Burning Vision* and its historical context can push their ideas a little further. In an issue of the Journal of Literary & Cultural Disability Studies devoted to intersections between Indigenous studies and disability studies, Barker and Senier argue that to decolonize disability, "is to commit to a form of disability studies praxis that refuses to impose non-indigenous frameworks of health or disability upon native communities, whether these might be medical or more progressive social models" (137). Rather than choosing a model of disability to characterize the representation of disabling illness in Burning Vision, I would like to consider how the play, through its attention to the intimate connections between bodies and landscapes, illustrates the limitations of formal apologies and suggests the potential for a practice of environmental accessibility. Like many recent Indigenous activist efforts in Canada, from the Idle No More protests against Bill C-45 to the resistance to clear-cutting in Grassy Narrows, Burning Vision's critique of an environmental racism that places the risks of

industrial practices on Indigenous communities similarly points toward how access to health has been disabled as a result of environmental degradation.

Throughout the play, recurring statements from the characters refer to the impact of uranium tailings on the body. Their statements emphasize the permeable boundaries that exist between the body and the environment in which it is situated. The Miner, after coughing, claims that he can feel toxicity deep inside him. Similarly, when The Widow asks Rose how she managed to get so much black dust on herself, her response traces its movement:

The wind's blowing it everywhere. The kids are playin' in sandboxes of it, the caribou are eating it off the plants, and we're drinkin' the water where they bury it. Besides everybody's wearin it these days, so I guess there's no harm if a bit gets in my dough. It's as fine as flour anyways. (Clements 103)

Rose's description of how children would play in the ore reflects many of the accounts chronicled in *If Only We Had Known*, a history of the events at Port Radium and the people that they affected. Madeline Rabesca, who grew up in Port Radium, describes how the risks of exposure were not communicated to the Dene people:

When we lived at Port Radium we thought everything was fine. We'd get water and do chores for our mother. As children we played along the shore in the area where they piled the ore sacks. We even played right on the sacks...The Dene men always worked in their regular clothes. Sometimes they changed clothes when they got home. They didn't worry about any danger because they didn't know the risks. [My father] used to work with the non-Dene people. I think the non-Dene people used heavy coveralls when they worked but not my dad. Sometimes after work he had other guys came with my dad and visited

us in the evenings (sic). The non-Dene people were really nice to our family. At Christmas we were invited to eat with them at the mine. (33)

Rabesca's response provides historical context explaining the pervasiveness of the ore as discussed by Rose and The Widow in the play. In response to Rose's belief that the ore must be safe to handle, The Widow retorts, "That's what they pay scientists to say when they want something" (Clements 103). The Widow's words speak to how the Dene were not warned about the health risks of uranium mining. Indigenous rights and environmental activist Cindy Kenny Gilday, in her essay, "A Village of Widows," critiques the government's lack of action. She explains that the dust from the mines made the snow and ice in the bay near where the Dene live melt quickly. The miners were dumping leftovers from the mine into the water, and the dead fish that floated to the top of the water were offered to the Dene for subsistence. A report was issued in 1996 regarding the radioactive soil spillage, but Gilday notes that it would not be possible for someone without a scientific background to read and understand the report (116). Ryoko Kubota and Peter van Wyck both point to the 2005 Canada-Déline Uranium Table (CDUT) Final Report, published after *Burning Vision*'s composition, which concluded that the sample size of the population in Déline was too small to link their cancers to the Eldorado Mining Company.

The CDUT was created in response to the questions that the Dene brought to the Canadian Government after their visit to Japan in the late 1990s. At this time, they attempted to establish a claim with the government. Their questions concerned how much knowledge the government had when companies were mining uranium ore for the atomic bomb, and why the accompanying risks of handling uranium ore were not communicated to them (van Wyck 182). Many of the concerns surrounding recognition, compensation, and cleanup that the Dene brought to the government are very similar to the issues that concerned disabled Navajo uranium workers

in the United States. Although the U.S. Government and private mining companies knew that ventilation would improve mining safety conditions by mitigating exposure to radiation, companies did not inform the Navajo or other miners, and they did not implement the design recommendations of Public Health Services (Moure-Eraso 175). In 1990, the U.S. Government signed the Radiation Exposure Compensation Act (RECA) into law, extending an apology and financial compensation to the Navajo workers who extracted uranium from the 1940s until 1971. U.S. President Bill Clinton amended this legislation on July 11, 2000 (Brugge, Benally, and Yazzie-Lewis). However, despite the official recognition of the violence perpetrated against the Navajo workers, many of the workers and their families remain unsatisfied. On a practical level, financial compensation has proven very difficult to receive. But also, as researchers Doug Brugge, Timothy Benally, and Esther Yazzie-Lewis point out, many did not believe that the apology was sincere. Reparations in Navajo culture involve offering *nalyeeh*, which roughly translates as restitution but moves beyond this concept. They explain:

*Nalyeeh* is 'enough that there will be no hard feelings'. It insists on good intentions to undo the harm and restore order and safety. Those good intentions must become plans, and those plans must be executed. The parties must then think about the evil that was addressed and the way it was overcome, and reconsider how everyone must live in the future. (Brugge, Benally, and Yazzie-Lewis)

An apology, understood in this way, is not only concerned with the events of the past, but with plans for the future; an apology is not a single event, but an ongoing process. The researchers explain that the Navajo believe that the American government harmed everyone – not only workers, but also their family members – and that qualifying medical exams and other measures

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<sup>&</sup>lt;sup>25</sup> From the 1940s until 1971, the U.S. government was the sole purchaser of uranium from these mining operations (Brugge, Benally, and Yazzie-Lewis).

illustrate the insincerity of the official apology (Brugge, Benally, and Yazzie-Lewis). Many people living in Déline, as well as researchers and journalists like Peter Blow, Cindy Kenny Gilday, and Peter van Wyck, have similarly argued that the Canadian Government's actions toward the Dene betray a lack of apology.

The CDUT Final Report published in 2005 concludes that there is insufficient evidence linking the health of the community to the work performed by the Dene ore carriers and other labourers. A summary of the Final Report indicates that "a key finding of the community health profile was that the overall cancer rates for Déline are not statistically different from the Northwest Territories (NWT)" (v). Another key finding by physicians was "a profound and pervasive fear of radiation and a tendency to blame any and all health problems on the mine and the legacy of the mining activities" (31). Peter van Wyck argues that the phrasing of this and other key findings in the report invalidates the concerns of the Dene. Critiquing this finding, he writes: "So, although the community has been injured because of radiation, concludes the report, it has not been injured by it" (184). 26 Reading the language of this report from a disability studies perspective, I would suggest that what this passage reveals is a discursive construction of disability and a material denial of disability. As I mentioned in the second section of this chapter, Barker and Senier argue that "while settler colonialism has constructed indigenous people as ill or disabled discursively, it has also produced indigenous illness and disability materially" (129). While at times the report gestures toward an acknowledgement of the trauma that the community of Déline has experienced, these gestures are undercut by passages such as this one, which, in diagnosing individuals with a "profound and pervasive fear of radiation," pathologizes their concerns. This medical pathologization of individual and community concerns constructs any

<sup>&</sup>lt;sup>26</sup> Van Wyck asks: "A profound and pervasive fear of radiation. Should there be any other kind?" (184 emphasis in the original).

resistance to environmental racism and unsafe corporate practices as irrational. While Barker and Senier suggest that we can identify two very different ways in which colonialism shapes disability, this instance illustrates how the discursive construction of disability, and its pathologization of resistance, can function as an instrument for denying the embodied reality of disability by evading responsibility for its environmental cause.

The cancers experienced by people in Déline highlight the relationship between disability, in the form of cancer as a debilitating, disabling illness, and environmental conditions. Alaimo, positioned at the intersection of ecocriticism and disability studies, provides insight into official denials of the significance of this relationship. The lack of official recognition for the ways that chemicals disable the body is an important concern in Alaimo, and mirrors concerns in Clements's work. In her study of multiple chemical sensitivity or MCS, Alaimo argues that chemical manufacturers are so invested in absolving their own responsibility for their impact upon human health that they fund research to deny that MCS is an illness (126). As a researcher working in disability studies, Alaimo is careful to avoid reinscribing a medical model of disability that would position MCS as a pathology or deviation. Unlike Nixon, whose exploration of slow violence does not explicitly attend to what equating disability with violence against the body might mean for efforts toward disability acceptance, Alaimo foregrounds disability studies concerns as she considers how disability studies and environmental criticism might speak to each other. With respect to a model of disability that values deviation, Alaimo does caution that many people who are sensitive to chemicals would insist, "not all deviations in this world of toxicants and xenobiotic chemicals should be embraced" (139). Her development of the concept of an openness to deviation involves placing everyone on a continuum of sensitivity to the environment. She advocates, "tak[ing] the onto-epsitemological condition of chemically reactive

people seriously by making the world more accessible for them," which would require drastically changing global political and economic practices. The idea that environmental accessibility is denied to many individuals, and that the risks or side effects of technological development are unevenly distributed, are similarly articulated by The Widow. She considers the meaning of the word, "coolie": "Some word for people that do the dirty work, I guess. The people that get their hands dirty" (Clements 80). Her words capture the impact of barriers that prevent access to health because people are needed to perform labour that others, who have the power to refuse, refuse for many reasons, including the disabling nature of the working conditions.

The Widow also invokes the environmental impact of a legacy of colonialism in Canada, indicating how people could once tell time and determine their location based on the migration patterns of the caribou. In an interview with Marie Clements, Nelson Gray makes the observation that in many of her works, she situates human action as part of a world view that includes elements of non-human nature. He asks whether she intends to situate human action in this way, or whether this is an extension of how she sees the world. She answers that this is how she sees the world, and explains, "I now have chosen to move back to a small island where nature is just like a part of the day, or it's part of your world, not really separate from your being" (26). Burning Vision dramatizes how the porous nature of the body as a system has material effects. The play does suggest that one's connection with one's environment can bring peace, as demonstrated by the scene involving the return of the caribou and fall of cherry blossoms that offers hope for the future at the end of the play. While one might examine the spiritual dimensions of environmental connections in the play, such as by focusing on the four elements in relation to the play's four movements, it is important to note that these connections are not depicted in a utopian way; the material reality of bodies in pain are central to the drama.

The painful history of the disabling environments of Déline and Port Radium demonstrates the importance of pursuing intersections between disability studies and environmental criticism urgently yet cautiously, and to consider that ethical environmental policies can also be understood as promoting accessibility. *Burning Vision* certainly complicates the call to celebrate the 'disability to come' by showing how the speed at which disability is acquired can also depend on one's social position. However, if we attend to how human influences upon the environment adversely affect human health, perhaps "welcoming the disability to come," as McRuer suggests that we do, can involve recognizing our inherent vulnerability as the environments we are shaping are becoming less accessible for everyone (207). This would involve recognition that tracing environmental factors for debilitating conditions does not necessitate a reintroduction of the medical model, but instead suggest the need for deeper investigations into the risks that individuals with disabilities face in contexts specific to place, and specific to the environmental polices enacted in those places.

The imbrication of human culture and the natural environment needed to approach disability studies in this way is one that environmental humanists have explored in their deconstruction of the classical division between nature and culture. One of the perceptions that many thinkers in the environmental humanities challenge is the idea that nature is something that exists apart from culture. Lawrence Buell, even as he argues that there is still a need to differentiate the "natural' and human-built' dimensions of the palpable world," notes that the "nature-culture distinction itself is an anthropogenic product…" (3). He argues that literary studies and environmental studies should focus not only on traditional nature writing, but also on "the full range of historic landscapes, landscape genres, and environmental(ist) discourses" (8). Ursula Heise, in her brief history of the field of ecocriticism in *Publications of the Modern* 

Language Association, explains that the aims of environmental critics initially differed from those of many of their postmodern critical contemporaries. While many other postmodern projects that deconstructed established binaries were interested in extending subjecthood to those to whom it had previously been denied, ecocriticism focused on the nonhuman world (Heise 507). Heise summarizes how ecocriticism critiques modernity:

Environmentalism and ecocriticism aim their critique at modernity and its presumption to know the world scientifically, to manipulate it technologically, and exploit it economically, and thereby ultimately to create a human sphere apart from it in a historical process that is usually labelled 'progress.' This domination strips nature of any value other than a material resource and commodity and leads to a gradual destruction that may in the end deprive humanity of its basis for subsistence. (507)

As described by Heise, the critiques levelled by the field concern the destructive quality of a division between nature and culture that views the natural world as a set of resources for humans to use and exploit. However, a division between nature and culture that celebrates nature, and invests it with redemptive qualities, might also pose problems, Alaimo argues. Speaking specifically to an American context, she argues that, "characterizing nature as a liberatory wilderness, however, poses several potential problems: it may widen the nature/culture divide, and it may be complicit in the American glorification of 'free land,' which has underwritten colonialist exploits by depicting nature as an empty space" (*Undomesticated Ground* 17). In her recent work that examines disability studies in conjunction with environmental concerns, Alaimo extends this critique of the division between human culture and natural environments into a complication of the distinctions between human bodies and the environments that we inhabit.

Alaimo's contention that a global outlook on environmental concerns necessitates blurring the nature-culture divide is also a call to look to embodiment and trace the material effects of human practices, which is a task that Burning Vision also performs. As climate change is progressing, Alaimo argues, "we hardly have the luxury of imagining any expanse of land or sea as beyond the reach of humanly-induced harm," since, while the impact of human activity on the body occurs at a local level, "tracing a toxic substance from production to consumption often reveals global networks of social injustice, lax regulations, and environmental degradation" (Bodily Natures 15). Global networks of unjust regulations and environmental harm appear in Clements's play, as her work traces the presence of uranium across bodies and geographies, from the sand in the children's sandboxes, to Rose's bread dough, to Frances's paint, to the sacks the miners carried. Her depiction of the constant interchange between bodies and environments is one that sees nature and culture as intermeshed. Gray, in an ecocritical analysis of Clements's The Girl Who Swam Forever, reads transformations into nonhuman others in the play as offering an ecocentric worldview, in a way that, "consistently undermines the nature/culture binary" (205). Examining the female lead's transformation into both a white sturgeon and a train that eventually become one entity, he argues that, rather than offering, "an essentialist portrayal of a First Nations woman as inherently 'natural,' an identification that might relegate her to the misty forests and dusty plains of some long-lost wilderness era," Clements affirms cross-cultural hybridity (204). Although Gray argues that Clements's work demonstrates concern for environmental issues, he argues that her portrayal of individuals as existing in a Deleuzean process of becoming and transformation rather than as fixed entities moves beyond essentialist portrayals of Indigenous people as inherently ecological.<sup>27</sup>

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<sup>&</sup>lt;sup>27</sup> As discussed earlier, Sarah Jaquette Ray similarly argues that portrayals of Indigenous people as inherently ecological are problematic – particularly when environmentalism uses indigenous people as "an emblem of *healthy*-

Burning Vision also complicates distinctions between nature and culture. The list of characters in the play describes Little Boy as a Native boy who is 8-10 years old and the "personification of the darkest uranium found at the centre of the earth" (Clements 13). He and the character Fat Man, an American bomb test dummy, are named for the bombs that the United States deployed against Japan. Both characters watch as The Dene See-er transmits his prophecy in Slavey through the television set in Fat Man's 1950s home. Like *The Edward Curtis Project*, Burning Vision challenges the perception that Indigenous culture is a relic of the past, on the verge of extinction, by presenting the burning vision of the destruction to come through the medium of the television. The transmission interrupts the programming of Fat Man, as the highpitched sound of the broadcast bar transforms into the Dene See-er's singing, but it also interrupts his cultural programming, and programmatic nature as a test device; as his character description in the notes, Fat Man, who intended to be "unlikeable in a likeable way," "gets more and more human as the bombs draw closer" (Clements 13). He tells the audience that he is "manning the post. Manning it, get it?" and that even with the impending doom, he feels "comfortable with it coming with the doors locked" (Clements 34). Little Boy, the personification of uranium ore, like the Dene See-er on the television, similarly appears unexpectedly to Fat Man when he emerges on stage, stating, "I don't know locked doors" (Clements 46). The intrusions, interruptions and transformations in these exchanges foster an increasing sense of the impossibility of sealing oneself off from networks of social injustice, environmental degradation, embodied pain, and material threat.

I would argue that through its depictions of processes of becoming and through its imbrication of the technological with the human, *Burning Vision* complicates traditional distinctions between nature and culture in its exploration of the connections between resource

extraction, war, and illness. In its depiction of the attachments of bodies to landscapes, the work proceeds along the lines of a very different understanding of the individual than the Cartesian one that many western theories are grounded in. Rosemarie Garland-Thomson, introducing Foucauldian theory to disability studies, shows how Michel Foucault's characterization of society as a disciplinary regime bears relevance for disability studies thinkers by pointing out how, "architectural, pedagogical, and medical practices manipulated the body, both generating and enforcing the Cartesian image of an individual as a separate, isolated, efficient machine whose goal was self-mastery" (*Extraordinary Bodies* 39). In many ways, attention to disability, in the medical field and in our cultural representations, betrays a kind of fascination with the idea of mastering the body, a task that is only possible to imagine by proceeding with a conception of the body as impervious and inviolable in relation to its environment.

However, undoubtedly, many individuals with disabilities and illnesses embrace medical and prosthetic technologies. Indeed, many scholars argue that disabled people are often the first to explore new technologies. Donna Haraway suggests that people with disabilities often have, "the most intense experiences of complex hybridization with other communication devices," a hybridization that complicates our understanding of the boundaries of the body (*Simians*, *Cyborgs*, *and Women*). Similarly, N. Katherine Hayles rejects an ideal of wholeness that would exclude disability in *How We Became Posthuman*. She argues that the belief that human subjects *possess* bodies and are not understood as *being* bodies informs the ideas of both liberal humanist thinkers and transhumanist thinkers, who share the perception that the body is separate from the self (5).<sup>28</sup> But rather than holding onto the tethers of the liberal humanist subject, Hayles centres

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<sup>&</sup>lt;sup>28</sup> Transhumanism is a philosophical movement that emphasizes the importance of human enhancement technologies. The idea that prevention and cure should replace efforts to make built environments more accessible is characteristic of transhumanist thinking. Transhumanist thinkers are often interested in how biological changes will usher in social changes. In April 2015, Zoltan Istvan, U.S. Presidential candidate for the Transhumanist Party,

on materiality, explaining to readers that her dream is, "a version of the posthuman that embraces the possibilities of information technology without being seduced by fantasies of unlimited power and disembodied immortality, that celebrates finitude as a condition of human being..."

(5). While Haraway and Hayles suggest how we might look to technology to embrace difference and hybridity, many speculative works focus on how technology might enact the erasure of bodily difference, or even materiality itself. A common trope in science fiction is the use of technology as a medical 'cure' that allows for such mastery as it normalizes the disabled body (Allan 9). Celebrations of the curative and normalizing possibilities of technology, however, are not confined to science fiction. While celebrating medical possibilities for changing the body may appear politically innocuous, many disability studies scholars would argue that these celebrations are inherently ideological.

Connecting disability studies critiques of the presentation of cure as a master solution for the problem of disability with environmentalist critiques of technological-fix approaches to environmental problems can help to demystify this ideology. In my introduction, I explained that the term 'technological-fix' was coined by physicist Alvin Weinberg, who used it in a positive sense because he believed that it would be easier and more productive to invent new technologies than to change human behaviour and large social structures (Stunkel and Sarsar 81-82). However, while pervasive faith in technological solutions remains prevalent in scientific circles and the public at large, the term techno-fix itself has since acquired a negative connotation. Environmentalists Michael Huesemann and Joyce Huesemann critique western techno-optimism, arguing that technological solutions alone will not be able to prevent

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criticized the city of Los Angeles for devoting 1.3 billion dollars toward fixing broken pavement to make sidewalks more accessible. Istvan argued that the money would be better spent on exoskeleton suits and research that would eliminate physical disabilities altogether. He was criticized by disability rights activists like Emily Ladau, who pointed out the similarities between Istvan's attitude and eugenic practices (Cuthbertson).

environmental collapse. A techno-fix, they explain, is a technological solution to a social, economic, political, and psychological problem that addresses symptoms of problems rather than root causes (xxy). It is called a 'fix' because it is not a lasting solution. While Heusemann and Heusemann primarily discuss techno-fix solutions to environmental sustainability, they extend their discussion of the techno-fix to the medical field, arguing that many pharmaceuticals are temporary solutions for larger social problems. Certainly, discussions of the social determinants of mental health are often missing from discussions of depression and other mental disabilities, and alternatives to medication or additional forms of treatment are sometimes left unexplored. However, I would suggest that the preoccupation with cure in the medical field could also be termed a techno-fix. After all, disability studies scholars and activists have shown that the 'problem' of disability is located in society, as opposed to in the body. As well, while we may celebrate advancements in technology that are successful in preventing certain disabilities, new technologies, from new medications to new industrial practices, also create new disabilities. While we may think of cure as the lasting solution at the level of the individual body, I would argue that medical cures are more similar to techno-fixes when we apply them to communal experiences of mass disablement.<sup>29</sup>

Before turning again to the representation of disabling illness in *Burning Vision*, I wish to build a point of contrast by drawing attention to the political representation of the surgeries performed for Japanese women known as the Hiroshima maidens, as discussed in the work of David Serlin. In *Replaceable You*, Serlin describes the entanglement of post 1945 medical technologies in the United States with the rhetoric of Cold War nationalism. After World War

<sup>&</sup>lt;sup>29</sup> For example, activists in Kodaikanal, spearheaded by Sofia Ashraf, were successful in campaigning Unilever to provide medical treatment for mercury poisoning through a large social media campaign that included a music video set to the tune of Nicki Minaj's "Anaconda." However, while the company is assuming responsibility by compensating factory workers, they are not cleaning up the mercury through environmental remediation (Pereira). While this solution may help individuals now, the disabling environment remains a concern.

Two, medical technologies changed perceptions of the natural for the American public, disrupting the belief that anatomy was destiny. As these technologies advanced, the practice of altering one's physical body to make it commensurate with one's self began to characterize American identity (14). During this time, Japanese Reverend Kiyoshi Kanimoto, and photographer Norman Cousins arranged for a group of visibly disabled and scarred women from Hiroshima to undergo a series of surgical operations at Mount Sinai Hospital in New York (63-64). Serlin traces the State Department's anxieties surrounding the appearance of the Hiroshima Maidens, whose presence threatened both to lower public support for nuclear energy research and nuclear weapons testing, and to make the United States appear responsible for the physical pain that the Maidens had suffered. As a result of these anxieties, official publicity surrounding the Maidens positioned them not as atomic survivors, but as victims of conventional warfare (Serlin 67). Serlin describes how the Maidens came to represent, for the American public, the democratizing power of commodifiable medical procedures:

For the Americans that watched their transformation, the Maidens proved that plastic surgery, aimed at emergency cases as well as beauty's common denominator could serve as a democratizing force for these *hibakusha*, or for survivors of war, or for those with ungainly appearances, or even those with problem personalities. In this sense the Maidens became literally the public face of those foreign nationals to whom the magic and mystery emanating from American goods and services flowed, giving the aggressive foreign policy initiatives and equally aggressive conspicuous consumption of the Eisenhower years a visible manifestation that one could not look away from. (102 -103)<sup>30</sup>

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<sup>&</sup>lt;sup>30</sup> Serlin clarifies that the Maidens Project was not without critics, and he notes that one criticism of the project was a perceived conflation of surgical genres, as some believed that the blurred distinctions between reconstructive and aesthetic procedures were problematic. Robert Jacobs, analyzing the portrayal of the Maidens in mainstream media,

As Serlin illustrates, by way of celebrating the normalizing power and technological prowess of reconstructive surgery that eased the physical pain of the Maidens' keloid scarring and enabled greater functionality for their corrected hands, the State Department advanced its own agenda of mitigating fears surrounding nuclear weapons. As the State Department publicized its use of technology to fix the bodies of the Maidens, it simultaneously worked to obscure America's own role in disabling many Japanese citizens through the use of nuclear weapons.

Many of the Maidens, of course, expressed gratitude for the procedures that reduced their experiences of physical pain. My attention to this project is not a critique of the use of surgical technology; rather, I would argue that the visual and political rhetoric of a return to normalization suggests certain ramifications of linking disability and threat in the public imagination. The visual trail of the movement from disability to normalcy in this case served to ease anxieties. By promoting the use of medical technologies, the State Department worked to diminish the impact of the technologies of war, and obscure the reality that the development of more powerful nuclear weapons would result in further pain. Thy Phu, in *Picturing Model* Citizens, her study of civility in Asian American visual culture, argues that the apology in this instance was an act of civility, as she explores, "visual culture's mediation of the scarred female body as a means of rejuvenating national affect" (85). Here, I would return to the concerns introduced at the beginning of this chapter surrounding the use of disability as a sign of threat, environmental degradation, or social harm; one of problems that arises when disability, particularly as it is understood visually, becomes as sign of violence against the body is the accompanying response of normalizing technologies that would claim to eliminate this violence through a techno-fix at the level of the body. The strategy in this regard, of using disability to

suggests that the term maiden was significant because it illustrated how the focus of the project was on the limited romantic prospects of the young women (14).

signify an aberrant past and a return to normalcy as a sign of reconciliation is similar to that which Jason A. Edwards suggests that United States President Bill Clinton, Australian Prime Minister Kevin Rudd, and Canadian Prime Minister Stephen Harper used in their apologies toward Indigenous people. They engage in a practice termed dystalgia, first outlined by J.A. Janack, which Edwards defines as an instance in which "the rhetor depicts the past in a negative light so that it will not be used as a guide for decision making in the present" (69). Edwards explains that, "According to Clinton, Rudd, and Harper, the politics instituted by past American, Australian, and Canadian governments should be viewed as aberrations" (69). The representation of the Hiroshima Maidens reveals a similar strategy, as their bodies were used to symbolize the violence of the past, and their surgeries a promise for the future. 31 Robert Jacobs, who examines how the American media portrayed the Hiroshima Maidens, notes that this story faded out of public attention, despite the fact that the Maidens "faced a difficult readjustment in Japan, including the resentment of those who did not receive special medical treatment, as well as a return to a generally impoverished city with little economic prospects" (29). The praise that the American media offered for the return of the physically restored group to Japan illustrated the extent to which medical technologies were perceived as a solution to the problem of pacific nuclearization because they were understood to be a solution to the problem of disability.

It is against this background that I read the representation of disabling and life-threatening illness in *Burning Vision*. I would not presume to make an equation between the experiences of the Hiroshima Maidens and Marie Clements's portrayal of the Dene Ore Carrier, the Miner, and the Radium Painter in her play, for they are undoubtedly different experiences. But I think that comparing the means by which disability becomes a problem to be solved in the

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<sup>&</sup>lt;sup>31</sup> Many thanks to Heather Smyth, who suggested to me that the rhetorical strategy of dystalgia was relevant to my project of bridging of disability studies and postcolonial studies through apology discourse in this chapter.

case of the American representation of the Hiroshima Maidens is worth comparing to the play's exploration of the material effects of radiation. Bodily vulnerability is certainly connected to the trauma experienced by the community in Burning Vision, but its representation serves a very different rhetorical purpose than that pursued by the media in the case discussed above. In my previous section, when I discussed how the Geiger counter and the clocks signal the rapid pace of destruction in a play concerned with slow violence, I turned to the representation of Frances, the radium painter, whose exposure to radiation results in her cancer. As The Miner tells Frances that everything will be okay, the stage directions indicate what when she turns to face him, "half her face is missing and her beautiful hair is entirely gone" (Clements 117). The stage directions indicate that The Miner's response is one of horror. They read: "He sinks in horror and finally curls down and cries. The Geiger counter gets closer" (117). From a disability studies perspective, responding with horror to the physical changes that cancer brings about may seem troubling, as disability and illness have often been aligned with the grotesque in very problematic and stigmatizing ways. But I would suggest another context for interpreting the representation of Frances that is more politically and aesthetically disruptive.

Responding to disability with horror and fear is precisely the response to disability that critics like Robert McRuer argue we should move away from, with calls to welcome the disability to come. But perhaps the moment at which The Miner reacts with horror and begins to cry upon seeing Frances may be understood as a horror of recognition, a horror that foregrounds the reality of the disease. As Siebers suggests in *Disability Theory*, while disability studies rightly critiques a consistent focus on the negative aspects of disability, and the presentation of disability itself as a problem, accepting the reality that a woman may embrace one disability identity, like deafness, while hoping that her cancer will go into remission, is also important (4).

In the *Journal of Literary & Cultural Disability Studies*, Nadine Ehlers uses the example of David Jay's The SCAR Project to argue that visual depictions of disease not only serve to elicit discomfort, but also serve to highlight the realities of disease that contemporary culture obscures (331). Photographer David Jay's photographs trouble both the displacement of diseased bodies outside the public realm, as well as the commodification of cancer, and breast cancer specifically (Ehlers 333). While The Radium Painter's experiences are set at a very different moment from David Jay's work, a notable quality of Frances's representation is that her body is not posited as the site of the problem; rather, the representation centres on the risks that are inherent to her social position in this time and place. Unlike the representation of the Hiroshima Maidens, which celebrated technological triumphs to erase the markers of disablement and provide a clear solution, the play figures disablement as an ongoing process which occurs disproportionately in communities that bear the costs of viewing the natural world as a set of resources to extract.

As well as offering a different understanding of disablement, the play presents a different understanding of healing than healing as understood through western medical paradigms. Phu and Serlin, in their analyses of the portrayals of the Hiroshima Maidens in the American media, both reveal how these portrayals focused on technology's promise of a return to wholeness. As the play ends, release becomes possible through the sound of the radio carrying the voices of loved ones, speaking in English, Japanese, and Slavey. Michelle La Flamme, in a study of Clements's *The Unnatural and Accidental Women*, suggests that theatrical events can be understood as contemporary good medicine that work to alleviate trauma. She defines medicine, in this sense, as "an active process that is understood in a psychological or philosophical way, whereby individuals go through a form of catharsis," explaining that, "there is a participatory medicine involved in being a witness or participant to these ceremonies" (108). With respect to

the healing nature of ceremony, the participatory nature of the Dene visit to Hiroshima on the anniversary of the bombing that Blow addresses in his documentary, and that van Wyck describes as "irreducibly ethical" is a form of apology that works outside the cycles of insincere apologies on the part of governments and companies that Round Rose condemns (47). Even as the issues of sincere reparations, as well as the continued impact of industrial practices, are not resolved, the shared suffering and disablement of both the Japanese and Dene characters in the play, particularly as represented by the child of Rose and Koji, becomes a celebration of hybridity and collectivity as opposed to a return to a bodily wholeness.

Returning to the sign of the Doomsday Clock as a signifier, with which I began this chapter, I argue that *Burning Vision* is an important text to read from a disability studies perspective because it offers a different sense of threat than that represented by the clock, presenting threat as paradoxically both slow and urgent. As well, even as it shows the impact of industrial practices upon human health, it differs from other representations of disability as violence that would use disability to bolster the need for technological intervention; it presents instead a critique of the colonizing nature of intervention. In this sense, it moves beyond depicting disability as a problem to be fixed. Perhaps attempts to ease the perceptions of threat by using technology to make disability entirely an individual issue to be fixed at the level of the body suggest a kind of security like that of the backward movement of the clock. While a Doomsday Clock might appear to be the most cynical and critical symbol imaginable, its hovering on the verge, sometimes moving backward from the midnight it portends, is perhaps more conservative than it initially appears, actually serving to provide a strange sense of security.

Acknowledging that environments affect human health and ability from a disability studies perspective involves proceeding with the understanding that there are costs to positioning

disability as a risk to be feared; positioning disability in this way can not only perpetuate stigma and alienation, but can also create the perception that disability exists as a problem to be managed. My next chapter addresses this issue, taking up the issue of fear and risk once more. In this chapter, I build upon my discussion of disability, industry, and access by turning to Indra Sinha's novel *Animal's People* (2007), and its fictional representation of the Bhopal Disaster. I argue that this novel shows how disability should not define how closely bodies visibly conform or deviate from definitions of the normal body. Rather, barriers to access, such as inadequate medical care, toxic environments, and social attitudes create disability. I use the novel to explore the tension between a model of disability that celebrates human variation, and the material experiences of bodily difference originating from chemical poisoning. While this chapter focuses on considering a more expansive notion of access that takes into account the body in its social, political and environmental context, my next chapter looks at how this notion of access can be pursued alongside a persistent and demonstrable commitment to the generative possibilities of bodily difference.

## **Chapter Two**

Novel Embodiments: Deviation, Disability, and Industrial Disaster

## 1. "That Night": Animal's People and the Bhopal Disaster

During the spring of my first year of doctoral studies, I was working on my research amidst coverage of the upcoming Olympic and Paralympic Games that took place in London, England. Many controversies surrounding the 2012 Summer Olympics emerged, and two of them specifically concerned disability and corporate sponsorship. Many disability rights activists in England protested the Olympic and Paralympic sponsorship of Atos, a company that had been contracted to perform workplace capability assessments for Britain's Department for Work and Pensions (DWP), which determines eligibility for disability benefits. Many critics believed that the company's sponsorship of hypervisible athletes with disabilities was undermined by their role in revoking benefits and declaring disabled people, "fit for work," when many individuals could not realistically perform the labour that they were told they could manage ("Britain on the Sick"). Disabled campaigners participated in a week of action at the end of August in protest of how the company treated people claiming disability benefits (BBC News London). The company's sponsorship of the Games in many ways paralleled the dichotomy that media coverage creates between the athletic accomplishments of individuals represented as 'supercrips' and individuals who depend on work benefits to be able to carry out their daily lives.<sup>32</sup>

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<sup>&</sup>lt;sup>32</sup> Disability activists often critique the stereotypical representation of disabled people as 'supercrips' who compensate for their disabilities through their special talents and their ability to overcome adversity. Elaborating on the term in *Embodied Rhetorics: Disability in Language and Culture*, Ellen L. Barton explains that, "although extraordinary supercrips are the people with disabilities who climb mountains and jog across countries, ordinary supercrips are those who struggle, sometimes mightily, to wear the appellation, 'no one considers *you* handicapped'" (185). To clarify, disability rights activists and scholars who identify and critique the 'supercrip' trope do not suggest that individuals refrain from celebrating the accomplishments of people with disabilities. Rather, they argue that these celebrations often place an unrealistic expectation on people with disabilities to prove their worth through exceptional feats. Former Canadian Paralympian Danielle Peers discusses these attitudes as she considers how individuals that she encountered in her career differentiated her from other people with disabilities. She notes that

A second controversial sponsor of the 2012 Olympic and Paralympic Games was Dow Chemical, which has signed on to be an Olympic partner until 2020. Dow was able to place a decorative wrap around the Olympic stadium after British officials indicated that the wrap was too expensive to fund in a time of economic austerity (*The Independent*). Many individuals and organizations publically advocated against the sponsorship of Dow Chemical, including British Members of Parliament; Aslam Sher Khan, President of the Olympian Association of India; and representatives from the Bhopal Medical Appeal. Their belief that Dow Chemical was an inappropriate sponsor for the games was in part based on its purchase of Union Carbide, and its continued refusal to support the residents of India affected by the Bhopal Disaster of 1984. The Bhopal Disaster, often named the worst industrial accident of all time, was the result of a poisonous gas leak at a Union Carbide pesticide factory in India, which led to the immediate deaths of 5000 to 10,000 people (Mukherjee 134). 33 On the evening of December 2, a large amount of water entered one of the tanks in the factory, which caused a reaction that was accelerated because of contaminants and high temperatures (Eckerman 59). The resulting gas leak led to the release of methyl isocynate (MIC) gas and other poisonous chemicals. While some have suggested that the gas leak was the result of sabotage, others have cited poor maintenance of the factory and the inexperience of the workers present on the evening of the accident as causes. In an out of court settlement, Union Carbide paid US \$470 million to the Indian Government to settle the litigation arising from the disaster (Eckerman 132). While the Indian Supreme Court heard appeals to the decision, the original settlement amount was upheld.

one photographer asked her, "But, I mean, doesn't it piss you off when all these other disabled people just use it as an excuse to lie around all day and live off our tax dollars when you are out there trying to make something of yourself?" (183).

The official total is difficult to pin down, and many sources offer different estimates.

In 2001, Dow Chemical Corporation purchased Union Carbide. Although Dow has acquired the assets of Union Carbide, the company has refused to accept responsibility for the Bhopal Disaster. More than thirty years after the gas leak, many people in Bhopal are ill or disabled because of its prolonged effects. While some individuals' disabilities and illnesses resulted from exposure during the disaster itself, other individuals became disabled afterward. For over thirty years, the people of Bhopal have resided in a contaminated environment, without access to clean drinking water and medical care. When most people refer to the tragedy of Bhopal, they are not only referring to the evening of the industrial accident, but also to the ongoing suffering of its citizens. As Dow Chemical has not assumed accountability for the disaster, the Bhopal Medical Appeal, a charitable organization, provides medical treatment through the Sambhavna Clinic and the Chingari Trust Rehabilitation Centre. As critics pointed out, Dow Chemical's Olympic sponsorship was particularly inappropriate for the chosen year because one of the objectives set for London 2012 was to be the most sustainable Olympics yet. As the company's sponsorship extended to the Paralympics, its financial support of the competition amongst disabled athletes proceeded while the company continued to ignore individuals with disabilities that resulted from the Bhopal Disaster and its aftermath.

Many individuals came forward with public statements against Dow and wrote letters to the Olympic committee to express their concerns. Critics reminded the world of the company's production of Agent Orange during the Vietnam War. Hoan Tuan Anh, Vietnamese Minister of Sport, Culture, and Tourism, wrote a letter to the Olympic Committee requesting that they reconsider their choice of Dow as a sponsor. Pointing out that good health, equality, and progress are the central goals of the Olympic Games, he wrote, "Spending zero effort to recover their mistakes in the past, Dow continues to destroy the current living environment. In 2010, the U.S.

Environmental Protection Agency listed Dow as the second worst polluter in the world" (Tuan Anh). Meredith Alexander, who opposed Dow Chemical's sponsorship because of the company's refusal to clean up its contamination in Bhopal, publically resigned from the Commission for a Sustainable London in 2012. She told *The Guardian*, "I would like to see Dow take responsibility for the Bhopal Tragedy and finally ensure that real justice is achieved for the victims and the families of those who died. This would be a true Olympic legacy" (Alexander). However, despite significant international criticism from Alexander, Tuan Anh and others, the Dow sponsorship of the Olympics and the Paralympics proceeded.

In the thirty years since the gas leak in Bhopal, charitable groups, activist organizations, and artists have drawn international attention toward both the plight of the people in Bhopal, and the negligence of corporations like Dow Chemical. For the twentieth anniversary of the Bhopal Tragedy in 2004, Andy Bichlbaum and Mike Bonanno, who comprise The Yes Men activist duo, invented the fictional Jude Finisterra<sup>34</sup>, a spokesman for Dow Chemical Corporation, and landed an interview with the BBC. Although the troupe had considered reiterating Dow's established stance toward the Bhopal Disaster, instead, they announced to the BBC that to acknowledge the anniversary of Bhopal, they would provide medical treatment for those affected, perform a full remediation of the factory site, and work to extradite former Union Carbide CEO Warren Anderson to face trial in India (razorfoundation). The Yes Men believed that announcing such a drastic change in policy would lead to news coverage in the United States, and draw attention to the events of Bhopal for Americans, whom they suggested were largely unaware of the disaster's occurrence (Bichlbaum and Bonanno). Their message was broadcast on the BBC, and it took two hours for Dow Chemical to recognize the deception. In that time, Dow Chemical stocks

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<sup>&</sup>lt;sup>34</sup> The duo chose the name Jude Finisterra because of the significance of 'Jude' as "patron saint of the impossible" and 'Finisterra' as "earth's end" (Bichlbaum and Bonanno).

plummeted. While the BBC retracted the interview with an apology, Dow Chemical issued a statement that it would not be assuming responsibility for Bhopal. The Yes Men were ultimately satisfied with their actions toward Dow, believing that detailing what Dow should do was a more effective stunt than maintaining the company's actual stance. However, they express concern on their website that they may have devastated Bhopalis by providing false hope in those few hours only to take it away.<sup>35</sup> In their description of their "hijinks," they note: "Much as we try to convince ourselves that it was worth it, we cannot get rid of the nagging doubt. Did we deeply upset many Bhopalis? If so, we want to apologize. We were trying to show that another world is possible…" (Bichlbaum and Bonanno).<sup>36</sup> As with many catastrophes, in the case of the Bhopal Tragedy and the mass disablement of Bhopalis, questions of effective and ethical representation and advocacy surface, and many groups and individuals have pursued different strategies.

Many artists have told the story of the disaster through photographs and real footage; Bhopal is the subject of photographic expositions and documentary films. Raghu Rai, a photographer and photojournalist, covered the events in Bhopal in 1984 and returned seventeen years later, in 2001, to photograph survivors. His photographs of Bhopal form the subject of his book, *Exposure: Portrait of a Corporate Crime*, and the Bhopal Medical Appeal organizational materials display his photograph entitled, "Burial of an unknown child." *Bhopal: The Search for Justice* (2004), a documentary exploring the disaster by Canadian directors Peter Raymont and Linda Lee Tracey, was released in 2004. Other films about Bhopal are fictional retellings based

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<sup>&</sup>lt;sup>35</sup> The Yes Men acknowledge that they understood this risk before they went ahead with their trick:

There are some risks to this approach. It could offer false hope – or rather, false certainty – to people who have suffered 20 years of false hope that Dow and Union Carbide would do the right thing. But all hopes are false until they're realized, and what's an hour of hope to 20 years of unrealized ones? If it works, this could focus a great deal of media attention on the issue, especially in the US, where the Bhopal anniversary has often gone completely unnoticed. Who knows – it could even somehow force Dow's hand. (Bichlbaum and Bonanno)

<sup>&</sup>lt;sup>36</sup> Another risk that the Yes Men considered was that their actions would result in a loss of credibility for the BBC, which they argue, "have covered Bhopal very well, infinitely better than what we're used to in the US" (Bichlbaum and Bonanno).

on true events; the film *Bhopal Express* (1999) by Indian director Mayesh Mathai tells the story of the events of December 2 to December 3 from the perspective of a number of different characters. The recent Bhopal: A Prayer for Rain (2014), starring Hollywood actors Mischa Barton, Martin Sheen, and Kal Penn, follows the events leading up to the tragedy. Canadian playwright Rahul Varma's play *Bhopal* (2005) also traces the birth of the disaster, focusing on events prior to the gas leak at the factory. This chapter provides a reading of one artistic representation of the Bhopal Tragedy, and its representation of disability. I examine Indra Sinha's novel *Animal's People* (2007), which takes place in a fictional city called Khaufpur that is based on Bhopal. Unlike other fictional representations of the disaster that tend to focus on the evening of December 2, or on the events leading up to it, Sinha's novel is about the aftermath of the disaster, and what constitutes ordinary life in a place like Bhopal. Although I introduced the question of effective and ethical representation, my main intention is not to argue that Sinha's representation of Bhopal is more accurate, or more ethical, than other important representative efforts; rather, I wish to argue that it opens up different questions from the other works that I have surveyed because it focuses on disability and the prolonged suffering of individuals in Bhopal. While many works focus on the events of that night, and the tragic deaths of many Bhopalis, Sinha's work manages to celebrate bodily difference and question predominant western understandings of health even as it explores traumatic experiences of mass disablement.

Sinha's novel is based on his experiences working with activists from Bhopal and with the Bhopal Medical Appeal.<sup>37</sup> With *Animal's People*, Sinha assumes the voice of a nineteen year

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<sup>&</sup>lt;sup>37</sup> He is also the author of *The Death of Mr. Love* (2002), a novel exploring the events surrounding the famous trial of Naval Commander Kawas Manekshaw Nanavati, who murdered his wife's lover, Prem Ahuja, in Bombay in the 1950s. Sinha's memoir, *The Cybergypsies* (1999), details his struggles with an internet addiction. He is also the editor and translator of the works featured in *Tantra: The Cult of Ecstasy* (1993), and the translator of *The Love Teachings of the Kama Sutra: With Extracts from Koka Shastra, Ananga Ranga, and Other Famous Indian Works on Love* (1980). In addition to his literary work, Sinha is well known in advertising circles as a copywriter, and was voted one of the ten best British copywriters of all time (Pereira).

old Indian boy named Animal who walks on his hands and feet due to chemical poisoning from a fictional 'Kampani' disaster that has affected his spinal growth.<sup>38</sup> The novel features a cast of other characters that includes a well-loved activist leader named Zafar; a benevolent American doctor, Elli Barber, whom people suspect may be secretly working for the 'Kampani'; a retired singer, Somraj, whose lungs have been damaged by the company's poisons; and Ma Franci, a Catholic nun who believes that the apocalypse, or Apokalis, as Animal calls it, has come to Khaufpur. Together, Animal and the people of Khaufpur collectively advocate for justice. However, while the aftermath of the disaster is central to the novel, the book is Animal's story above all else. In an interview with Mark Thwaite, Sinha explains why he chose to write about a fictional city instead of writing a story set in Bhopal:

[Bhopal] was the background, but novels are about people, not issues. I knew Bhopal too well. To write freely, I had to imagine another city. In this fictional place, which I call Khaufpur ("khauf" is an Urdu word that means "terror") the characters could come to life. Even so, the attempt to transcribe a screenplay to novel at first wouldn't work.<sup>39</sup> No matter what I tried, the matter remained dark and lifeless. One day, a friend said he had met a boy who went on all fours. Two days later my daughter Tara told me about an old Frenchwoman she had met, who had forgotten how to speak all languages except her childhood French, and thought that everyone else was just making meaningless noises. Thus were Animal and Ma Franci born. Animal decided that he, not I, would write the book. And he did. ("An Interview with Indra Sinha")

<sup>&</sup>lt;sup>38</sup> The novel uses non-standard spelling for some English words to suggest how they might sound aloud. Company appears throughout the novel as 'Kampani'.

In answer to the interview question, "What gave you the idea for *Animal's People*?" Sinha explains that in 1996, he had written notes for a screenplay called *Green Song*, which would not attempt to tell the story of the gas disaster in Bhopal, but would instead tell of the human suffering of its aftermath ("An Interview with Indra Sinha").

With Animal as the narrator, Sinha's book is not only about the gas disaster and the suffering of the community. The book is also about the character's struggles with navigating poverty, unrequited romantic love, sexual desire, and his feelings toward his unique corporeality.

While the novel's fictional setting is one way in which it differs from earlier works about the Bhopal Disaster, it stands apart in other ways as well. Other representations of the Bhopal Gas Tragedy understandably assume a serious and respectful tone, evoking *pathos* from their audiences. Sinha's Animal, on the other hand, is irreverent and his antics throughout the novel tend toward the comedic. Critics such as Rob Nixon and Anthony Carrigan argue that the novel borrows from the picaresque tradition, which M.H. Abrams characterizes as typically following, "the escapades of an insouciant rascal who lives by his wits and shows little if any alteration of character through a long succession of adventures" (198). Animal warns the reader at the novel's outset: "I can't make fancy rissoles of each word. Blue kingfishers won't suddenly fly out of my mouth. If you want my story, you'll have to put up with how I tell it" (2). Perhaps the novel's exploration of the humorous elements of ordinary life, even amidst extreme pain and suffering, is possible not only because of its fictional setting, but because of its temporal setting as well. The events of 'that night' are largely left out because they are not part of the story that Animal wants to tell; instead, the story of 'that night' is the story of its painful aftermath, and the protracted and ongoing reality that is Khaufpur, and Bhopal, its real life counterpart. The novel's focus differs from that of the film *Bhopal Express* (1999), a thriller based on the traumatic events of the evening of December 2 that falls more within the realm of horror or disaster cinema, albeit based on a true story. The film is a gripping story about the horror of that night, but it does not explore the reality of what people in Bhopal contended with in the years afterward. Similarly, Varma's Bhopal (2005) recounts the evening of the gas leak, and the events leading up to it, in an effort to

establish a sense of causality. As Nixon suggests in his critical work on *Animal's People*, Sinha manages to capture the slow violence of the Bhopal Tragedy, which is a difficult task for a novelist in a society accustomed to thinking of violence as immediate and hyper-visible (47).

Reviewers recognized the novel's achievement. Animal's People was shortlisted for the Man Booker Prize in 2007. The novel has received scholarly attention as well, with many literary critics merging critical approaches from postcolonial studies and environmental criticism in their analyses of the work. Disability studies scholars have recently turned their attention to the novel as well. In an introduction to a special issue of the Journal of Literary & Cultural Disability Studies on intersections between disability studies and postcolonial studies, Barker and Murray note that the novel "showcases how a combination of disability and ecocritical perspectives can illuminate the complex interrelations inherent to disabling postcolonial environments" (232). In a more extensive piece on the novel, Jina Kim explores connections between spatial theory and disability studies to suggest how the novel calls upon us to revise western models of disability. She argues that, "Animal's unique spatial imaginary, which wrests meaning from the symbolic and material topography of Khaufpur, engenders a local, collective, and embodied knowledge that resists the erasure of the local and the dissolution of survival networks under the disabling forces of neoliberal globalization" (Kim). Her argument significantly highlights the value of Animal's unique corporeal knowledge within the text, which speaks to how the novel navigates the tension between celebrating disability and condemning disabling violence. As Barker, Murray, and Kim show, the novel's representation of disability is nuanced, challenging traditional medical models of disability, as well as challenging disability studies scholars to rethink some of the early assumptions of the field.

Perhaps this nuanced approach to disability is also possible because the novel is set many years after the disaster has taken place. In contrast, the film *Bhopal Express* (1999), set during the evening of the gas leak, does not delve into the mass disablement of the people of Bhopal, but instead frightens and saddens audiences with the trauma of the imminent and painful deaths of many Bhopalis. Disability does receive some treatment in Varma's *Bhopal* (2005). At several points, the play depends upon disability to viscerally communicate the horror of the disaster in Bhopal, and to illustrate the effects of MIC that were present in advance of the gas leak too. 40 One of the protagonists is a Canadian doctor performing research, who at one instance declares, "If you want to see a human baby that is not necessarily a human baby, go to the slum" (Varma 15).<sup>41</sup> Another crucial moment in the play involves the uncovering of an infant's blanket, which reveals the infant's disabled body. While there may be multiple ways to perform this scene, the stage directions would suggest that disability becomes a spectacle with a clear, rhetorical end. While Animal's People similarly considers the bodily effects of the company's dehumanization, Sinha's decision to tell his story from the perspective of one of these 'inhuman' survivors allows for a strong interrogation of the category of the human itself. The unusual syntax of the novel's title, which, in a reversal of traditional relationships, would appear to attribute ownership of human beings or responsibility for them to an animal, can alert us to the extent to which how we define and characterize the human affects how we define and characterize disability.

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<sup>&</sup>lt;sup>40</sup> In Varma's introduction to his play, he describes how MIC made its way into the bloodstreams of the people neighbouring the factory in Bhopal. Emphasizing the dangerous nature of the factory's work, he writes: "The MIC-based method of manufacturing Sevin Carbaryl was banned in Europe and the US – an example, it would seem, of the multinationals placing a higher value on Western lives than on lives in the Third World" (iv).

<sup>&</sup>lt;sup>41</sup> It is interesting to compare Doctor Elli Barber of *Animal's People* with the Canadian doctor in this play. While the doctor in Varma's play speaks to citizens as an external authority, citizens in *Animal's People* call Elli's authority into question, and she has to learn about the complicated history of oppression and resistance in Khaufpur from Animal. Elli's inclusion speaks to issues of effective allyship. The novel demonstrates how she is not someone who should impose her external knowledge on others, but is someone who must learn about the struggles from the people themselves in order to become a proper ally in their fight.

Comparisons of Sinha's novel with other representations of Bhopal draw attention to the uneasy connection between disability and death that a discussion of Bhopal necessitates; while in many instances, distinguishing the predicament of people with disabilities from people with illnesses is important to ensure that disability is not only defined by suffering, in the case of Bhopal, to sever this connection between disability and death would be irresponsible, as many people in Bhopal are dying from the company's chemicals. This issue appears at the outset of the novel, which commences with an encounter between Animal and a foreign journalist in India. Animal recalls, "When you saw me your namasté had that tone I've come to know, a hushed respect as if you were speaking prayer, like you were in the presence of the lord of death" (4). As I discussed in my previous chapter, the perception that disability signifies suffering and that disabled bodies are closer to death is one that disability studies scholar Robert McRuer addresses in his analysis of global bodies. Remember that McRuer expresses concern that the saying that everyone who lives long enough will become disabled might prompt fear as opposed to identification. He asks what it would mean to, "welcome the disability to come, to desire it?" (207). Knowing that this question presents difficulties in an era of advanced capitalism, in which global bodies can refer to corporations that function as autonomous agents, McRuer asks, "in such terrible times, is it even possible to ask the question this way?" (207). In this chapter, I will use McRuer's question as a jumping off point to consider the intersections amongst disability studies, postcolonial studies, and ecocriticism in Animal's People. To return to many of the questions introduced in the introduction to my dissertation, what might it mean to "welcome the disability to come" even as we recognize that unsustainable practices are creating disabling environments? How can we critique these practices while resisting the tendency to point toward

disabled bodies as the undesirable outcomes of social injustice or environmental degradation? How can we celebrate disability without justifying violence that leaves the body in pain?

As I hope my discussion of the politics surrounding Bhopal at one snapshot in time, the London 2012 Olympics, will illustrate, the events that I explore in this chapter through a reading of the novel are real and ongoing. In this chapter, I read Animal's People to explore the tension between a model of disability that celebrates human variation, and the material experiences of bodily difference originating from chemical poisoning by multinational corporations that remain unaccountable. In my introduction and Chapter One, I note that Alaimo, studying multiple chemical sensitivity from an ecocritical and disability studies perspective, cautions that many people who are sensitive to chemicals would insist, "not all deviations in this world of toxicants and xenobiotic chemicals should be embraced" (139). This caution is also worth bearing in mind when considering the situation in Bhopal, as exposure to toxic gases and toxic wastes in the groundwater have led to painful and debilitating illnesses and disabilities. Alaimo's formulation of an openness to deviation, as discussed in my previous chapter, offers insight into critiquing how corporate practices have made bodies vulnerable without positioning disabled bodies as undesirable or expendable (139). In this chapter, I argue that Sinha's fictional protagonist, who wants to tell his own story instead of deferring to the written authority of the journalist characters in the novel, illustrates how positioning disabled bodies as representative of suffering alone places a limit on the meanings that readers might derive from bodily experience.

The character Animal, who lives in the fictional city of Khaufpur, refers to himself by his childhood nickname and continually reminds the reader that he is not human. Nixon's reading of *Animal's People* suggests that the character's disablement represents the social and political situation of Bhopal. He shows how the novel plays with apocalyptic eschatology as it depicts the

slow violence endured by the citizens of Khaufpur. Nixon offers a symbolic reading of how Animal's posture "embodies a crushing, neoliberal, transnational economic relationship and also marks him as a literal 'lowlife,' a social and anatomical outlier whose physical form externalizes the slow violence, the unhurried metastases coursing through the community" (56). He writes:

A novel narrated by a human animal – "a beastly boy" (*Animal's* 9) – bent out of shape by his foreign load simultaneously questions other forms of mutability, not least the plasticity of ownership, how foreign corporate practices inside India can be owned (for short-term profit) and disowned (for long-term consequences to environmental and human health). (454)

Nixon's analysis crucially emphasizes how irresponsible corporate practices have shaped Animal's body, but as he positions Animal as representative of undesirable mutation, Nixon insists that he is "bent out of shape" (454). As Barker and Murray argue, the tension between disability studies and postcolonial studies has often been one of materiality and metaphor, or, of reading disability as symbolic of the postcolonial nation in development versus reading disability as a material experience (219). I do not wish to contest Nixon's reading, or to suggest that metaphorical readings of disability are necessarily incompatible with disability studies readings. Instead, I wish to build upon Nixon's analysis by emphasizing how Animal's rejection of interpretive readings of his own body by journalists, doctors, and even imagined readers that he refers to as Eyes on the page reveal the limitations of humanist representations of disability that invoke suffering by referencing an essential shape to which individuals must

<sup>&</sup>lt;sup>42</sup> I agree with Clare Barker's argument that metaphorical and material readings are often compatible and productive. In *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality*, Barker argues that, "Metaphors can enhance awareness that disability is a complex, resonant human condition, and is frequently used to establish empathetic connections between characters, communities, and readers – an effect that is especially important when narrating stories of mass disablement and/or collective trauma that often occur in postcolonial narratives" (20).

conform. In this chapter, I return to the urgency of acknowledging the relationship between disability and environmental conditions that I explored in Chapter One, but in this chapter, I consider in more depth how we, as readers, scholars, and activists, might value bodily difference even while recognizing the physical pain that can often accompany difference. Then, bridging the concerns of this chapter with the upcoming second section of my dissertation, I consider the novel's interrogation of traditional means of communicating one's story.

## 2. Reading the Text of the Body

The novel's transgressive resignification of the term "animal" illustrates how Sinha's character differentiates his own embodied difference from the painful disabilities that other community members in the novel experience. Barker and Murray suggest that concepts of normalcy may not be relevant to cases of mass disablement, as "'normal' lived experience in postcolonial and developing contexts might be disabled experience, drastically altering the categorical and exclusionary implications of 'normalcy' and 'normativity'" (232). In many ways, Sinha's Khaufpur is a city in which people find themselves united in shared struggles. Yet when Animal's friend Faroug insists that, contrary to his assertions, he is not an animal but a human, Animal responds, "and I'm an animal, why? By my choice, or because others named me Animal and treated me like one?" (209). Within disability advocacy circles, many terms once used to debase people have been subverted and redeployed through writing and performance. The term 'animal' also invites resignification; for instance, disability studies scholar and activist Sunaura Taylor states, "I am an animal" to argue that insulting comparisons between disabled humans and animals reveal the mistreatment of both groups (195). Animal's self-naming allows him to eschew definitions of the human that insist upon a certain degree of bodily uniformity. He

explains to the reader: "if I agree to be a human being, I'll also have to agree that I'm wrong-shaped and abnormal. But let me be a *quatre-pattes* animal, four footed and free, then I am whole, my own proper shape..." (208). Despite the fact that the Kampani's chemicals have influenced the development of Animal's body, he refuses to offer himself as representative of collective suffering. Beginning with Animal's rejection of the passive role that journalists would have him take in telling his own story, the novel follows his agential role working with Zafar and other activists who protest against the Kampani's long evasion of the Khaufpuri court.

One might argue that Animal's refrain that he is an Animal is a rhetorical strategy that allows Sinha to communicate the humanity of the survivors, in the wake of the company's dehumanization. Other survivors portrayed in the novel question the extent to which the 'Kampani' views them as human beings. An older woman named Gargi, whom Animal describes as having a back almost as bent as his own, confronts one American lawyer on this front, stating, "You were making poisons to kill insects, but you killed us instead. I would like to ask, was there ever much difference, to you?" (306). Bearing this character's critique of the 'Kampani' in mind, one might be tempted to read Animal's self-naming as an internalization of the company's views of human life, and Indian lives specifically. A reviewer in *The New York Times*, explains that "Animal embraces his cruel nickname, claiming he has 'no wish' to be a human being," but then adds, "it's all bravado of course" (Mishan). In *The New Statesman*, Lucy Beresford describes Animal's People as a novel concerning the human condition. She notes that the novel closes with Animal's recognition of his own humanity and his need to take responsibility for his actions because "sometimes you have to stand up for what you believe in – even if you can't stand up" (Beresford). She explains that throughout the course of the novel, Animal develops a conscience, noting that, "just as the Kampani lacks any conscience about its accountability, so Animal, in his

attempts to deny the hope fluttering in his breast, concentrates on baser instincts" (Beresford). Absent from the majority of reviews of the novel is an acknowledgement that, despite the fact that Animal occasionally uses his status as an animal to avoid certain tasks and duties, his understanding of his own position outside the category of the human has philosophical and cultural weight. In other words, Animal is not just stubborn or sensitive; his refusal to call himself human is an important critique, not only of the dehumanizing actions of the Kampani, but of the definitions of the human that make such processes of dehumanization possible.

The figure of speech that Beresford uses in her review, as she distinguishes between the metaphorical act of standing up for one's beliefs and the literal act of standing up, reveals the extent to which we symbolically associate moral rightness with physical uprightness; it is not accidental that the metaphor Beresford chooses does not work. As B.E. Gibson et al. argue in their examination of beliefs about walking in rehabilitative settings, "independent walking and 'standing on your own two feet' symbolizes largely taken-for-granted virtues – rectitude, dignity, autonomy" (62). Animal is right that an ableist logic governing contemporary culture repeatedly tells us that human beings are distinct from animals because of their ability to stand upright, and I would argue that an acknowledgement that Animal's understanding of the boundaries dividing human beings and animals is shaped by real ideologies needs to occur in order to understand his self-naming as more than a playful means of hiding his insecurities or evading his responsibilities. Beresford concludes that Animal is human, that "physically deformed he may be, and the butt of much peer contempt, but he is still human – a sentiment he strenuously denies until the book's close" (Beresford). However, the novel's focus on categorical distinctions between human beings and animals persistently interrogates traditional definitions of the human, as well as what it means to be disabled; whether we find a celebration of common humanity at

the end of the novel is open to debate. While I will delve into the novel's ending in more detail later, my reading of its conclusion is that, rather than accepting his status as a human, Animal actually questions whether he is deformed, and even whether he is disabled. He refuses to call himself a human even at the novel's close, preferring his identity as an animal because it allows for a less fixed idea of what the body should and should not be.

History, medical science, religion, art, philosophy, and other disciplines have contributed to our cultural understandings of how the human body should look. They have also led to the establishment of hierarchies; even though understandings of the ideal body are culturally and historically contingent rather than universal, such hierarchies deny human status and rights based on sex, race, and ability. 43 Such hierarchies have also worked to establish how humans differ categorically from other animals. Understandings of what differentiates humans from nonhuman animals are deeply rooted in the body, but another presumed distinction between humans and animals is the ability to create and use language. Animal studies scholar Cary Wolfe questions the tendency to recognize an individual's subjectivity when we recognize their language ability. Critiquing the "too-rapid assimilation of the questions of subjectivity, consciousness, and cognition to the question of language ability," Wolfe offers the autistic animal scientist Temple Grandin, who describes her own thoughts as consisting of pictures as opposed to words, as an example of an individual who troubles the status of traditional linguistic ability as the master characteristic of the human (129). As he describes Grandin's thought processes and her unique dependence upon visual thinking, Wolfe shows how defining the human through language can

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<sup>&</sup>lt;sup>43</sup> Beliefs about race influenced scientific research. During the eighteenth and nineteenth centuries, much of the research surrounding race in the United States and Europe was designed to prove the differences between western people and those of African or Asian descent, in order to provide a scientific basis for the social order. Although many people were reduced to the objects of scientific study within laboratories, science has also demonstrated that there is no biological basis for the concept of distinct races. (See, for example, Katherine McKittrick, "Science Quarrels Sculpture: The Politics of Reading Sarah Baartman.")

categorically dismiss individuals with disabilities. In the argument that follows, I couple Wolfe's criticisms of the relationship between linguistic ability and humanity with postcolonial critiques of the relationship between language and empathy. I argue that *Animal's People* calls into question the relationship between literature and empathy fetishized in literary circles.

A long-lasting belief in such circles is the idea that narrative allows individuals to develop empathy, as readers become more human through the act of being able to imagine another individual's perspective. Suzanne Keen explores this belief in *Empathy and the Novel*. One of the questions that guides her analysis is, do we have evidence that reading novels makes people more empathetic, or that empathy leads to positive or altruistic interactions in the real world? Without dismissing the value of narrative empathy wholeheartedly, Keen cautions that it is not enough "to rely on the assertions of authors, on introspection, or on personal conviction to prove that reading certain canonical works of fiction inevitably yields the cultural and civic good of altruism and engaged world citizenship" (145). While works of fiction and non-fiction have certainly been instrumental in shaping cultural attitudes in ways that have led to important political change, cultural understandings of the link between literature and empathy may be too generous, and more than that, may be exclusionary in ways that go unrecognized. At many points in history, memoir has been a valuable resource for marginalized and persecuted groups who can share their stories, and earn recognition from mainstream readers who begin to see the world through their eyes. I would argue that two genres, in particular, depend not just on the quality of stories themselves to persuade and influence readers, but on convincing audience members that the words in question have actually been written by the authors themselves. I am thinking here of eighteenth and nineteenth century slave narratives and 'autiebiographies', or the biographies of autistic people (of which Grandin's book, described in Wolfe's study, is one). While I do not

wish to conflate these unique experiences by discussing them together, I think there are similarities between how expertise is constructed in the paratextual content of these stories.

One convention of the slave narrative as a genre is for former slaves to describe to the audience how they acquired their knowledge of reading and writing, which was usually in secret, sometimes from a benevolent master, and often through studying a sacred text like the Christian bible. This convention is present in influential slave narratives such as *The Interesting Narrative* of the Life of Olaudah Equiano, or Gustavus Vassa, the African, and the Narrative of the Life of Frederick Douglass, An American Slave. Written By Himself. During the eighteenth and nineteenth centuries, slave narratives were usually released with an accompanying preface from a white abolitionist, who would attest to the veracity of the former slave's claim that he or she had written the work in question. It was important, rhetorically, for slaves to tell their stories themselves, not only so that they could recount their experiences from an evocative, first-person perspective, but also because audience members would understand writing to be inherently human – and a slave's ability to write, and furthermore to write with the allusive and poetic quality of established writers, would be taken as evidence of the individual's humanity. A preface written by a doctor or a psychologist, in the case of an autiebiography serves, I would argue, a somewhat similar function to that of the preface in a slave narrative. 44 For the accomplishments of the autistic writer to be celebrated, they must first be believed; in early autiebiographies, the preface serves as evidence that one, the writer is autistic, and two, that the

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<sup>&</sup>lt;sup>44</sup> Many autiebiographies include prefaces from psychologists and clinicians. Examples include *Emergence: Labeled Autistic* (1986) by Temple Grandin, *Nobody Nowhere: The Extraordinary Autobiography of an Autistic Girl* (1992) by Donna Williams, and *The Mind Tree: A Miraculous Child Breaks the Silence of Autism* (2003) by Tito Mukhopadhyay. The more recent *The Reason I Jump*, by Naoki Higashida, includes a preface by the well-known English novelist David Mitchell. Mitchell, who is the parent of an autistic son, is one of the translators of the work. The anthology *Loud Hands: Autistic People, Speaking*, which features essays and poems by autistic writers, is an important collected work of autistic writing. As the collection is designed to speak back to experts, it does not include a preface by a neurotypical writer.

individual wrote the words themselves.<sup>45</sup> While demonstrating one's writing ability is an important strategy in these and other cases, I think it is worth questioning why we have, over time, been so often convinced by this strategy, and why we invest so much faith in the relationship between writing and humanity.

Postcolonial critic Srinivas Aravamudan takes up this question in his work on Olaudah Equiano and the politics of literacy. Aravamudan problematizes how the relationship between literacy and empathy has been fetishized within literary criticism:

It is true that eighteenth century racialists deemed slaves irrational by pointing to their illiteracy, yet why should the act of literate – idealized as literary – persuasion be privileged as *an end in itself* (to the extent that it is conflated with the a priori definition of humanity) if not for the fact that we believe, perhaps too much as literary critics, in the transformative power of literature and are all too willing to demonstrate literature *as* the sign of humanity? (270 emphasis in the original)

Aravamudan contrasts the reception of Equiano's *Interesting Narrative* with the writings of the black settlers of the experimental colonial settlement in Sierra Leone in 1787. He describes how Prince Hoare, the biographer of abolitionist Granville Sharp, addressed spelling in the letters of the Sierra Leoneans that he reproduced. Although he edited the spelling of many words throughout the text, the words "anarchy" and "senate" are left deliberately misspelled. Aravamudan notes that readers were, "encouraged to think that if the settlers cannot spell these political words, they are probably still undeserving of the substantive content to which the words

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<sup>&</sup>lt;sup>45</sup> However, changing dominant perceptions of autism through writing is more complicated than I discuss in this chapter; I will take up this issue again in Chapter Three. Some charitable organizations, like Autism Speaks, have called into question whether it is ethical for autistic people to represent themselves in writing, arguing that autistic people who can write should not be taken as representative of the majority of autistic people. Melanie Yergeau outlines this position, and how it has created barriers to self advocacy that go against the 'Nothing about us, without us' ethos of disability rights in "Circle Wars: Reshaping the Typical Autism Essay."

refer" (264). Unlike Equiano's narrative, which has secured a place in the English literary canon, the writings of the Sierra Leoneans are marginalized, along with other forms of resistance, like music and fables, which Aravamudan suggests are not often considered in critical works because of the status of the book as a colonial fetish. Criticism of the eighteenth century, he argues, should be suspicious of the project of canonization and the correlation between the rise of literacy and the rise of nationalism. He suggests that criticism should, "pa[y] greater attention to the multiple ideological significations of the culturally variable technology and the historically different constructions of the institution of 'Literature'" (287). By characterizing the book as a fetish object, Aravamudan shows how the argument that we might use the "transformative power of literature" to produce identification is a political one that elevates literacy to such a degree that literacy becomes a sign of subjecthood and humanity. While Aravamudan demonstrates why such a correlation is damaging from a postcolonial viewpoint, clearly, this correlation is problematic from a disability studies perspective as well, as disability studies has also shown how we continually deny subjecthood to people whose processes of composition range outside the scope of what society has deemed to be normal. Both Wolfe's critique of the privileging of language as an inherently human prerequisite for consciousness and Aravamudan's critique of our investment in the acquisition of literacy and the production of literature inform my reading of the conceit of *Animal's People* as a book, and the protagonist's skepticism of the "transformative" power of literature" at the beginning of the novel (Aravamudan 270).

The novel tells readers that the book in their hands has not been written in the traditional sense but has been composed orally, on a series of tapes. Accordingly, the novel is not divided into chapters, but into tape numbers. The fictional "Editor's Note" that describes the relationship between Animal and the journalist who befriended him is part of the diegetic story of *Animal's* 

*People.* The fictional arrangement between Animal and the journalist demonstrates the novel's self-consciousness of the fetishization of the novel as a product. At the outset, Animal reveals his skepticism in the power of literature to usher in meaningful change. He asks the journalist, "how many books have been written about this place, not one has changed anything for the better, how will yours be different?" (3). Questioning the use of telling stories "so strangers in far off countries can marvel there's so much pain in the world," Animal calls upon the journalist to consider whether experiencing fine feelings might actually reflect an attraction to the drama of catastrophe for journalists who are "drawn by the smell of blood" (5). Animal convinces the journalist that he should be able to tell his own story in his own words. The second tape thus involves Animal's transition from speaking to the journalist to speaking to readers that he refers to as Eyes on the page since the journalist, upon leaving Khaufpur, tells Animal to speak directly to those who will read his words (10). Animal tells his readers that some time has passed, and time and circumstance have persuaded him to try to relay his story (10). While Animal's critique of the journalist's book project suggests how we might think of the book as a fetishized object for western readers, his insistence on telling his own story draws attention to Sinha's status as an author and his own role in telling the stories of Khaufpur – which in turn draws attention to the fictional city's real counterpart, Bhopal.

Sinha makes this parallel explicit on his website; in fictional interviews, he takes on the persona of Animal to complain that Indra Sinha has received all the credit for his work. The "Editor's Preface" at the beginning of the novel guides readers to a fictional website for the city of Khaufpur. The fictional interview transcripts suggest how a storyteller like Animal might feel about the mediation of a writer like Sinha. In one interview, Animal complains that Sinha's name is all over the book while his own name is absent from the cover page ("Katie Price vs. Animal

Spice"). <sup>46</sup> Heather Snell suggests that Sinha's playful account of Animal's charge of exploitation is humorous, but, on a more serious note, "highlights the need for authorial accountability and places in check the pleasure some readers might take in consuming and subsequently exotifying, the tragic and ostensibly true account of a traumatized young man living in the so-called 'Third World'" (3). Also worth noting is Animal's contradiction of the claim in the "Editor's Note" that "Apart from translating to English, nothing has been changed," for Animal tells us the book has some missing pieces after all: "I told him many things he did not put them all in his story if I had my chance I would do it with some good writer" ("Katie Price vs. Animal Spice"). While the book may function as a vehicle for change, these self-deprecating paratextual materials suggest an acknowledgement of the privileging given to books and their writers in a way that legitimizes many concerns about the power dynamics of storytelling.

Within the novel's diegesis then, Animal speaks his book. He speaks his book in a multitude of languages. If we follow the belief I have worked to criticize that the use of language is inherently human, Animal certainly meets and exceeds this criterion. The text of *Animal's People* is predominantly in English – which, as the "Editor's Note" tells us, is a translation from Hindi. However, the novel also includes many words and phrases in other languages, from French, to Urdu, to (untranslated) Hindi. Additionally, the novel is accompanied with a "Khaufpuri Glossary," which translates localisms into English. Among other entries, the glossary clarifies that *Amrika* means "America" and *jarnail* is "a corruption of English 'general'" (370). Throughout the novel, non-traditional spellings reflect how words might sound to a listening audience. For instance, when Animal clandestinely looks into the affairs of the doctor, Elli

<sup>&</sup>lt;sup>46</sup> After the Booker short list was announced, a writer in *The Guardian* compared the soaring sales of a fictional memoir by Katie Price to the comparatively low sales of the Booker nominees, offering suggestions of what Booker writers might do to achieve sales in the future, like, not wasting their time reading books and making sure that language is varied (Cadwalladr). Animal responds to these suggestions, often noting he is on the same page as Katie.

Barber, he refers to himself as Jamispond, which denotes James Bond, the fictional English spy. Animal has a wonderful facility with languages, having learned French from being cared for and subsequently looking after Ma Franci. Studying English under Nisha's instruction, he begins to read from Zafar's copy of *Pride and Prejudice*, quoting the famous first line for his listeners (36). 47 48 He also notes that for those English words that he does not recognize, "words spit themselves into" his ear (8). He hears voices that translate the world for him, telling him at one point that a locust lying in the sun is crooning about how gorgeous he is, and at another, allowing him to converse with the "Khã-in-the-Jar," an unborn corpse residing in Elli's laboratory as an object of study. 49 Ma Franci worries about Animal's voices, wondering if they are a blessing or a curse, but she benefits from Animal's linguistic prowess. Animal tells his Eyes that many people lost things on "that night," but that Ma's loss is perhaps the most unusual; she completely forgot every word of Hindi and reverted back to speaking French, her mother tongue. In a manner that recalls the biblical story of Babel, she cannot even recognize other languages as languages, believing that everyone around her is grunting and making animal sounds. Animal, who refuses to call himself human, is the only character in the novel who can speak French, or as Ma Franci would have it, the language of humans. The novel's focus on a character whose body acts as an affront to physical descriptions of the human, but whose adept mastery of language signifies that which we have held up as most inherently human, further troubles systems of classification. I

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<sup>&</sup>lt;sup>47</sup> Although Animal speaks many different languages, he does not necessarily choose the most respectable terms. Animal swears profusely and his humour often alternates between sexual and scatological. His language is an issue brought up in the fictional Khaufpur Gazette ("Street kid Animal attends Man Booker shortlist party").

<sup>&</sup>lt;sup>48</sup> I also read the allusion to *Pride and Prejudice* as a means of foreshadowing the relationship that develops between Nisha's father, Somraj, and Elli Barber, who opens up a free clinic next to Somraj's house. While Somraj is actually critical of Zafar's decision to boycott the clinic because he believes that aid is essential, Elli believes that he is the chief organizer of the boycott. While Elli believes that Somraj intentionally begins to play ragas every time she plays the piano so that he can drown her out, Somraj believes that Elli, in turn, is attempting to drown out his music. Despite their poor first impressions of one another, the two end up falling in love. In some ways, Animal continues to tell a story very much like that of Jane Austen's novel after quoting the first sentence.

<sup>&</sup>lt;sup>49</sup> The recent work of disability studies scholar Ellen Samuels focuses on cultural representations of conjoinment, one of which is Animal's friend the Khã-in-the-Jar.

will explore the centrality of language and translation in the work in more detail later in this chapter, in an exploration of how the characters, in helping one another engage in prosthetic acts through both the literal act of helping one move forward and the symbolic act of carrying meaning across through translation.

Despite Animal's facility with languages and his gregarious personality, his body is often interpreted in and of itself by the various perspectives of characters in the novel that adhere to different religious and philosophical systems. Animal's body becomes a talking point for religious debates, in which he varyingly represents God's imperfection, abandonment, nonexistence, or promised deliverance. When Zafar tells his companions about how devout carpet weavers in Khorasan tie one knot the wrong colour to remind themselves that only the divine is capable of perfection, Faroug retorts, "Hark at Animal...god's knot in humanity" (123). While suggestions that karma will enrich his next life would seem a more favourable belief system, Animal counters, "Trouble with that way of looking at things is by the same logic my situation is the result of evil things I did in my past life, some people do look at me like they're wondering how many children I murdered last time around" (207). His comments voice how in some Indian contexts, as Pushpa Naidu Parekh explains, "disabilities, whether birth or acquired, low caste status, widowhood, as well as gender destiny are often conceived of as karmic payments for past sins, as trials and tribulations that one must bear in this life" (154). Animal is certainly critical of the western eyes that would interpret him, for religious reasons or otherwise, as a sign of suffering, but he is also critical of the stares that he receives in Khaufpur because of his very visible disability, and the assumptions that people make about his body and its significance in their interpretation of the world. Animal's criticisms of interpretations of his own body may temper the critical impulse to interpret his disability in traditional ways.

Animal becomes the object of interpretative gazes that are socially disabling in a way that encourages one to consider disability as more than an individual struggle, whether spiritual or otherwise. A parallel can be found in the novel's treatment of Khaufpur. Outsiders in the novel reduce Khaufpur to a place of unimaginable suffering, a place where people can only tell stories of "that night, always that fucking night" (5). However, for Animal and the others, Khaufpur remains valuable even as a toxic environment where garbage litters the street. The Urdu word Khaufpur translates to "city of terror," but the centre of the town is Paradise Alley (Nixon 456). While Farouq and Animal discuss what heaven might contain, Zafar, as an atheist, asserts, "hameen ast-o, hameen ast-o, hameen-ast," which Animal translates as "If there is a paradise on earth, it is this, it is this" (209). Zafar echoes the words of the thirteenth-century poet Amir Khusrau, whom Emperor Jahangir echoed upon viewing the Kashmir valley; his couplet is inscribed upon buildings throughout India (Blake 44). By ascribing these words to the visible reality, and the reality of an impoverished and polluted area like Khaufpur, Zafar emphasizes the urgency of the legal struggle for the company to clean its factory, urging his followers to focus on the life before them rather than thinking of the next one.

The struggles that Zafar leads are intimately connected to a need for medical care. Animal recounts how an American doctor opens a free clinic that the residents of Khaufpur are eager to visit. However, they refrain from visiting at the request of Zafar, who suspects that the clinic may be used to collect data that will support the company's defense. When Dr. Elli Barber arrives in Khaufpur, Animal takes up his role as *Jamispond* to investigate whether she has a connection to the company. When he first encounters Elli, he finds himself disassembled by her diagnostic gaze. Michel Foucault describes how within the space of the clinic, the medical gaze sees and knows truth, as medical experience, "is made up, as one entity, of those who unmask

and those before whom one unmasks" (110). When Animal describes his first meeting with Elli, he notes that her first words concern his back: "she steps back and's staring at me like she did the first time. 'Your back. How long's it been this way?'" (71). As a medical doctor, Elli assumes authority to call out abnormality, which frustrates Animal, who recalls, "You got angry because when you looked at her you thought sex, when she looked at you she thought cripple" (72 emphasis in the original). Animal resents how Elli focuses upon his deficiencies as she observes his body, unmasking its truth with the medical knowledge that she uses as an interpretive lens.

As Animal becomes closer to Elli to find out more about her, and also, unbeknownst to Zafar, because he is interested in the possibility that she will grant his dream to walk upright, he begins to see how she interprets other aspects of his life as well. When he overhears Elli talking to a government doctor about the state of the city, he similarly feels as though she has 'unmasked' Paradise Alley. He begins to see Khaufpur through her description of its faults:

Up to that moment this was Paradise Alley, the heart of the Nutcracker, a place I'd known all my life. When Elli says earthquake, suddenly I'm seeing it as she does...like drunks with arms round each others' necks, the houses of the Nutcracker lurch along this lane which, now that I look, isn't really a road, just a long gap left by change between dwellings. Everywhere's covered in shit and plastic. Truly I see how poor and disgusting are our lives" (106).

When Animal considers Elli's perspective, he begins to identify Khaufpur's symptoms of poverty, from its poor infrastructure to its pollution. While he initially feels debased by Elli, as he turns inward to name himself a cripple and to view the lives of the people in Khaufpur as disgusting, Animal later criticizes Elli for what she terms her show of respect, stating, "it's not

respect, is it? I can read feelings. People like you are fascinated by places like this'" (184).<sup>50</sup> Elli's charitable approach to medicine as a form of salvation and the charitable efforts of journalists both depend upon Animal's visible disability. Again, Barker's argument that representations of global trauma depend upon the docile body of the child to "emphasiz[e] its susceptibility to disablement in order to heighten the senses of humanitarian crisis and to insist on the urgency of western intervention..." is important here (11). While Sinha's novel does show how people living in areas of mass disablement *do* experience pain, it highlights how Animal's disabled body has been used to create a narrative of suffering in which his life can *only* signify endless injustice. The novel demonstrates the limitations of the postcolonial, spiritual, and medical gazes that zero in on Animal. *Animal's People* remains critical of exported solutions that promise to cure disability through surgical intervention, as it continually shifts its focus away from Animal's body and toward neo-colonial corporate practices.

I am going to shift my own focus away from Animal's body, in the section to follow. Although thus far I have focused on Animal, both because he is the protagonist and because I think his relationship to disability deserves lengthy consideration, in my next section, I examine Sinha's use of Animal's voice to represent the other characters in the fictional community of Khaufpur. While Animal often distances himself from experiences of pain by revelling in the different possibilities that his body affords him, like venturing into spaces without notice due to his height, or climbing tall trees to perform his duties as a spy, he often highlights how the people around him endure great physical and emotional pain. However, he also recounts how they support one another, and manage to offer care despite their lack of access to medical

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<sup>&</sup>lt;sup>50</sup> Kim notes that Elli's suggestions for ameliorating Khaufpur's environment by organizing people to pick up litter or bringing in new pipes and proper latrines reveal how she "fails to consider the larger systemic forces – such as overurbanization – that decimate Third World urban infrastructure, and instead views the garbage, open sewers, and toxic well as evidence of civic laziness and 'tolerance'" (para. 21).

treatment and supplies. I examine the novel's depiction of how the characters resist the promise of medical aid from Elli, and argue that the characters understand that in the political and institutional frame that includes the company as an actor, the physical reality of their pain can be manipulated and denied on paper. By representing how the residents of Khaufpur resist medical aid even when their disabilities cause them extreme pain, Sinha's novel imagines the limitations of charitable approaches to disability from the perspectives of those who would receive aid.

## 3. Disability and Difference in Khaufpur

As a narrator, Animal often questions whether concentrating on suffering is productive. As demonstrated in his interaction with the Australian journalist in the opening tape of the novel, he objects strongly to the pitiful gazes of those who would see his body as emblematic of the suffering of Khaufpur. But he does not deny that many of his fellow citizens live in pain. In response to Ma Franci's assertion that the apocalypse has come to Khaufpur, that terror will return to the city and the world will end, Animal tells his readers, "Fucking world didn't end. It's still suffering" (*Animal's People* 64). While Animal's impressions of Elli invite a critique of the normalizing gaze assumed by the medical profession, the text does not suggest that people in the community are without need of medical attention. This is true of disability studies as a discipline as well; while disability studies scholars emphasize that the medical profession is not capable of addressing the social and political issues that shape disability, the field does not position itself against all medical attempts to alleviate pain. Turning to scholarship and activism that critiques the discourse of dignity that circulates in discussions of physician-assisted suicide, and to many cultural beliefs that disability constitutes a burden on society, clarifies this position. In response

to those who would suggest that people deserve to die with dignity, disability scholars problematize understandings of the term dignity as it relates to health and wellness, and argue for the right of people with disabilities to receive the medical attention that they need to survive. <sup>51</sup> Metzl and Kirkland, in their collection *Against Health*, argue that one can take a critical stance toward definitions of human health without positioning oneself against attempts to alleviate human suffering; similarly, one can be critical of the concept of disability while encouraging attempts to alleviate disabling pain. <sup>52</sup> The novel presents a critical view of the form that medical aid can take, and the tense relationship between care and data collection, through its depiction of a boycott that the characters mount against Dr. Barber when she establishes her free clinic. Elli Barber, whose research has provided her with knowledge of the ailments that the characters face, is unprepared for the resistance that she meets. While she expects to find potential patients gathered at her door when her clinic opens instead, she finds herself facing Animal, whom she takes the liberty of approaching and examining as her first patient.

Zafar, a student who has travelled to Khaufpur to aid with the legal struggle, calls upon everyone to boycott Barber's clinic until they have confirmed whether or not the suspicions that she has been sent at the behest of the company are true. Animal explains that it is out of love, respect, and trust for Zafar that the citizens of Khaufpur support his boycott, even though medical attention is precisely what they have been struggling to receive for nearly twenty years. Elli does not understand why Zafar and his supporters decide to boycott her free clinic. When she hears that Zafar started the boycott to coincide with protests against the company's refusal to appear in court, she responds, "what the hell has this got to do with me?" to which Somraj

<sup>&</sup>lt;sup>51</sup> For example, see the editorial "There can be dignity in all states of life" by Catherine Frazee.

<sup>&</sup>lt;sup>52</sup> Vincanne Adams, in her essay on global health, explores how the concept of health becomes detached from individual people. She examines the differences between how health is understood in different cultural contexts, and whether health is determined based on the patient's outcome or the efficacy of the treatment (48-49).

replies, "Everything. It has everything to do with you" (*Animal's People* 159). Zafar's explanation to his followers suggests that Elli might be sent to manipulate data:

'You are the Kampani...Thousands more claim that your factory has poisoned their water and made them sick. To refute them you'll say that whatever may be in the wells, it does not come from the factory, that the chemicals in the factory don't cause those kinds of illnesses. To make such arguments, you need facts and figures. You need case histories, a health survey. Now do you see? Abracadabra-funtootallamish! Out of the blue appears an Amrikan to start a health laboratory.' (69)

Zafar and the other Khaufpuris who share his politics call Elli's hospital a laboratory, a term that suggests that the clinic may be an extension of the laboratory of Khaufpur itself, a city that has functioned as experimentation ground, with citizens serving as test subjects. While many citizens question Zafar's boycott because they recognize that free medical care would help alleviate their pain, the boycott proceeds successfully because the Khaufpuris recognize that the data that could be collected within the laboratory could be manipulated so as to absolve the company of its responsibility for 'that night' (7). While medical aid may benefit individuals temporarily, the health data could be devastating for the collective cause and for long-term health of individuals in the community who will need ongoing medical support.

The intersection of legal and medical issues in this novel offers insight into how we can recognize the painful embodied reality of many forms of disability, while remaining critical of the discursive manipulation of disability. The boycott that the citizens undertake demonstrates an awareness of the rhetorical nature of science and health; it challenges any claims that medical research is always benevolent and apolitical. As discussed earlier, Alaimo argues for a critical take on the priorities of medical research, as she explains that many chemical manufacturers are

so invested in absolving their own responsibility for their impact upon human health that they actively fund research to deny that MCS is a material illness (126). Her focus on how such denials cast individuals with MCS as irrational, as having 'complaints' as opposed to real symptoms, speaks to the concerns represented in the novel through the voice of Zafar and those who support him. A government doctor within the novel dismisses a woman's concerns that her breast milk is poisoned, insisting, "I can cure bodies, not fairytales" (107). Her comment highlights the vulnerability of Khaufpuris as their health concerns are subject to denial.

Eventually, the events of the novel do reveal that Elli does not work for the company, and that her efforts to help are well-intentioned and sincere. However, as Elli becomes more involved with Zafar's group to understand their motivations, and as she gains an understanding of the complexities of the legal situation, the novel does not suggest that the boycott was simply an example of unnecessary caution. Rather, the boycott illustrates the precarious situation of the disabled citizens of Khaufpur, who fear corporate denials of disability, and who trust Zafar's judgment when he urges them to exercise patience and restraint.

Support for the boycott of the health clinic, however, is not unanimous. Somraj, a former singer whose lungs have been damaged from chemical exposure, attempts to dissuade Zafar from his rigid stance toward the reception of care at Elli's clinic, arguing that people may die waiting for the company to be held accountable for its actions. Zafar is sympathetic to this risk, but he demonstrates how much he is willing to sacrifice for the cause when he and a few select followers attempt a hunger strike during the hottest period of the year, deciding to fast without water for expediency. Zafar's decision to draw attention to the cause in this way might be read in the context of Nixon's argument concerning how cultural amnesia attends slow catastrophe. Although Nixon does not specifically explore the hunger strike in his own work on *Animal's* 

*People*, this activist demonstration within the novel itself functions as a means of accelerating a process that is already ongoing in the community, so as to make it visible in a culture that associates violence with immediacy. The efforts of Zafar, Faroug, and the others who choose to fast for the cause are in some respects enacting a more expedient microcosm of the society at large, in which people are starved of the essential resources that they need to survive. They are cognisant of the ways that the spectacle of the body carries political weight, and they exert agency over that process of representation through their decision to engage in this form of protest. Perhaps the efforts to transcend the needs of the physical body that the protestors exhibit, and the discipline and restraint that the residents of Khaufpur show in staying away from the clinic in the name of politics, might appear as a celebration of the triumphs of the inner strength over the needs of the body. Animal, Elli, and Nisha are particularly critical of the way that Zafar chooses to draw attention to their cause, arguing that they need him as their leader and he should not risk his life by refusing food and water (290). Rather than celebrating the physical triumphs of the individuals who boycott the clinic, or suggesting that they are ill-informed for staying away, the novel illustrates the conflicted place of global aid efforts - even medical global aid efforts - when these efforts stem from countries that export their own risks and hazards to the Global South. When Zafar asks Elli who is funding her clinic, she is hesitant to answer, noting that the donor would prefer to remain unnamed (132). This immediately strikes Zafar and the others as suspicious, but Elli is not able to understand why the source of the funds that her clinic receives are of interest to the people that she wants to help, and why they are skeptical of a wealthy, benevolent doctor who wants to help them.

Elli's own story of why she entered into the medical profession is revealing, as she explains that her reason was to be able to help people like her parents. Her story reveals how her

mother's illness affected her father, and caused him to be violent toward her. However, when she relates this story, rather than blaming her father, she blames her mother's illness, explaining that her mother's illness can explain his violence:

My mother was ill with a sickness that affected her mind. There'd be times when she wouldn't know who she was, who we were. One day, on my mother's arm I found red marks, they could only have been made by a man's strong fingers. My father's. The realisation that he'd been momentarily cruel filled me with anger, but not against him. I was angry with my poor mother, whose illness had caused him to lose self-control, also I was angry with myself because I could do nothing to help either of them....I became a doctor to save not my mother, but my father. (*Animal's People* 202)

Elli's attribution of blame here is disturbing, but it speaks to how she understands illness as an enemy that she can arm herself with the tools to fight through her medical education. Elli is critical of the company, and blames them for the illnesses that the people in Khaufpur face. She tells Animal that she hates the company as much as they do in an effort to earn their sympathies. However, she is not able to understand why they would expect her to be secretly working for the company, even though she was once married to one of the company's lawyers. Although Elli herself does not work for the company, she hides her affiliation with her ex-husband, and her knowledge of his role in defending the company, from the community because she believes that they will not understand. Her frustration with the boycott leads to her calling out to the people in the Nutcracker, "HEY, ANIMAL'S PEOPLE! I DON'T FUCKING UNDERSTAND YOU!" (183). This moment, in which the novel's title is spoken, is significant because it complicates what might otherwise appear to be a portrayal of a white, able-bodied saviour entering the

community.<sup>53</sup> While Elli certainly has the tools and resources to be able to help Animal's people, she finds that she needs to engage on a political level to earn their trust and respect.

Elli's potential patients are numerous; as Animal introduces the characters in his tale, he relates how "that night" has affected them without talking about the events of "that night" directly. One of the characters closest to Animal is Aliya, a young girl who lives with her grandparents because her parents were killed on the evening of the gas leak. Animal likes her because she is cheeky, and lets her travel on his back. Aliya has a lung infection and a bad cough, and the grandparents with whom she lives find it extremely difficult not to go to Elli's free clinic. The threat of Aliya's death persists throughout the novel. Animal is at times resentful of his own disability because of the looks that people give him, but he also manages to celebrate his own bodily difference. In Aliya's case, the reality of painful disability becomes apparent. The distinction made here reflects the point that Tobin Siebers makes in *Disability Theory*, which is that even the same person may respond differently to deafness and cancer; there are some cases in which differences should be preserved (4). In my introduction, I explained how Erevelles critiques Garland-Thomson's statement in her landmark essay on feminist disability studies that we often think of disability as a tragedy when it is a normal, everyday experience. As Erevelles points out, this statement holds true in certain cultural contexts, but at times, the acquisition of a disability under particular circumstances can be traumatic (130). As Barker and Murray point out, in the case of mass disablement like the case of Bhopal, scholars may need to revise the frame. Perhaps we might want to consider, instead, that painful disability is a normal experience in this case, and that it should not be. This is a very difficult statement to consider because using certain bodies as examples of unnatural embodiments is objectifying and stigmatizing. Here,

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<sup>&</sup>lt;sup>53</sup> In a critique of the KONY 2012 video and the representation of postcolonial countries in popular culture, novelist Teju Cole suggests that uncritical approaches toward aid might be characterized as a White-Savior Industrial Complex (Cole).

criticisms of technological fixes for environmental issues are useful for thinking about the body as well. In my first chapter, I explain the concept of a technological fix as a technological solution for a social problem, and suggest that medicine often operates within discourse as a technological fix for the body. A disability studies approach shows how attending to the body in pain without examining the environmental conditions that produce that pain leads to the perpetuation of inaccessible, disabling spaces for everyone.

Before Elli's arrival and before the boycott, Animal shows how people create communal spaces in the absence of medical care. Social relations are by no means utopian, but the shared experience of disaster has strengthened bonds between community members in the face of attempts at division. Animal points to attempts to divide the community along religious lines, noting, "so many times the politicians have tried to stir trouble between the communities in Khaufpur. Always the Khaufpuris say, we have suffered together, we will not be divided" (302). Zafar and his group attempt to provide aid for individuals who have been severely affected by that night, providing financial assistance, as well as assistance with daily tasks. While western medicine would define Animal as severely disabled because he is unable to walk upright, he himself carries Aliya, the child, when she is out of breath. Another prominent disabled member of the community whose disability changes the way that he perceives the world is pandit Somraj, the former singer, who is unable to perform because the company's chemicals have affected his lungs.<sup>54</sup> When Animal accesses the internet for the first time, he finds many references to Somraj, who was known as 'The Voice of Khaufpur' (155). Animal explains that Somraj is a very serious man who only tells one joke:

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<sup>&</sup>lt;sup>54</sup> In contemporary India, people use the term "Pandit" as a respectful title for a talented musician (Oxford English Dictionary).

'Sa, Re, Ga, Ma, Pa, Dha, Ni, Sa, these are the notes which all recognise. Somraj says that for him the octave now runs Sa, Re, Ga, Ma, Khã, Si, Khã, Si.' ... Eyes, this is the pandit's joke, he tells it against himself. It's not meant to be funny, it's a way of spitting in the eye of fate, of saying fuck you to the world which so carelessly mangled his life. Of course this joke is wasted on you, dear Eyes, first because no one has ever mangled you, but chiefly because you don't speak our language. Khã and Si are not really notes in the scale, if you join them they make khaaňsi, which means 'cough'. What Somraj is saying is, every time I start to sing I begin coughing and can't stop. (155-156)

Animal's use of the term "mangled" to describe Somraj's state captures the violence and trauma surrounding his acquisition of a disability (156). He cannot bring himself to listen to his old records because he finds it too difficult to be reminded of things that he once could do, much in the same way that Animal finds it difficult to listen to Ma Franci describe the time in his life when he could walk. However, Somraj does not abandon his love of music, but realigns his focus to non-traditional music. Somraj is able to find music in frogs, bicycle pumps, taps, *bhutt bhutt* pigs, and other sounds that would ordinarily be labelled noise. Animal wonders if Somraj has "lost his noodle" for being able to hear music in ordinary things (49). I would argue that in the context of the novel, we might read the attention that Somraj, a careful listener, devotes to alternative forms of music as a model for political attention as well.

Somraj's characterization as a careful and constant listener exemplifies the attitude that Animal hopes to cultivate in his readers, an attitude that intentionally clashes with the corporate mentality that the novel critiques. Somraj appreciates the sounds that most people would characterize as noise, telling Animal that if you listen closely, there is music in everything (49). As Animal describes Somraj's unusual proclivity for sound, he explains: "Listen, listen, listen,

it's all he does all day and night" (77). For Somraj, croaking frogs and falling raindrops have a place on the musical scale (49). His attitude toward his surroundings is an expansive one that values ordinary things and small creatures that are often deemed insignificant. While Animal portrays Somraj's perspective as humorous, this ability to listen is one that he attempts to cultivate in his readers. The imperative 'listen' is one that Animal repeats throughout the novel, an expression that serves to reinforce the frame that Animal is recording his story for a journalist. Listening is the task that he sets out for his reader, as he proclaims, "[m]y job is to talk, yours is to listen. So now listen" (14). The imagery of Somraj's natural choir recalls the imagery that Animal uses to describe his own story, as he tells the Eyes on the page that, "words want to fly out from between my teeth like a flock of birds making a break for it," explaining, "[y]ou know that sudden clap of wings when they take off in a hurry, it's that sound, listen, clap, clap, clap, (12). With reference to one of Somraj's stories of a writer whose poetry dried up inside him until his ulcer began reciting verses, Animal calls his own tale, "a story sung by an ulcer" (12). As he hopes that his story will be able to effect change, he understands paying attention as a social duty, a duty that Somraj's unusual attention to the aesthetics of ordinary sounds usefully models.

The amalgamation of Somraj and Elli's worldviews that Animal articulates provides insight into the novel's indictment of negligence and denial as corporate crimes. While Somraj believes the world is made of music, Elli believes that it is made of promises; Somraj notes that perhaps these two things are not so different (204). Animal works through this comparison:

So I've explained that if Somraj is right, then it's obvious how a world made of such music is also a world of promises made by auto-rickshaws and blacksmiths, bees, rain and railway engines, for the squeaky bicycle of Gangu who pedals round the Nutcracker selling milk would not be heard if he did not keep his promise to be a milkman, there'd

be no rattle of truck exhausts if the drivers and their assistants who perch in the cabins with their feet out the windows weren't all keeping their promises and doing their jobs...

(250)

A society that manages to keep its promises, Animal concludes, is a world of reverberating ordinary music. Within this framework, the silence surrounding the factory represents a series of broken promises to the citizens of Khaufpur. Grey herons would sing notes of the scale, but they are often found dead near the factory. Animal, who often sleeps in the factory, advises his reader: "Listen, how quiet it's. No bird song. No hoppers in the grass. No bee hum. Insects can't survive here. Wonderful poisons the Kampani made, so good it's impossible to get rid of them" (29). Animal's portrait of the factory as an emblem of the silence of broken promises is a disturbing description, but also one that suggests how environmental impact upon human health and ability might be understood through a social lens as well. While the permeable relationship between humans and their environments might be understood through a scientific lens that would appear to give more explanatory authority to medical explanations of disability, images like that of the factory featured in Sinha's work connect bodily pain to a lack of accountability. Rather than drawing on tropes of fear by presenting Somraj as possessing a polluted body, the text shows how his disability allows him to come to generate meaning from a new aesthetic.

Animal offers other brief portraits of the citizens who surround him, and the survival strategies that they have adopted out of necessity in the wake of broken promises. The novel explores the tension between interpreting their experience of 'that night' as an inevitable tragedy or a preventable accident. One of these characters is Chunaram, the owner of the local chai shop, who attempts to earn money by facilitating Animal's encounter with the journalist. Chunaram is missing one finger because he charged people to watch him tear it off (3). Another portrait is that

of a man called I'm Alive, who earned his nickname for surviving so much while the rest of his loved ones perished. The presence of these and other characters in the novel who have been profoundly affected by the events of 'that night' suggest the uneasy way in which disability can signify proximity to death in these contexts. Yet at the same time, their portraits suggest that the exact problem that plagues Khaufpur is that people view their fate as inevitable, and become complacent. When Elli dines with a more senior doctor in Khaufpur, he urges her to move forward from 'that night' because of the inevitability of the loss of lives of the poor. He tells Elli that the poor people in Khaufpur were doomed from the outset because, "[i]f it had not been the factory it would have been cholera, TB, exhaustion, hunger" (153). As Elli recalls the memory of this dinner when she is with Animal, she remembers how the doctor told her that the moon appeared the colour of blood through the gas on that night, and laments, "I should have said, 'I am a doctor, I know about blood.' Instead I sat there drinking his whisky listening to him reduce the terror of dying people to a moon in a second rate poem" (153). Elli critiques a tragic reading of 'that night' that downplays any accountability. The criticisms that Animal and other characters in the novel level toward these depoliticized responses to the disaster highlight how death and the acquisition of disability are considered normal fates for certain populations, but not others. Although the character portraits in the novel associate disability and death, they also challenge the idea that such suffering should be viewed as inevitable, as they show how the disabling and often fatal conditions that the people of Khaufpur live in are processes of disablement.

Another character whose life has been affected by the events of "that night" in a disabling way is Ma Franci, who, as mentioned earlier, loses her ability to speak and understand any language but French. Ma Franci cannot recognize Hindi as a language; she hears everyone who is speaking Hindi making animal noises like grunts, and she cannot understand why the people

around her communicate in this way. Her story is in part an allusion to the story of the tower of Babel, which suggests that God created multiple languages to prevent those who had attempted to build a tower to the heavens from communicating with one another (Genesis 11:1-9). Although a priest visits Khaufpur to bring Ma Franci back to France so that she can rest after years of service, Ma Franci insists on staying because she believes that the apocalyptic events of the Book of Revelation from the Christian bible are beginning to occur (143). The home that she and Animal share is infested with scorpions, which will have a role to play in the Apokalis: 'Well, my little Animal, they'll still have their tails, only much longer, ten feet at least with a sting the size of a bull's horn, what they'll do is they'll go around stabbing people, the ones who've done evil to others.' (62) Ma Franci's prediction recalls the Book of Revelations, which notes that the "scorpions of the earth" will be given the power to strike "only those men which have not the seal of God in their foreheads" (Revelations 9: 304). Ma Franci's preoccupation with the apocalyptic is one way in which the novel foregrounds and reconfigures traditional understandings of tragedy. Ma Franci believes that the events that are occurring in Bhopal are a sign of the end of days, and the impending revelation of truth. Animal calls Ma Franci crazy because of her loss of language and her apocalyptic anticipation, but he notes that he himself has "mad times" (2). While critics have called Animal schizophrenic for hearing voices, Animal's own choice of epithet – "mad"- is very straightforward, and perhaps functions as a resignification in much the same way that "Animal" functions as a re-signification. He applies terms like "mad," and "crazy" to describe his and Ma Franci's experiences. 55 In recent years, the discipline of mad studies has emerged to challenge dominant medical ways of viewing

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<sup>&</sup>lt;sup>55</sup> Ato Quayson's *Aesthetic Nervousness* considers the representation of madness in postcolonial literature with reference to texts such as *Wide Sargasso Sea* by Jean Rhys, a novel that imagines the story of Bertha Mason from the novel *Jane Eyre* (38).

neurology. While I would not argue that Sinha is playing into this discourse specifically, Animal's unique perspective allows for privileged insight in this text.

In closing this section, I will return to Animal once more. Animal was diagnosed as schizophrenic in Heather Snell's study of humour in *Animal's People*, which was one of the first scholarly analyses of the novel (1). Sinha's characterization of Animal is in some ways based on his late friend Sunil Verma, an activist looking for justice for Bhopal. Sheila Jasanoff notes that Verma was receiving treatment for paranoid schizophrenia when he passed away (92). Some of Animal's internal experiences reflect those of Sunil, as described in Sinha's tribute to him. <sup>56</sup> In this tribute, Sinha recounts a time in which Sunil ran off to the jungle to live as a dog, in a similar respect to how Animal runs off to the jungle after an altercation with Nisha at the novel's climax. The tribute, written to the late Sunil, addresses the issue of psychological disabilities and social determinants of mental health. Sinha writes, "Dear Sunil, we tried to get help for you but although some 60, 000 gas survivors suffer from depression, bouts of panic, and other psychological afflictions, the government refuses to accept mental health problems as a consequence of the gas disaster" ("A tribute to Sunil"). Sinha urges the need for not only physical aid for gas survivors, but psychological support as well. His comments point toward a lack of accountability on the part of the government, and toward the problematic but pervasive belief that psychological disabilities are innate to the person and pathological.

## **Prosthetic Bodies and the Contingencies of Place**

The issue with which I would like to close is that of prosthetic relations, and Animal's refusal of surgery and the use of assistive devices. As I will discuss below, although Animal has the option of undergoing a corrective surgery to fix the curvature of his spine, he ultimately refuses and

<sup>&</sup>lt;sup>56</sup> Sinha's character's stature is an invention, and not based on the physique of Sunil.

decides that he will use the money that he would have used for an operation for another purpose. Although Animal decides not to undergo surgery, and thus decides not to use a wheelchair or crutches, I intend to argue that his story speaks to the concept of prosthetic as it has been conceptualized in disability studies by David Wills' Prosthesis and David Mitchell and Sharon Snyder's Narrative Prosthesis. Mitchell and Snyder outline how a disabled character can serve as a prosthetic to the narrative itself. Their theory outlines how disability acts like a crutch to support a narrative; often stories that include disabled characters are not actually about disability, but about how a character with a disability helps a non-disabled person to gain perspective. Mitchell and Snyder use the concept of the prosthetic from David Wills, who argues that language itself is prosthetic through an analysis centering on the body, and specifically on his father's wooden leg. Wills understands each body as prosthetic rather than self-contained, imperfect in its meaning in the way that language is also imperfect. Dolmage explains that Wills suggests that, "the very essential and natural disarticulation between the fragmentation and partiality of our body and our cognition and our idealization of an objective view and an objectively knowable world constantly interacts as we stumble for meaning (108). Looking at the etymology of translation as a carrying across, Wills explains:

In translation, what is carried across or transferred is borne by the body. But it doesn't just carry itself; it carries a self that is divided in its function – walking, carrying. Before it begins to carry anything external to itself it bears that effect of its own internal scission. Thus it is the otherness that the body must carry in order to move that begins – that a first-person adjective is now ready to bear it - this is our prosthesis" (13).

Prosthesis, in Wills, does not only refer to a specific assistive device, even though he returns to the image of his father's leg throughout the text; rather, it is a condition of human being itself. Wills explains that the connection between the body and language helps to explain the partiality of both, an original fragmentation that makes any task of translation naturally imperfect. Animal, at the end of the novel, opts against using any kind of assistive device like a wheelchair or crutches. He is not outfitted with a real prosthetic, and he also does not act as a crutch supporting a narrative about another character. However, I think considering the novel with respect to David Wills and his concept of the prosthetic is important because it denaturalizes language in such a way that challenges how we traditionally think about the meaning of disability in literature.

The novel ends with Animal's refusal of a medical cure for his disability. Disability studies scholars have identified many stereotypes surrounding representations of disability within narrative, including the erasure of disability occasioned by what David Mitchell and Sharon Snyder term "cure-or-kill endings" (169). Lennard Davis argues that the novel itself is a normalizing technology because "the novel form, that proliferator of ideology, is intricately connected with concepts of the norm..." (49). Despite Animal's rejection of sympathy, Elli's arrival inspires his interest in a surgical 'cure' that would allow him to walk upright. However, the perceptions and exclusions of others fuel Animal's desire for a cure, as he never accepts that his body is inherently flawed. He confides to the Eyes on the page, "sex was the only thing I could never forget, my second impossible wish. My first wish was to stand upright, but why did I want that if not because it led to the second" (76). Animal's attempts to manage his desires permeate the narrative, and sex becomes a means by which he hopes to assert the validity of his own body. When he dreams of being with Zafar's fiancé Nisha, he anticipates questions from his imagined readership: "In such dreams was my back straight? Did I stand upright? No and no. I was exactly as I am now, and it did not matter" (78). Animal will not repeat these dreams to anyone. He asks, "what would they do, laugh at me, pity me?" (78). For Animal, to tell his dream to another person would be to dismantle the persona that he has wilfully crafted. Animal's assurance that his body does not change in his fantasies of being with Nisha complicates what might otherwise appear as a simple desire to be cured or fixed by a doctor. Juxtaposing this passage with Animal's desire to walk upright shows how the perceptions of others have influenced Animal's own understanding of his body as flawed.

Concluding with Animal's refusal to accept a surgical cure, the novel shifts attention away from his corporeality and toward the built environment of Khaufpur. Rather than purchasing an operation, Animal affirms how his body grants him possibilities.<sup>57</sup>

See Eyes, I reckon that if I have this operation, I will be upright, true, but to walk I will need the help of sticks. I might have a wheelchair, but how far will that get me in the gullis of Khaufpur? Right now I can run and hop and carry kids on my back, I can climb hard trees, I've gone up mountains, roamed in jungles. Is life so bad? (366).

Within a medical model of disability, Animal's spine requires correction and an operation would ensure that this need is met. Ironically, the cure that the medical model proposes would create further disablement for Animal, preventing him from accessing familiar places. The inaccessibility of Khaufpur indicates how disablement is a process rather than a static condition; disability is not located within Animal's body, but imposed upon him. This is an aspect of the text that Kim emphasizes in her analysis as well, as she describes how Animal rejects a medical cure, a solution she characterizes as one that "narrowly frames and 'diagnoses' the violence of

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<sup>&</sup>lt;sup>57</sup> One might read Animal as fulfilling the stereotype of the supercrip because of his abilities. He also possesses an enormous facility with language, perhaps an example of overcompensation. However, while supercrip narratives tend to erase the social aspects of disability by positioning it as an individual struggle, *Animal's People* turns outward to focus upon the disabling impacts of attitudes, environments, and unsustainable corporate practices.
<sup>58</sup> The focus on how the environment of Khaufpur would be inaccessible to a wheelchair user is one way that Animal's refusal might be seen as different from other refusals to use a wheelchair, such as Ramón Sampedro's refusal, as represented in the film *The Sea Inside*, which captures his real life struggle for the right to physician-assisted suicide. While others may refuse to use a wheelchair because of its stigma as an assistive technology, Animal refuses to use it because it would not be remotely assistive in the inaccessible space in which he lives.

neoliberalism (Kim). Animal's acceptance of the shape his own body has taken, however, does not signify a passive acceptance of the situation in Khaufpur; in embracing his shape, he does not absolve those who influenced it. At the end of the novel, he insists, "All things pass, but the poor remain. We are the people of the Apokalis. Tomorrow there will be more of us" (366). Unlike many other novels that resolve the problem of disability through either curing or killing the disabled character, Sinha's novel escapes tidy resolution, insisting that the story is not over.

While the novel presents western medicine as in part a technology of normalization through its representation of Elli's process of seeing and diagnosing, and Animal's subsequent critique of her gaze, Animal's People also exhibits a certain self-consciousness surrounding how the novel form itself has often been linked to normalization on accounts of its presentation of a contained story and its structural movement toward resolution. Literary critic Pieter Vermeulen, in a discussion of novels of globalization, suggests that Foucault's concept of biopower and the novel genre have certain affinities (384). As the biopolitical norms that Foucault outlines are not designed to distinguish between "the permitted and the prohibited, but rather to draw as many identities and phenomena into the domain of the calculable and the accountable," Vermeulen outlines, so the novel as a form brings both the normal and abnormal into its domain (388). He explains that "the novel's intensified penetration of the everyday, in other words, is complicit with biopower's colonization of life through norms" (389). For Davis, this colonization and normalization is part of what makes the novel form such a hostile one toward disability, and potentially also what would make it appear inimical to the intrinsic partiality of bodies and languages that Wills would have us recognize. And yet, Vermeulen suggests these entwined histories of normalization can be a subject of exploration for novels of globalization, as they

experiment with form to show the workings power that come across as mere management.<sup>59</sup> Animal's People may be bound in the form of a novel, but it also allows for such explorations.

In addition to references to the book's readers as Eyes who are physically reading the pages, and to the market forces that the journalist in the opening pages represents, the book also references the difficulty of attributing agency to neoliberal forces, and the companies that help shape them. Sinha's text explores the challenges associated with achieving clear justice in a globalized world through a dream from Zafar. During his fasting, Zafar has a dream in which a passing crow offers him three wishes, all of which are deemed impossible. The crow scoffs at Zafar's first wish that natural justice should prevail, asking, "If justice were simple what need for fancy dress? Why do they charge so much?" and similarly refuses to make this first wish possible by making the impossible possible (228). However, the inability to attribute a clear antagonist to the issues facing Khaufpur - and, by implication, other regions like Bhopal that have been affected in similar ways – becomes clear when Zafar asks, as his final wish, to see the face of the Kampani. Instead, Zafar sees a fictional headquarters of the Kampani, with various floors depicting its many operations. While one floor is "devoted to living things waiting in cages to be killed" another features chemists bearing slogans like "SHAKE HANDS WITH THE FUTURE and NOBODY CARES MORE" (229). Instead of an individual's face, Zafar sees an ongoing Kampani party, with "generals and judges, senators, president and prime ministers, oil sheiks, newspaper owners, movie stars, police chiefs, mafia dons, members of obscure royal families etcetera etcetera" (229). The ongoing list here, including everyone from the movie stars known to champion charitable causes to the police chiefs tasked with protecting the public, reveals the difficulty of achieving meaningful justice, as everyone is implicated in the system

<sup>&</sup>lt;sup>59</sup> Vermeulen's own example is David Mitchell's novel *Ghostwritten*.

that Zafar wants to dismantle. Rather than portraying a clear antagonist, the novel surveys the distributed networks that contribute to the ongoing exploitation of Khaufpur.

As well, Sinha's extension of his text to the online realm shows how a novel's form can serve other functions besides a normalizing one. Sinha's website, functioning as a prosthetic to the novel itself, is a fictional tourist site for Khaufpur that offers select links to the ongoing struggle for justice in Bhopal. 60 Fictional interviews with Animal include his complaints that Sinha has received credit for his story, complaints that Snell argues, "serve as a playful reminder of the very material, and often exploitative, relations of production through which an oral tale may be turned into a book without crediting the original author of the tale" (3). By maintaining Animal's voice, Sinha makes visible his own role in speaking for the disabled residents of Bhopal as a writer who has not been disabled by the Bhopal Disaster; he paradoxically maintains a fiction to expose his own fiction and highlight the material realities of Bhopal. Animal's fictional responses to the author's success are humorous and self-deprecating on Sinha's part, but they also demonstrate a self-consciousness of speaking for a survivor, and perhaps, when we consider Sinha's tribute to Sunil again, a recognition that he is in many ways taking up Sunil's story, and attempting to 'speak with' in what he acknowledges is a necessarily imperfect way. In addition to maintaining this website, Sinha has continued to write about Bhopal in the form of editorials and news stories. Although Animal's People is a story that exists within the confines of the novel form, a form that has been linked to normalization, its conclusion remains open.

Sinha's fictional representation of the aftermath of disaster complicates the question of how we can welcome the disability to come, as it reminds us that the disaster is ongoing - not an event but a lived, everyday reality, and one sustained by larger networks of power than Animal,

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<sup>&</sup>lt;sup>60</sup> When I first commenced writing this dissertation in 2013, Sinha's website was offline and I accessed material through the Wayback Machine archive. The website is now active once more.

Zafar, and the others Khaufpuris are capable of tackling alone. Like Burning Vision, the novel suggests the urgent need for a recalibration of the timeline of disaster symbolized by western metrics like the Doomsday Clock. We can think here of the concept of apocalypse and its relationship to meaning. The Oxford English Dictionary defines "apocalypse" as both the final destruction of the world and as an event involving destruction on a massive scale, and notes that the term originates from the Greek apokalupsis, from apokaluptein, which means to uncover or reveal (OED "apocalypse"). In "No Apocalypse, Not Now," Jacques Derrida reminds us that apocalypse means the revelation of truth, or unveiling (24). Readers might be tempted, like Elli's doctor friend, to view Khaufpur as a tragedy, to see the blood in the moon and think of revelations. But the novel insists that at the end, Animal and the people of Khaufpur are still the people of the Apokalis. While Nixon notes the significance of the continual apocalypse for reinterpreting disaster, some of the theological contexts of "apocalypse" suggest the message that the text offers with respect to disability. Sinha's novel works within a number of traditions that we can name, with respect to the religious identifications of his characters, as Islam, Hinduism, and Christianity. While Animal does not subscribe to any of these religions, the interpretive lens of each is featured in the novel. <sup>61</sup> While the idea of the apocalypse is often associated with the revelation of truth and transcendence into a new realm, the novel's apocalypse defies the concept of an end that the term apocalypse would seem to signify.

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<sup>&</sup>lt;sup>62</sup> While Ma Franci's interpretation of the apocalypse borrows from the imagery found in the Book of Revelations, the novel also engages with other traditions as well. In Hinduism, the final age of the four cycles of time is Kali Yuga, or the Kali Age (Patton 811). Animal tells the reader that on the factory grounds, he sees "mother Kali stalking in the forest below, her skin black as a roasted corpse" (32). When he begins to flee to the jungle, he envisions Ma as Kali:

Garlanded with bones she'll stalk the streets of Khaufpur crying the end of the world, with great strides she'll come to the factory to rouse the hungry and desperate spirits that live there, then the soldiers will shoot her. Fools, they cannot kill Ma. Ma is the beginning of time. Ma will unstring their guts and hang their severed heads on her belt. (333)

Animal's use of Apokalis instead of the English apocalypse would also seem to allude to the time of Kali Yuga.

Animal's recognition of the possibilities that his body affords him suggest that critiques of disabling processes might take an alternative approach to using disabled bodies to tell a single story of suffering or tragedy. The novel shows how the term 'disability' should not define how closely bodies visibly conform or deviate from definitions of the normal body. Rather, to reiterate, barriers to access, such as inadequate medical care, toxic environments, and social attitudes create disability. New paradigms of accessibility need to attend to how, as Alaimo argues, "materiality, at a less perceptible level – that of pharmaceuticals, xenobiotic chemicals, air pollution, etc. – affects human health and ability" (12). If we attend to how human influences upon the environment adversely affect human health, perhaps welcoming the disability to come can involve recognizing our inherent vulnerability as the environments that we are shaping are becoming less accessible for everyone. Sinha's narrative representation of the ongoing disabling impact of the chemical disaster in Bhopal points toward a new challenge for developing an accessible, global environment, an accessibility that would involve a drastic revision of global environmental, political, and economic practices. While medical attention and environmental support is needed, situations like Bhopal suggest that a technological fix or individual intervention will not be enough. Structural change is needed, and systemic issues of exploitation must be addressed before meaningful change can take place; 'fixing' characters like Animal through surgery is not enough because the problem of the text is not disability.

Animal's People is a significant novel for drawing attention to the intersections amongst postcolonial studies, disability studies, and the environmental humanities. Other scholars have discussed the novel in this regard, and my own analysis extends their concerns while suggesting how the novel speaks to the imperfections of meaning and ties questions of empathy, language, and literacy to disability studies. The next section of my dissertation considers possibilities for

exploring intersections and tensions between disability studies and the environmental humanities in cases where individuals with disabilities are understandably critical of easy associations between their disabilities and the environment. I draw on existing research concerning the more insidious connections amongst disability, environmentalism, and eugenics to examine the circulation of theories surrounding a global autism epidemic, and I show how efforts at knowledge translation link autism and environmental degradation in a problematic way. Drawing on Ray's work on the ecological other, I will suggest that throughout the history of autism as a condition, many different societies have positioned autistic people as ecological others, as people whose bodies demonstrate the detrimental effects of the world that we live in. I will then turn to the writings of autistic people to examine how their interrogation of an illness model of autism and promotion of diversity should affect the way that scholars consider the relationship between autism and environmentalism. Specifically, I turn to documentary, poetry, autobiography, and fiction, and the important critiques that these writers offer of the way that we think about the rhetorical nature of language, and their challenges to the assumptions of readers and clinicians who suggest that autistic writing is disabled for its lack of metaphors and its lack of empathetic feeling. In putting into dialogue activists and writers who are critical of the lack of attention toward the relationship between nature and embodiment versus those who are critical that there is not enough recognition of environmental influences of disability, I look at the rhetorical nature of scientific research, and how the similarities between belief in the technological fix and 'cureist' thinking are useful for articulating a disability studies perspective to environmental accessibility that resists a turn to the medical model of disability for explanatory authority.

## **Chapter Three**

Documenting Global Connections: Autistic Self Advocacy and its Reframing of Awareness

Discourse

## 1. Addressing an Epidemic of Autism Discourse

On December 18, 2007, acknowledging the importance of efforts to increase global public knowledge of autism, the United Nations General Assembly adopted a resolution to celebrate World Autism Awareness Day every year on April 2, beginning in 2008. The text of the official resolution notes that the General Assembly is "deeply concerned by the prevalence and high rate of autism in children in all regions of the world" and its resultant impact on "long-term health care, education, training, and intervention programmes undertaken by Governments, nongovernmental organizations and the private sector, as well as its tremendous impact on children, their families, communities and society" (U.N. General Assembly). Over the past eight years, U.N. Secretary-General Ban Ki-Moon has issued an official message for Autism Awareness Day, and the tone of the message has shifted over time to reflect a message of inclusion, as opposed to prevention. While Ki-Moon's Message for 2011 frames autism through the language of deficit, noting that, "autism is a complex disorder... in many cases the right treatment early on can bring improvements," ("Secretary-General's Message for 2011") the message for 2016 calls, "for advancing the rights of individuals with autism and ensuring their full participation and inclusion as valued members of our diverse human family who can contribute to a future of dignity and opportunity for all" (Message for 2016). Comparing the U.N. official statements on autism awareness from year to year shows an increasing movement toward recognition of autism as neurological difference, as opposed to deficit, as well as an important shift from advocating prevention research to championing the significance of meaningful inclusion. This change not

only reflects evolving scientific understandings of autism, but is also informed by the perspectives of many autistic advocates and their supporters.<sup>62</sup>

However, despite growing recognition of autism as neurological difference, many organizations, institutions, and journalists continue to discuss autism as a global crisis, in which the individuals themselves are the greatest problem. Additionally, even as the accomplishments of some autistic people are celebrated by mainstream western media, other autistic people are still viewed through the deficit paradigm if they depend upon significant support to live their daily lives. Much of the global public discourse surrounding autism perpetuates the idea of autism as a risk as opposed to a meaningful form of difference, deploying statistics to show how many children autism affects and suggesting which populations are particularly susceptible. Continual references to rising diagnoses often suggest that autism is a health crisis, when the crisis could also be framed as a lack of accommodations, services, employment opportunities, housing options, access to healthcare, and access to communication supports. Ari Ne'eman, founder of the Autistic Self Advocacy Network, and Alicia Broderick clarify that autistic people may not have any health problems. 63 They argue that positioning autism as a crisis of health, "draws upon a medicalized discourse in which people who have labels of autism are constituted not as neurologically different, nor even as disabled, but rather as diseased, not healthy, or as ill"

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<sup>&</sup>lt;sup>62</sup> Some people prefer the terms "autistic person" and "autistic" while others prefer "person with autism". Stuart Murray, in *Autism*, explains that those who prefer "person with autism" appreciate the person-first language associated with the removal of stigma that serves to emphasize that autism does not define the person as a whole. However, some people prefer the term "autistic person" because it emphasizes that autism is an aspect of a person's identity, as opposed to a condition that can be cured (Murray XIV). I predominantly use "autistic people" or "autistic person" to reflect activist preferences unless I am specifically referring to an individual who prefers "person with autism" or uses it interchangeably with "autistic person".

<sup>&</sup>lt;sup>63</sup> Of course, some autistic people do have severe health challenges, which are often referred to as co-morbid conditions. Additionally, many autistic people face discrimination in accessing and receiving medical care, including access to life-saving procedures like organ transplantation. However, in differentiating autism from a health issue, Broderick and Ne'eman clarify that autism is not a disease, or a terminal condition that presents an immediate, life-threatening risk to the autistic individual. That said, many autistic people tragically live shorter lives than the average person, which I will discuss later in this chapter (Autistica).

(468). Characterizing autism as a disease suggests the need for its eradication, and creates the perception that individuals can recover when autism is a lifelong experience.

Additionally, Global organizations and media now frequently refer to rising rates of autism as an emergency, and as an epidemic. A Jerusalem Centre called ICare4Autism noted in its mission statement in 2012 that, "the number of children diagnosed with autism is growing by epidemic proportions. A new case is diagnosed every 18 minutes...." ("Our Mission").<sup>64</sup>
Similarly, after the U.S. Centers for Disease Control and Prevention (CDC) released their 2012 estimate that 1 in 88 children and 1 in 54 boys are diagnosed as autistic, the American organization Autism Speaks called for "a new, coordinated strategy to take on a national public health emergency – the autism epidemic" ("Autism Speaks Demands an Urgent, New Response").<sup>65</sup> Along with its stated objective of supporting individuals and families, in 2016 organization remains "dedicated to funding global biomedical research into the causes, prevention, treatments, and a possible cure for autism" ("Mission").<sup>66</sup> While increased research on an international level may demonstrate rising awareness and prioritization, research efforts singularly directed toward normalizing behaviour and discovering a cure presuppose the

<sup>&</sup>lt;sup>64</sup> While ICare4Autism's web materials foster a sense of urgency surrounding autism as an imminent health challenge, the organization has featured autistic voices at their annual conferences. Ari Ne'eman, the president of the Autistic Self Advocacy Network, was a guest speaker at their conference in 2014 ("2014 ICare4Autism International Conference").

<sup>&</sup>lt;sup>65</sup> Throughout this chapter, I discuss how activists have critiqued Autism Speaks and offer my own criticisms of the limitations of its practices. My critique is not necessarily directed at Autism Speaks supporters, who may come to the organization with very limited prior knowledge of autism. On this topic, I adopt a similar perspective to that of autistic self-activist Amy Sequenzia, who explains that she believes that many people who support Autism Speaks, from families to celebrities, likely do not know the organization's mandate. She writes:

Autism Speaks is a powerful organization, with support of many celebrities and easy media access. I believe that most of the celebrities that help making [sic] Autism Speaks so recognizable don't have an understanding of what autism is. They probably want to help and buy into the picture of despair spread by Autism Speaks. The same is true for the thousands of people going to "autism walks" and donating money to Autism Speaks. (Sequenzia)

Like Sequeniza, my critique is not of individual supporters, but of an organization that repeatedly offends and silences those whom it claims to represent.

<sup>&</sup>lt;sup>66</sup> Although part of the organization's mandate is to help autistic people, critics point out that Autism Speaks only devotes a small portion of their budget to helping individuals and families, directing the majority of their funds to scientific research ("Before you donate...").

undesirability of autism even as the global community is still learning about autism, and even as autistic activists are voicing their beliefs that they do not need a cure.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines autism through a series of deficits in communication and social interaction ("Autism Spectrum Disorder"). The crisis surrounding autism may be one of communication, but in this chapter, I argue that an analysis of creative work by autistic adults, and specifically the films "In My Language" (2007) and Wretches & Jabberers (2010), suggests that ameliorating the position of autistic people worldwide necessitates modifying the discourse surrounding, and approaches toward, communication. Disability studies theorists Snyder and Mitchell, who examine the cultural sites of disability to deconstruct normative positions, offer a paradigm that moves away from pathology to examine how cultural environments shape definitions of disability. They explain that, "disability functions not as an identification of abnormality but rather as a tool of cultural diagnosis" (12). A model they define as the 'cultural model' of disability, "provides a way of understanding how formulas of abnormality develop and serve to discount entire populations as biologically inferior" (12). Similarly, proponents of neurological diversity contend that societies construct neurological inferiority. Neurodiversity is, according to Ne'eman, "the idea that the paradigm of acceptance extended toward racial, religious and other similar differences should apply to neurology as well" (Qtd. in Broderick and Ne'eman 470). As Ne'eman and others have shown, the terms 'epidemic' and 'crisis' and the statistics used to measure autistic people against a normative position suggest that the cognitive processes and communication methods of autistic people are inferior to what society considers normal.

In this chapter, I draw upon disability studies, postcolonial theory, and posthumanist theory, as these areas of study complicate the relationship between language and subjectivity,

and so provide a framework for recognizing non-traditional forms of communication that the neurodiversity model calls upon society to acknowledge. Disability studies theory, the paradigm of neurodiversity, and the creative work of autistic activists all offer possibilities for recognizing and de-pathologizing the ways that people communicate through movement, repetition, and typing. Viewing autistic behaviours as forms of communication does not necessarily undermine the difficulties that autistic people do face as they communicate with others, but rather shows how, "living in a society designed for non-autistic people contributes to, and exacerbates, many of the daily living challenges that autistic people experience" (Robertson). In other words, the onus for effective communication should not only rest on autistic people, but on society as a whole. In this chapter, I specifically argue for the importance of considering how the rhetorical nature of scientific knowledge affects research into autism and perceptions about autistic people.

In the next section of the chapter, I start with a very brief history of how autism has been understood, as it has changed in popular and medical understanding from a disorder of psychological development to a neurodevelopmental condition. This shift has helped to dispel many assumptions, but it has also generated a practice of knowledge translation that has created its own myths, which I will discuss. After recounting this history, I will turn to the current moment of a confrontation between the notion that we are experiencing a global autism crisis and the increasing appreciation of and respect for autistic difference as it flourishes under threat. This will involve an examination of the risk discourse surrounding the prevalence of autism, and how autism itself is framed as a problem on a biological level. In my second section, I consider how autistic communication has been discounted, and how disability studies and posthumanist theory offer insight into new ways of reframing the challenges associated with autism. To do so, I examine the performance piece "In My Language" by popular activist Mel Baggs. In my third

section, I offer a close analysis of *Wretches & Jabberers* (2010), a film that I argue reframes the challenges surrounding autism, emphasizes the importance of recognizing alliances across cultures, and offers insight into communication as interdependent and relational - an important consideration when one considers how the *DSM* discounts autistic communication as inferior. Finally, I compare the global connections forged in this film to the global strategies of charitable organizations, offer a critique of the exceptionalism surrounding western attitudes about disability present in some attempts at global coalition, and discuss emerging alternatives. I conclude that autism awareness discourse has capitalized on the use of the terms risk, crisis, threat, and intervention with respect to autistic children in order to draw attention to the immediate needs of autistic adults. However, this has in many cases led to what Nixon would call a social 'amnesia' about the particular needs of autistic adults.

The argument that we need to challenge perceptions about autism and intelligence may already be familiar to audiences who have encountered stories of well known autistic individuals, from animal scientist Temple Grandin to mathematician Daniel Tammet, who are often referred to as geniuses. In a recent article, disability studies scholar Marion Quirici makes the important point that while autistic people often face assumptions about the limited nature of their communication, they also often face stereotypes concerning savantism and genius. Arguing that disability studies has not begun to engage with the stigma of genius, she suggests that, "to call on the possibility of genius as a means of redeeming autism in the public eye is to measure

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<sup>&</sup>lt;sup>67</sup> Quirici's argument has some similarities with Andrew Elfenbein's argument in *Romantic Genius: The Prehistory* of a Homosexual Role. Elfenbein argues that same-sex desire has been linked to genius, focusing his own attention on how the connection between these two terms functioned in the Romantic period. Elfenbein acknowledges that the link between sexuality and genius has "a dark side," as it encourages the "continued pathologizing of homosexuality as disease, madness, or disorder" (4). In other words, "the popular association between genius and homosexuality provides one point of containment by giving genius's deviance a name" (6). Quirici calls on disability studies to reclaim the positive aspects of the term 'genius' by reframing it to emphasize creativity and hard work, as opposed to innate ability. Elfenbein's own claim that genius, as it is often framed, tends to "reinforce[e] a myth of individualism" suggests similarities between their projects (6). Many thanks to Tommy Mayberry for suggesting to me that Elfenbein's scholarship could be useful for providing a discussion of autism, disability, and genius.

their potentially superior abilities" (72). Quirici also notes that the particular framing of autistic people as geniuses tends to stress their strengths in the fields of science, technology, engineering, and mathematics (STEM) fields; when creative pieces by autistic artists do enter public discussion, it is often through a lens of pathology (72). Quirici's argument helps to clarify the position that I am working toward, as I argue that the films that I discuss do not just call upon viewers to recognize autistic people as intelligent, but to question definitions of communication, intelligence, and subjectivity more broadly.<sup>68</sup> In other words, while it is fair to celebrate how the artists discussed here were able to make and disseminate their films in a social environment that is often hostile to difference, their rhetorical message that viewers need to extend respect to all autistic people, regardless of the ways in which they aid a neurotypical majority, is pivotal. In this chapter, I follow Quirici's example by examining the creative production of autistic adults through literary and rhetorical studies, as opposed to through a psychological analysis of what the films themselves reveal about the various deficits and abilities of the individuals portrayed.

Although my discussion of disability and neurological difference in this section differs in many ways from the questions surrounding physical disability and illness that I introduced in my first two chapters, the texts that I discuss in this section undertake similar cultural work. The work that the writers that I discuss undertake concerns how to conceptualize and discuss risk so that individuals who are disabled or ill are not presented as risks to a larger, non-disabled and healthy population, but are understood to be facing risks themselves. While the first section of my dissertation looked at risks to human well being at the level of the body from a disability studies perspective, this section looks at the implications of classifying particular bodies and

<sup>&</sup>lt;sup>68</sup> Her work aptly captures a greater need for an interrogation of how both ableism and disablism influence social perceptions of autism. I will discuss the distinction between ableism and disablism in Chapter Four.

minds as unnatural. With that in mind, it bears repeating that the main question my dissertation explores concerns how we can examine environmental factors that contribute to human health and ability from a disability studies perspective without returning to the dominant model of disability as pathology that the discipline has worked to critique. Answering this question means bridging conversations from different disability communities across different cultures, which means examining disability advocacy that has focused on the need for greater recognition of the relationship between environments and causation, as well as disability advocacy that points to environmental causation discourse as unscientific, ableist and dismissive.<sup>69</sup>

As explored in my previous chapters, a consideration of what we can call 'critical ecologies of embodiment' allows us to critique disabling environments that affect human health while acknowledging the rhetorical nature of scientific research. By critical ecologies of embodiment, I mean an examination of environmental factors that contribute to disabling experiences. While buildings, campuses, and cities are frequent culprits for creating disabling spaces, the discipline can also create space to consider how environmental policies and the outsourcing of environmental risk create disabling conditions too. The reason why this question is difficult, however, is not only that individual disabilities are different from one another, but that people have different relationships to disability and identity. One of the avenues that allows for a nuanced consideration of the relationship between disability and environments while acknowledging these difficulties is thinking about critiques of technological fixes for environmental and social problems that can apply to disability as well. <sup>70</sup> In other words, while

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<sup>&</sup>lt;sup>69</sup> I discuss this topic in more detail in Chapter Four, when I examine how autistic people have been represented as ecological others, with the resultant consequence that many children in particular have been subjected to violent treatments and 'cures' that are said to relieve the presence of toxins.

<sup>&</sup>lt;sup>70</sup> Writers in the environmental humanities have been critical of representations that present purely technological solutions to environmental issues. For example, David Ingram, who examines the representation of environmental disaster in Hollywood cinema, argues that, "the technological fix provides an apolitical solution to environmental problems, and in this sense endorses the values of mainstream environmentalism" (125). Writers in disability

individuals may have varying interests in the development of medical technologies based on their own disabilities and the disability communities in which they circulate, increased technology alone will not address disabling conditions as they relate to social inequality pertaining to disability, but also as they relate to intersecting identity positions.

The idea that what disabled people need most is medical attention is one that the texts that I have looked at thus far complicate. Burning Vision, by Marie Clements, is a text that emphasizes the dangers of technological development without regard to risk; however, the emphasis of the work is not on the pursuit of medical cures, but on a measure of respect toward human beings and their environments that would ensure that some people are not disproportionately exposed to risk. Similarly, in *Animal's People*, while medical aid is crucial for the fictional community of Khaufpur, even purveyors of aid need to recognize that health, as it has been traditionally defined in the west, is not an apolitical concept; science and medicine can have rhetorical dimensions too. The texts that I have looked at so far are not characterized by luddism, but are rather marked by a turn toward social justice issues and a recognition that greater technology will not result in fewer disabling environments because the allocation of resources is uneven. Similarly, the work that I undertake in this section of my dissertation acknowledges the usefulness of scientific research about autism in dispelling normative assumptions, while also pulling open the curtain of objectivity that often surrounds scientific practice. In this section of my dissertation, I complicate and expand upon my earlier argument by looking at cases in which an increased focus on environmental causation is not always consistent with the expressed needs of disability activists.

studies similarly embrace the possibilities of technology while recognizing that disability is not a medical problem that needs to be solved, but a social and political issue. Disability studies scholar Kathryn Allan explores representations of the use of technology to fix the body in science fiction, suggesting that a common trope in the genre is the erasure of disability through use of a medical cure (9). I take up these issues again in my next chapter.

## 2. A Brief History of Autism Research and Advocacy

One of the most prominent symbols associated with autism is a puzzle piece. The logo of Autism Speaks, a U.S. based autism charity with powerful global reach, is a blue puzzle piece. Many autistic people object to the idea that autism is like a puzzle with a missing piece that needs to be found in order to solve the mystery of autism or unlock an individual child.<sup>71</sup> For many, the puzzle piece calls up the belief that autistic people need to be cured, as finishing the puzzle symbolizes a return to a normative neurology and a whole self. I am going to engage with and trouble this idea of autism as a departure from a normative self, but for now I would like to suggest a different focus – not on autistic people as puzzling, but on the very confusing history of autism as a condition, and the many assumptions that have attended research about autism.<sup>72</sup> Diagnoses of autism began in the mid twentieth century, when two researchers working separately both identified autism in the early 1940s through studies of groups of children. Leo Kanner, a child psychiatrist in the United States, and Hans Asperger, a pediatrician in Germany, independently identified a disorder that they both described with reference to the term "autistic" (Autism 46-50). 73 Kanner observed that his subjects did not possess intellectual delays, but rather seemed to avoid affective content, and so concluded that his subjects were characterized by "extreme autistic aloneness" (qtd. in Autism 48). Similarly, Asperger noted impairments in social interaction in the children that he observed, but he also noted that they had obsessive tendencies and possessed strong linguistic abilities (50). In a recent history of autism written from a neurodiversity perspective, Steve Silberman discusses how, in contrast to Kanner, Asperger's

<sup>&</sup>lt;sup>71</sup> An instructive piece on this topic that reverses this logic is "Unlocking my Self" by Estée Klar.

<sup>&</sup>lt;sup>72</sup> For a fuller account of the history of autism, please see Stuart Murray's *Autism* and Steve Silberman's *Neuro Tribes*. My own account of this history is very much indebted to these works.

73 Murray points out that there is some debate as to which researcher named the condition first (50).

approach to autism was progressive, as he believed that the best way to 'treat' autism was through education that was tailored to the needs of individual children (129).

Psychoanalyst Bruno Bettelheim, building on the criteria for diagnosis established by Kanner and Asperger, proceeded to treat children diagnosed with autism in the 1960s. Kanner had coined the term 'refrigerator mother' in his research to describe the cold behaviour of the parents that he had observed during his studies. Bettelheim similarly believed that parental behaviour caused autism; he suggested that autistic behaviour arose when a child's cold and distant parent withheld affection. Bettelheim believed that the best results could be achieved by separating the parent and child, so that the child could receive more nurturing care. Murray suggests that biographers have traced his theory to his own experience of trauma as the survivor of a concentration camp during the Second World War (Autism 56). He notes that Bettelheim's mistaken assumptions and unethical treatments shaped understandings of autism and approaches toward research in the years to follow. The figure of the "refrigerator mother" is central to rhetorical theorist Jordynn Jack's work on autism, gender, and rhetoric, as she points to this haunting character's legacy as one that contemporary parents must still navigate as accusations of blame circulate. 74 Another unfortunate legacy of Bettelheim's claims is the idea that autism can somehow be cured through behaviour, a belief that some continue to hold.

Autism, in some form, has always been included in the *DSM*. However, in the *DSM*-I and *DSM*-II, autism is not listed as its own diagnosis, but as a type of childhood schizophrenia. The diagnosis "Pervasive Development Disorder" (PDD) became a distinct category in the *DSM*-III, which was published in 1980. Its subcategories included "Infantile Autism," "Childhood Onset

<sup>&</sup>lt;sup>74</sup> As I will discuss in my next chapter, Jack also points to how the issue of blame and parenting resurfaces in contemporary accounts of autistic mothers and their children. She suggests in the memoirs of mothers of children with autism, such as Jenny McCarthy, blame for a child's health and well being rests upon the mother, who is expected to ensure that the child follows a proper, specialized diet (88).

Pervasive Development Disorder," "Infantile Autism Residual State," "Childhood Onset PDD Residual State," and "Atypical Pervasive Development Disorder" (Grinker 136). Its definition was later modified to emphasize that autism is not just a childhood state, but a condition that persists into adulthood. However, some professionals continue to understand autism as a psychological condition. In France and Argentina, the psychoanalytic approach to autism remains popular (Grinker 83). A 2012 press release by *Autisme France* states that one in four doctors, "assimile encore le handicap à une psychose alors que la Haute Autorité de Santé le définit comme une trouble neuro-développemental" (Campagne Nationale Autisme 4). In South Korea, researchers often attribute blame to mothers of autistic people, whom they view as lacking the social skills and sensitivity needed to respond to their children (Grinker 91). Reactive Attachment Disorder (RAD) and autism are largely viewed as synonymous in Korea (Kim 537). In the United States, organizations that are more inclined to view autism as defined by physiological components, such as Generation Rescue and the Son-Rise Program, will also still suggest that it is possible to recover children from autism.

Autism also appears in the International Statistical Classification of Diseases and Health Related Problems (ICD-10), which outlines the disordered communication that is said to characterize the condition. The document defines both childhood autism and atypical autism as the presence of "characteristic abnormal functioning" in "reciprocal social interaction, communication, and restricted, stereotyped behaviour" (World Health Organization). Murray notes that despite the fact that suffering does not appear in the ICD-10 or the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, "the problem/deficit model at work in both manuals can lead to the kind of slippage that assumes that 'absence' must somehow equal

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<sup>&</sup>lt;sup>75</sup> In English, this would read: One out of every four doctors considers autism a psychological disorder, despite the fact that the Health Authority defines autism as a developmental disorder.

'suffering', given the language itself appears to invite the connection' (*Autism* 21). Rather than suggesting that those with autism do not suffer, he argues that other forms of suffering do not necessitate diagnostic criteria, and that, "*presupposition* of suffering...produces a working version of the condition that has an assumed negativity and normalized judgment built into its medical/diagnostic baseline" (*Autism* 21). Representations of people with autism often describe them as suffering from the condition. The term sufferer necessarily creates a distinction between the child and the pain that autism causes. While one might argue that such separation may be beneficial because it recognizes the child as more than simply a deficit, the newly formed neurological diversity perspective pushes further to argue against deficit.

Recently, the diagnostic criteria for autism and the official diagnoses associated with it were revised to reflect new research. The *DSM-5*, which was published and released in 2014, amalgamates classical autism, childhood autism, Asperger's syndrome, and pervasive development disorder not otherwise specified into one diagnosis of autism spectrum disorder, with a closely related diagnosis of social communication disorder. The latest version of the *DSM* marks the first time that the American Psychiatric Association encouraged the general public to comment on the draft words by soliciting their opinions through the *DSM-5* website (Kuhl, Kupfer, and Regier; Stein and Phillips). Ne'eman suggested that the project would have benefitted from still greater community input. However, he noted that attention to some of the issues that ASAN raised to the *DSM-5* working group in 2010 were reflected in the final version of this document (Ne'eman). One of the concerns surrounding the amalgamation of the diagnoses of autism and Asperger's syndrome was that people would receive reduced support, or would lose their diagnosis, as individuals must now meet three of the characteristics of autism listed in the document instead of two. However, many activists are pleased about the combined

diagnosis that the new manual provides, not only because different diagnoses have worked to divide the spectrum in the past, but because of the recognition that some individuals reflect the characteristics of more than one definition listed in the previous manual because how they feel and behave depends on context (Kapp and Ne'eman 2).

Individuals who critique the use of the term 'epidemic' to describe autism often examine the changing diagnostic criteria in the DSM and changing cultural contexts, contesting the accuracy and meaning of statistics. Anthropologist Roy Richard Grinker, who has visited India and South Korea to explore how other cultures understand autism, argues that, "if culture does affect the way we view autism, we ought to look at autism around the world to see if it exists in cultures very different from ours and, if so, what people do about it" (3). He contends that rising figures only suggest that doctors are increasingly diagnosing the condition, since "the old rates were either inaccurate (because cases went unreported or misdiagnosed) or based on different definitions of autism than the ones we use now" (5). Hyun Uk Kim, an educational psychologist who undertook a similar project of examining perceptions of autism across cultures, noted that in Léon, Nicaragua "autism only existed to those who knew about it," as the only individual with a diagnosis that she encountered had one because this child's teacher had learned about autism in the 1970s (542). Others argue that rising rates of diagnosis have resulted from mass deinstitutionalization in the 1960s (Eyal et al. 3). Michelle Dawson, an autism researcher and self-advocate from Montreal, specifically criticized the epidemiology of Autism Speaks in 2008, noting that their stated figures surrounding autism prevalence deny the existence of autistic adults, as they only discuss autistic children (Dawson). Whether the numbers represent a legitimate change in the neurology of the global population remains an area of scientific and social inquiry, but examining the implications of the terms crisis, epidemic, and risk in public

discourse is similarly important because these words affect how the public perceives autism, as well as how autistic people understand their own positions in society.

Historically, the term epidemic has referred specifically to disease. The Oxford Dictionary of Biomedicine describes 'epidemic' as, "an outbreak of infectious disease that spreads rapidly and affects a high proportion of susceptible people in a region," and notes that, "epidemiology is the study of such outbreaks, and the theoretical requirements for epidemic speed, in terms of infectivity, transmission rates, susceptibility, etc., are well understood" ("epidemic"). However, the parameters of epidemiology have expanded to examine the regional distribution of other conditions, such as disabilities. China Mills, a researcher in critical educational psychology, argues that researchers must pay attention to the framing involved in using the term 'epidemic' to refer to non-infectious diseases. She explains that using the framework of epidemiology often serves to individualize and render biological issues that are social in nature (Mills). <sup>76</sup> Autism has become the province of epidemiologists, who study how its prevalence can vary from one region to another, and the factors that influence this variance. Over the past five years, leading peer-reviewed journals in the field of epidemiology include articles that describe potential environmental factors that influence the development of autism, such as particulate matter exposure. While the authors in most cases recognize autism not as a disease but as a neurodevelopmental disorder, many still indicate prevention as a primary goal of their research. For example, in the January 2015 issue of *Epidemiology*, writers state this goal clearly:

Autism spectrum disorder (autism) is a developmental disability characterized by impaired social interaction, communication problems, and restricted and stereotyped behaviour patterns. Autism manifests in functional deficits in relations and work achievement that last a lifetime, affecting an average of 1 in 68 children in the US.

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<sup>&</sup>lt;sup>76</sup> The specific examples that Mills discussed in her public lecture were depression and obesity.

Identifying environmental chemical exposures that contribute to autism is important, as they represent potential targets for environmental pollution reduction efforts that could prevent autism. (Kalkbrenner, Amy, et al. 30)

In describing autism to their readership, the writers note that its deficits affect relationship and work achievement. However, any suggestions concerning changing social attitudes about relationships, or challenging strictures in work environments and promoting accessibility, are missing from the article. While admittedly the neurological as opposed to the social aspects of autism are the purview of scientific researchers, making a medical solution unsurprising, the deficits that they list are specifically social ones. The specific goal of this study is prevention, and the opposition of many autistic adults to this curative thinking remains unaddressed.<sup>77 78</sup> My critique, therefore, is not that autism is addressed by epidemiologists who expand beyond the traditional parameters of the field, but of the assumption that prevention is needed.

While the authors above may believe that autism is a disability as opposed to a disease, they still argue that we should prevent its onset. While those who describe an autism epidemic may be using the term more colloquially to describe autism rates as reaching epidemic proportions, the presence of autism may still be the target of concern for these thinkers. The language that attends the theory that global society has been experiencing an autism epidemic has been contested by autistic activists, whose voices, often via their typed words, are

<sup>&</sup>lt;sup>77</sup> Concerns surrounding cost and the financial burden of autism might also influence assumptions that the solution is prevention as opposed to increasing accessibility to provide for individuals with sensory and communication differences. Tyler Cowen criticizes how researchers often neglect to consider how their financial assessments affect autistic people. Noting that Michael L. Ganz, who teaches at the Harvard School of Public Health, published an essay called "Costs of Autism in the United States," he asks, "Can you imagine a comparable essay titled: "Costs of Native Americans"? Ganz might think that autism is strictly a disease, but he never mentions the fact that a great number of autistics reject this view and find it insulting" (Cowen). I will discuss this issue of discussing autism in financial terms at greater length in my next chapter.

<sup>&</sup>lt;sup>78</sup> Irva Hertz-Picciotto, an epidemiologist at the University of California, Davis, is another professional who has articulated prevention as a main goal of autism research within epidemiology. She told *E-Magazine*, "'The exciting thing about looking at environment, or environment and genes in conjunction with each other, is this provides the possibility of intervention'" (qtd. in Belli).

increasingly accessible to the general public. As Murray suggests in his work on narrative, we are living in a strange climate in which people fear autism but are also incredibly fascinated by it (Representing Autism 3). The fascination surrounding autism would only seem to have increased since Murray's monograph was first published in 2008. In particular, the development of distinct online autism cultures has been informing and changing the representation of autism in contemporary media, enabling greater access to cultural production by autistic people and their allies. Many individuals are speaking back to the predominant representation of autism as a tragedy, which has been promoted by autism charity organizations with international pull. Self-advocates and their supporters have described how autistic people view autism as part of their personality, and believe that efforts to eradicate an 'epidemic' may foreclose the possibility of thinking about neurological diversity as being generative. Yet despite the important work of self-advocates and the favourable reception they have received, research continues to prioritize medical cures or behavioural interventions over quality of life research.

The popular U.S. autism charity Autism Speaks celebrated its ten year anniversary on February 25, 2015. To commemorate the occasion, the charity encouraged individuals to speak out about how the organization had affected their lives, and provided a hashtag to organize tweets on the subject. Activists used the hashtag, however, not to celebrate the organization and its accomplishments, but to draw attention to the irony that an organization called Autism Speaks has played a dominant role in silencing autistic perspectives. The overarching goal of the organization, founded by former NBC director Bob Wright and his wife Suzanne Wright, is to discover ways to treat, prevent, and cure autism. While awareness of autism has certainly increased in the ten years since the creation of the charity, one of the messages that activists expressed was that not all awareness is useful or productive - some awareness efforts can

actually be disabling (Joss). Although greater representation of autism is now available through blogs, YouTube, and other online forums, as the public space of the internet has facilitated advocacy for autistic people who can now self organize despite geographical separation and oral communication differences, charities and other stakeholders often question this representation, with some suggesting that if an autistic person can write, they are not autistic enough to be representative. 79 One of the popular and oft-repeated slogans of the disability rights movement is, "Nothing about us without us". However, the public has traditionally shown more support for this message with respect to physical, visible disabilities than with respect to intellectual or invisible disabilities. 80 While many charities have moved away from representing disability through a lens of pity and suffering, this practice is still common with respect to autism in countries where awareness is prevalent. National and international self advocacy groups that challenge mainstream representations of autism include the Autism Network International, The Autism Women's Network, the Autistic Self Advocacy Network (United States, Canada, Australia), The Autism Acceptance Project (Canada), The Autistic Community of Israel, The E.A.S.E. Network (Sri Lanka), and the London Autistic Rights movement.

Other scholars before me have offered important critiques of the ways that some autism charity organizations have drawn on such rhetorical strategies as fear and pity that perpetuate

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<sup>&</sup>lt;sup>79</sup> For example, Amy S. F Lutz, Slate columnist and author of *Each Day I like It Better: Autism, ECT, and the Treatment of Our Most Impaired Children* argues that the media has obscured the realities of autistic people with intellectual disabilities and self-injurious behaviour. She argues that, "Amanda Baggs, Tracy Thresher, and others offer a sanitized version of low-functioning autism, which is all the public sees" (np). Talha Burkhi, in a film review of *The Lancet*, suggests that fictional representations like, for example, *Snow Cake*, which she describes as "sugary," ignore the clinical realities of the condition (213).

<sup>&</sup>lt;sup>80</sup> This is not to say, however, that physically disabled people are always included in decisions made about them, or acknowledged for the expertise that they have about their own bodies and experiences as writers. For example, in July 2013, Paul Wilson named his "top ten books about disability" in *The Guardian Book Blog*. Clearly using "book" to mean "fiction," he awarded first place to Harper Lee's *To Kill a Mockingbird*. Although Wilson claimed to have compiled a list of books that concentrate on lives frequently overlooked or misunderstood, he overlooked a crucial absence in his own selection – the inclusion of writers with disabilities. While Wilson's list includes texts that address stigma and othering, it also suggests whose perspective on disability is valued. In this case, it is the perspective of able-bodied writers and the voice of fictional narrators that are valued over writers who know disability from the inside. Kaite O'Reilly wrote a follow-up piece that addressed this issue.

stigma, and how they have depended upon a characterization of autism as a disease worse than death as opposed to a disability or a neurological difference. Others have shown how a charity like Autism Speaks hires few autistic people and provides little for them and their families compared to how much financial support they devote to medical research. My own work takes a similar approach, but emphasizes different concerns. My concern is that popularized environmental discourse characterizes autistic people as ecological others, polluted bodies who signify our worsening environmental conditions. While progressive environmental advocacy has been central to my earlier chapters, as environmental activists have been active in campaigning for Bhopal, and protesting unsustainable activities on or near Indigenous land in Canada, an activist focus on correlative evidence for autism and environmental factors, as well as its connections to anti-vaccine movements, demonstrates a lack of engagement with the perspectives of autistic people and their concerns. To date, there has been limited engagement with the autistic rights movement on the part of scholars in the environmental humanities, who have, in other cases, been attentive to distinctions between environmentalism and environmental justice, and how environmental movements have sometimes lacked attention to race, class, and gender. While some scholarship considers how environmental movements have characterized disability problematically, there has been no sustained focus on how the discourse of an autism epidemic fits into these crucial discussions. This section of my dissertation takes on this issue, arguing that autistic people have been represented as 'ecological others' by mainstream media, and examining how autistic activists respond to this characterization.

While my next chapter examines environmental organizations and their engagement with autism discourse, this chapter shows how the autistic writers and performers that I study rethink traditional understandings of subjectivity and intelligence, and offer alternative modes of raising

awareness of autism and its attendant communicative differences. Their opposition to a medical model that understands autism as defect is instructive for thinking about how sharing a message of autism acceptance internationally can similarly articulate these concerns, and emphasize the importance of working within local understandings of disability. Anita Ghai, who discusses perceptions of disability in India, explains that the paradigm shift that took place with the introduction of medical explanations for disability only served to naturalize many stigmatizing beliefs (91-92). Linguistic shifts occurred in the terminology used to describe disability. Understandings of impairment as resulting from "the wrath of fate," were supplemented by medical understandings of disability as disease. But such changes did not reduce stigma or provide an alternative to the charitable or philanthropic model of disability (91). Her critique of the lack of potential of the medical model to provide an alternative response to disability than philanthropy provides insight into how the message of Autism Speaks might circulate. Autism Speaks promotes biomedical understandings of autism that may helpfully serve to dispel beliefs that autism is psychological, or that mothers are to blame for their children's autism diagnoses. This biomedical understanding, however, aligns autistic difference with disease, and stigmatizes certain ways of behaving. Ghai's discussion of how medicalized understandings of disability have been deployed in a postcolonial context suggest the perils of a biomedical understanding of autism that is coupled with messages of fear, pity, and suffering achieving a greater global reach.

As researchers like Grinker and Kim have discovered, perceptions of autism vary across cultures, and some cultures have more awareness of autism than others. However, Kim in particular highlights how awareness does not necessarily translate into acceptance. For example, she notes that individuals in Léon, Nicaragua were very accepting of disability and difference:

I went to Léon to learn how people with autism are perceived; however, I experienced first-hand how the absence of autism is socially constructed in Nicaragua. During my stay I searched for information on the people with autism. Instead, I found the people who knew how to care for their people, which was a humbling experience through the eyes of a guest. There were no studies done about the prevalence rates of people with autism and many people did not know anything about autism in Nicaragua. Students in public schools did not have papers to write or books to read. In the midst of limited resources and lack of information, however, nothing seemed to matter because the people were more than willing to accept individual differences. (Kim 542)

Kim notes, following this reflection, that her perception of Nicaragua might change if she were to spend more time there or to venture to different regions. However, what she witnessed here was that acceptance and educational accommodations were possible for students with disabilities in Léon because teachers were willing to provide helpful instruction. In introducing Kim's reflection, I am not suggesting that awareness about the specific challenges that individuals with autism face is unimportant, but rather that her example complicates the belief that autism awareness framed through a clinical lens automatically generates autism acceptance.

Kim's field reflection also implicitly suggests that a western model of disability rights activism does not translate perfectly from one county to another. Ghai, for example, is critical of how the biomedical model of disability has influenced understandings of disability in India, but she is also critical of transporting a western disability rights model to other countries, noting that that, "in our attempts to change the meaning [of disability in India], we must recognize ... multiple political, social, and economic realities" (99). Ghai's message for a disability studies that is more self-reflexive is important for scholars examining different cultures, and also for

those who may be speaking to disability from outside the embodied experience of disability. One of the difficulties that autistic people have encountered is that others will attempt to speak for them, suggesting that they are not able to represent their own interests due to disability, or are not autistic enough to be representative; speaking, within some autism circles, actually calls into question the legitimacy of one's diagnosis. In Gayatri Spivak's "Can the Subaltern Speak" she worries that even well-intentioned criticism runs the risk of silencing the very people whose silencing it wishes to critique. As a researcher, I am imbricated in this issue as well. My intention in this section is to introduce the writings of autistic people to those writing on global risk - and specifically environmental justice writing - by positioning autistic people themselves as writers with expert knowledge. As those who live with autism are so often left out of conversations surrounding them through insufficient citation, I depend on their literature very strongly in order to make the argument that I present in this chapter and the next.

3. Autism, Language, and Communication: "...it is a way of thinking in its own right" Mel Baggs is an autism rights activist and a prolific writer who captured significant media attention in 2007 when hir short film "In My Language" became a viral hit on YouTube. 181 The year that hir film appeared was the same year that the United Nations had adopted the resolution to celebrate World Autism Awareness Day, a resolution that focused on deficit (U.N. General Assembly). In this film, Baggs draws attention to mistaken assumptions about autistic communication. When this video was released, doctors described Baggs, who does not speak orally, as "low-functioning" (Gupta). However, hir video, as well as language that sie employs through typing, trouble traditional understandings of functioning labels within the autism spectrum. The first part of the video, entitled, "In My Language," captures Baggs interacting

<sup>&</sup>lt;sup>81</sup> As Baggs identifies as genderless, I use the gender-neutral pronouns sie and hir outlined on hir *Ballaexistenz* blog.

with hir environment. As the video opens, sie waves hir hands and sways back and forth while making an "e" sound. The camera proceeds to show hir engaging hir senses, by such actions as stroking the surface of a laptop and repeatedly pressing hir face against the page of a book. In the second part of the video entitled "A Translation," Baggs uses a text to speech synthesizer to create a monologue that serves as voiceover as sie continues in hir embodied language. Sie explains that the purpose of hir translation is not to describe the symbolic meaning of hir actions, as sie describes hir language as, "about being in a constant conversation with every aspect of my environment" ("In My Language"). Rather than claiming hir performance is specifically about autism, Baggs describes hir message as, "a strong statement on the existence and value of many different kinds of thinking and interaction in a world where how close you can appear to a specific one of them determines whether you are seen as a real person or an adult or an intelligent person" ("In My Language"). After the video became viral on YouTube, Cable News Network (CNN) published a series of articles on autism. The many responses and questions sie received from both online and television viewers formed a public dialogue.

Baggs's video foregrounds the importance of translation and collective efforts to ameliorate the position of autistic people through recognition. Sie trouble the idea that thought cannot be present without language by validating hir own communication and interaction as responses to hir surroundings. Baggs explains: "The way I naturally think and respond to things looks and feels so different from standard concepts or even visualization that some people do not consider it thought at all, but it is a way of thinking in its own right" ("In My Language"). Other autistic people, such as animal scientist Temple Grandin, have similarly articulated the legitimacy of their own thought processes. Explaining that she thinks in pictures, often with no words in her head at all, Grandin notes in her autobiography, "I would be denied the ability to

think by scientists who maintain that language is essential for thinking" (129). Referring specifically to Grandin's case, posthumanist thinker Cary Wolfe argues that the judgement of these scientists "is founded in no small part on the too-rapid assimilation of the questions of subjectivity, consciousness, and cognition to the question of language ability" (129). The importance that Baggs and Grandin attribute to their own thought processes, despite their ability to communicate in words, is instructive for considering the legitimacy of modes of thought of autistic people who do not speak or write, or who only engage in one of these forms of communication.

Wolfe, a posthumanist thinker, suggests that humans (and non-humans) share the finitude, or limitation, of language, but he distinguishes his understanding of language from that of other theorists. We should appreciate an alternative mode of thinking, Wolfe argues, "not because it is a diminished or dim approximation of ours but because it is part of a very different way of being in the world that calls on us to rethink, ever anew and vigilantly so, what we mean by 'person', 'mind', 'consciousness'"(47). 82 Baggs makes similar claims in hir performance piece. Describing the purpose of hir video, Baggs explains to hir audience:

I'd been planning on doing something like it for a long time to counteract the idea that there is only one kind of real language, real communication, real person...It applies to people with severe cognitive or physical disabilities, autistic people, signing deaf people, the kid in school who finds she is not taken seriously as a student because she does not know a lot of English, and even the cat who gets treated like a living stuffed animal and

<sup>&</sup>lt;sup>82</sup> Wolfe's argument for the importance of difference extends to the communication of nonhuman animals as well as people with cognitive disabilities. Wolfe's comparison between disabled humans and animals may seem unfavourable, given that self-advocates have expressed feeling as though public perceptions of autism threaten their very personhood. However, other disability activists have suggested that productive comparisons might be made between disability studies and animal studies, like Sunaura Taylor, whose work I introduced in my second chapter. It is worth noting that Baggs also extends her argument to animals.

not a creature with her own thoughts to communicate. ("Why we should listen to 'unusual' voices")

Accepting and celebrating difference, Baggs argues, involves recognizing a myriad of different thought processes. It involves a powerful commitment to value these thought processes, in the face of those who would prefer that autistic people assume efforts to become more normal, to pass as neurotypical rather than embrace their own preferred modes of being in the world. This passage reveals how portrayals of autism that only concentrate on suffering overlook the preferred thought processes that Baggs and other self-advocates adamantly defend.

Even as Baggs advocates that society recognize neurological diversity with the same legitimacy as cultural or linguistic diversity, sie does not suggest that all cultures and languages are equally valued in practice. Hir reference to the student who does not speak English fluently is particularly relevant to the increasing prevalence of the English language as a *lingua franca*. Sie argues that people who do not communicate in dominant languages are denied power, stating in hir video: "The thinking of people like me is only taken seriously if we learn your language," and "failure to learn your language is a deficit, but failure to learn my language is seen as so natural" (Baggs). While "people like me" are ostensibly autistic people, hir words may also describe the position of linguistic minorities. Baggs's discussion of how hir message resonates with linguistic minorities suggests another critique that hir piece puts forward somewhat less overtly. As hir video criticizes definitions of communication and the limits placed on personhood by comparing autistic communication to non-English communication, it creates space for a critique of what we might call an exceptionalist attitude toward disability, or in other words an attitude that assumes that understandings of disability informed by western medical science are more progressive, and ideals for other countries to aspire toward. Jasbir Puar addresses similar approaches toward

sexuality that criticize homophobia in the Global South without acknowledging that opposition to these attitudes exists locally as well as internationally ("Global Circuits" 1045). She argues that citizens in western countries have been accepting of Islamaphobic rhetoric as they criticize homophobia in Iran, and position the United States as superior for being more accepting of differences in sexual orientation, without addressing the homophobia of the American military (*Terrorist Assemblages* xi). A similar criticism could be made of how western countries present their approaches to disability as more progressive, even as western ideologies and neoliberal politics make living with disability arduous. By combining hir critique of attempts to control and discipline autistic communication with attempts to drown out other forms of communication, Baggs clearly differentiates hir efforts toward awareness from other efforts that promote fear or stigma to create a sense of urgency, or that present western approaches to understanding disability as exceptional.

Baggs explains that one of hir favourite viewer responses to the video, "was not about disability at all, but a discussion among several people about the experience of growing up

<sup>&</sup>lt;sup>83</sup> Puar specifically looks at queer tourism and local queer movements in her essay on transnational sexuality and Trinidad. She wanted to investigate how globalization has affected gay and lesbian movements so she visited Trinidad during Carnival season. Carnival, she argues, is increasingly being coded as a gay and lesbian affair throughout the Caribbean, particularly through the performance of "Diva" in Trinidad. Puar focuses on a controversy surrounding a gay cruise ship. In February, 1998, a gay cruise was denied entry into ports in the Cayman Islands. After this happened, other Caribbean governments released statements indicating that they would also refuse this ship entry. U.S. based rights organizations advocated protection for gay cruise ships when this occurred, and Tony Blair did step in and said that the codes barring gay and lesbians from entering were a violation of human rights, but he did not acknowledge that these codes are a legacy of colonial legislation. Puar explains that she felt torn because she wanted the former colonies to tell Britain and the US not to intervene in their affairs, but she also felt solidarity with queer activists. But one of her concerns was the impression that the tourists would receive from this intervention – potentially an impression that local gay and lesbian movements don't exist in the Caribbean, combined with misperceptions about the nature of postcolonial struggle that was part of this conflict. She writes, "It seemed ironic to me that the United Kingdom and the United States advocated protection for cruise ships in the Caribbean while granting no such absolute rights for the passengers upon their return home. Even so, official actions and statements of the two nations may well allow European-American cruise goers to leave the Caribbean with only a surface understanding of the complex homophobia of local governments, of local cultural assumptions about modes of sexual repression and liberation, and of the supposed internalized homophobia of local gays and lesbians rather than with any knowledge of the specific postcolonial struggles at issue in the nation" ("Global Circuits" 1045).

Spanish-speaking in a country that values English" ("Why we should listen"). Baggs's connection between autism and linguistic minorities occurs not only during a time in which global discourse clashes with the neurological diversity perspective through the use of terms such as crisis and epidemic, but also at a time in which global discourse is increasingly in English. Hir statement is instructive for considering how privileging English as necessary for communication denies power to those who cannot, or prefer not, to speak the language. Truchot, in a study of language use in Europe, describes how Gret Haller, a mediator in Bosnia, explains that when you speak in a language other than English, "no one listens to what you say because English is the language of power, and by speaking another language you show that you have no power" (18). Comparisons between linguistic minorities and autistic people illustrate how society and culture influence understandings of power and ability. Deficits, as the cultural model of disability shows, are culturally determined, which means that a region or place in which people must speak English is a disabling experience for linguistic minorities. While the experience of speaking a minority language is in many ways different from the embodied experience of disability, the experience of possessing knowledge that is not valued is similar.

The performance of autism that Baggs provides in this short film, which calls on us to value autistic communication and other languages, can also be considered a practice of what Rosemarie Garland-Thomson refers to as conserving disability. Garland-Thomson, in arguing that working to conserve disability should be a collective goal, positions herself against those who desire the elimination of disability from the human community. Without dismissing the very real psychological or physical pain that people with disabilities experience, Garland-Thomson offers a counter-eugenic argument that disability itself is generative, meaningful, and an important part of our world. She parallels her definition with biological diversity, suggesting, as I

do throughout this dissertation as well, that we value disability as another meaningful form of difference. He Disability, she suggests, is "the transformation of flesh as it encounters world" ("Conserving Disability" 342). Perhaps, this definition does not immediately seem relevant to autistic people, whose disabilities are often invisible, and leave the body unmarked. One could even charge that Garland-Thomson's definition in this instance privileges physical disability. However, in many ways what Baggs dramatizes in this film is disability as the interaction between flesh and world, as sie shows the ways in which different sensory perceptions change one's experience of an environment. In Baggs' case, however, these interactions are not just disabling, but pleasurable. However, while these interactions are meaningful for Baggs, many autistic children who engage in these acts of stimulation for pleasure are prevented from doing so because our culture focuses on changing the behaviour of disabled people, as opposed to attempting to change attitudes in a way that would allow for greater acceptance.

Research suggests that trying to change how autistic people behave so that they appear more normal can actually be detrimental. The extent to which autistic patterns of movement and speech can actually facilitate communication for people demonstrates how the global crises may not simply be a question of increasing diagnoses, but a question of how we define communication. The *ICD-10* defines one of the communication deficits of autism as that of "restricted, stereotyped, repetitive behaviour" (F84.0). The *DSM-IV* specifies that such patterns of behaviour may include, "hand or finger flapping or twisting, or complex whole-body movements" (299.00). The updated *DSM-5* similarly lists "stereotyped or repetitive behaviour" in the diagnostic criteria for autism spectrum disorder, noting that some examples are hand

<sup>&</sup>lt;sup>84</sup> Importantly, Garland Thomson's concept of conserving disability is not a form of protectionism ("Conserving Disability" 341). It is, rather, a means of recognizing disability as a significant and often defining aspect of human existence that persists throughout history; disability, in other words, has a sturdiness.

flapping, finger flicking, spinning coins, and lining up toys (299.00). Such descriptions characterize the embodied language of Baggs and other autistic people as communication deficits. In education classrooms, a focus on correcting behaviour can actually detract from the more important work of exploring communication. In an article describing the creation of Bridges-Over-Barriers, an Ontario advocacy group for adults who type to talk, founder Andrew Bloomfield reflects on his own experiences in the education system. He notes:

At first I admired the teachers who knew I needed intellectual stimulation. Later the classroom was a place where I acted from my gut. I did not get much there. It seemed that everyone looked at our behaviour more than our minds and communication. I think my mind was less engaged and so I acted out more. (117)

Bloomfield, who began using augmentative and alternative communication later in life, proceeds to explain how supported typing allowed him to express his thoughts, demonstrate his intelligence, and have more control over larger life decisions. His account of the Bridges typing community focuses on the need for greater recognition of the intelligence and opinions of autistic people, and greater acceptance of non-normative ways of communicating, thinking, and being.

While some treatments for autism work toward eliminating or repressing "behaviours," other research suggests that preventing individuals with autism from engaging in preferred movements actually inhibits communication. Amundson, drawing attention to the construction of normal, argues that, "much of the education [given to children with autism] is oriented toward getting the child to *appear* normal" (50). He notes that self-stimulation or "stimming" is beneficial because it, "reduces the chaos [autistic people] experience, chaos created by their heightened sensitivity in 'normal' environments, and allows them to concentrate on particular features of the environment (e.g. the voice they are listening to)" (50). Within a disease model of

autism as epidemic, behaviours that facilitate communication appear as symptoms. The rhetorical links established between applied behaviour analysis theory and recovery similarly position behaviours as symptoms in need of treatment (Broderick). Examples of how behaviours associated with autism can help individuals focus and communicate illustrate how focusing on correction as opposed to alternative modes of expression could prevent meaningful interaction.<sup>85</sup> An important parallel here is the way in which educational approaches to teaching Deaf children have at times stressed the importance of teaching them how to communicate in a normative way as opposed to teaching them the actual content that other children their age are exploring. When oralism came into favour as a method of instruction and children were prevented from using ASL, teachers would spend more time teaching vocalization than they would spend teaching mathematics, science, history, and other subjects. Although Deaf students in the United States in the 1850s who received education in ASL performed comparably to hearing students, when medical model approaches aimed at erasing markers of deafness were implemented, student performance suffered; in 1972, the average reading level of a Deaf student was rated at a fourth grade level (Napoli and Lee-Schoenfeld 186). Although measurements of literacy are complicated (and even at times ableist), this statistic illustrates how prioritizing the appearance of normalcy over flexible education methods can be detrimental for disabled students.<sup>86</sup>

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<sup>&</sup>lt;sup>85</sup> In some contexts, "correction" is even more insidious. In an article entitled, "The Crisis of Disability is Violence" activist Lydia Brown (also known as Autistic Hoya) chronicles the abuse and torture of autistic people at the Judge Rotenberg Centre in Canton, Massachusetts, where individuals can receive electric shocks for refusing to obey staff members. Brown describes one case in which a man named Andree McCollins received an electric shock for refusing to take off his jacket. He screamed after the initial shock, which led to staff members placing him in restraints and administering more than 31 shocks (Brown 31). On April 22, 2016, the United States Food and Drug Administration (FDA) proposed a ban on electrical stimulation devices "used for self-injurious or aggressive behavior because they present an unreasonable and substantial risk to public health that cannot be corrected or eliminated through changes to the labeling" (FDA).

<sup>&</sup>lt;sup>86</sup> Many thanks to Nicole Markotić, who suggested that I might consider the parallels between the education of Deaf children and the education of autistic children.

The lessons that have been learned about the value of ASL in Deaf education should be considered when thinking about education approaches to teaching autistic children. For example, echolalia, or the borrowed phrases that autistic people repeat, may help them communicate. Arguing that autism is a rhetoric, Paul Heilker and Melanie Yergeau explain that, "if we listen rhetorically, this repeated use of stock material starts sounding more like a traditional and valued kind of invention" (490). They compare the practice of repeating favourite words and phrases to the practice of creating commonplace books of favourite quotations and other written material during the Renaissance (490-491). Such a comparison illustrates how cultural understandings of what we consider normative or appropriate behaviour shift over time. Such norms can also vary extensively across cultures; for instance, J.L. Connors and A.M. Donnellan point out that maintaining eye contact during conversation is not conventional within Navajo culture, so Navajo teachers do not mind instructing autistic children whose gazes may wander (273). Formulating new ways to understand and value non-traditional and embodied communication are part of the efforts toward translation that Baggs's video depicts as both imperative and problematic. Hir explanation, "My language is not about designing words or even visual symbols to interpret," proves difficult for the majority of people who, despite evidence that non-verbal messages comprise a considerable percentage of communication, remain dependent on words ("In My Language"). Rather than providing an index for translating hir behaviour, or that of other autistic people, Baggs provides a translation through hir message in the etymological sense of translation as to carry across meaning. Yet hir message also is one of a reluctant translator, who restricts hir own responses to written language so that sie can exercise power. The irony of having to apply restrictions to hir own communication when sie hirself is described as having

limited communication is one that Baggs explores in depth through direct statements and through the structure of the video itself.

Hir video models irony and scepticism, perspectives that may be useful for considering both the current climate of crisis, as well as past controversies surrounding autism and causation. Hir video and other online discussions of autism suggest the intimate connection between autism and personality for people who are diagnosed. Certain linguistic preferences, such as preferences for the use of "autistic people" over "people with autism," indicate desire for recognition of autism as integral to identity, as opposed to a disease or incidental condition. While scientists understand autism as neurobiological with associated genetic influences, they continue to consider external factors that might influence brain development after birth (Autism 77). Murray suggests that theories of causation often attach the condition "to a contemporary fear (that society is failing its children) because of its status as some kind of enigmatic, mysterious, unknowable – and yet malign – force" (Autism 80). One examination of external factors that proved disastrous was research suggesting that autism was a form of mercury poisoning that children could contract from the Measles, Mumps, Rubella (MMR) vaccine administered in over ninety countries, a hypothesis that the media popularized by publicizing research that was not always peer-reviewed (Autism 83). The initial loss and subsequent renewal of public confidence in vaccination illustrates the persistent construction of autism in the media as a threat and a risk.

Such fears reflect Ulrich Beck's characterization of the current era as a society of global risk. We now question, "Where is the boundary between prudent precaution and overwhelming fear and hysteria?", and wonder whether scientists can define this boundary when these scientists are people, "whose results are mutually contradictory, who change their opinions so fundamentally that the pill which one can safely swallow today can turn out to be a 'cancer risk'

in a couple of years" (80). Vaccines, introduced to improve health, were precautionary measures for the public until allegations that autism was a type of mercury poisoning rendered them unsafe in the public view. The irony of how discourse framed and reframed vaccination is characteristic of the unpredictable nature of Beck's concept of world risk society, a society in which risks result from triumphs rather than defeats (Beck 8). Admitting that he does not know how to answer this question surrounding precaution, Beck concludes, "insight into the irony of risk suggests responding to the omnipresence of risk in everyday life with sceptical irony" (80). Autistic people have created an online culture, or a postmodern space, infused with irony and scepticism, and particularly with scepticism toward considering autism itself a risk.

Observations on the ironic nature of attitudes toward autism are prevalent in online communities. One popular irony invoked relates to the belief that some people with autism do not have what is called theory of mind, or the ability to recognize and attribute thoughts to other people, which subsequently prevent them from having empathy. Baggs also comments on the many ironies, or unexpected conclusions, surrounding expert knowledge on autism:

Ironically, the way I move when responding to everything around me is described as 'being in a world of my own' whereas if I interact with a much more limited set of responses and only react to a much more limited part of my surroundings people say I am opening up to true interaction with the world." ("In My Language")

Baggs also comments on the irony of using a puzzle piece to represent autism by stating, "people like me are officially described as mysterious and puzzling rather than anyone admitting that is they themselves who are confused, not autistic people or other cognitively disabled people who are inherently confusing" ("In My Language"). By revealing how professional expert knowledge compares to the knowledge of autistic people, sie emphasizes the many assumptions that

structure thinking about autism that need to be challenged. The structure of the video, moving from a display of embodied communication to a poetic monologue, is itself ironic in form. The performance piece subverts viewer expectations of the capabilities of a so-called low-functioning autistic person who engages in the repetitive behaviours associated with autism. Yet even as Baggs challenges the assumption that autistic people are not capable of representing themselves through language, by discussing and employing irony, a rhetorical device that autistic people have been deemed incapable of using or understanding, sie also complicates the association between language and empathy that I discussed in the last chapter with reference to postcolonial theory and Aravamudan. As a result of the popularity of Simon Baron Cohen's concept of mindblindness, or the idea that autistic individuals lack a theory of mind, autistic people have been denied the ability to empathize, an ability that has been strongly linked to writing literature. 87 Contemporary philosopher Erin Manning, who has worked with autistic people in performance art exhibits, explains that language is a "double-edged sword" for advocates who want to deemphasize language, but who also understand that language has been held up as central to inclusion (163). As Baggs demonstrates through hir reluctant translation, while taking the written word "as the sign of humanity..." may appear democratizing, it can also serve to problematically limit the borders of personhood (Aravamudan 270).

Baggs's focus on the ironies surrounding misperceptions of autism suggests the difficulties with declaring that autism constitutes an epidemic. The rhetoric of crisis and epidemic and its accompanying statistics often obscure and mask autistic people themselves, who find themselves so often characterized as problems, burdens, or puzzles. Describing autism as a burden or a form of suffering creates questions surrounding the quality of life of autistic

<sup>87</sup> For a full account of the concept of mindblindness, see Simon Baron-Cohen's *Mindblindness: An Essay on Autism and Theory of Mind*. For a critical analysis of theory of mind as a narrative, please see John Duffy and Rebecca Dorner's article "The Pathos of 'Mindblindness': Autism, Science, and Sadness in "Theory of Mind Narratives."

people. Beck, who opens his discussion of world risk by staging scenarios to come, cautions that soon couples, "will have to assess whether their wish to prevent suffering, even though they cannot be certain that it will occur, justifies the conscious selection of an embryo and the 'rejection' of potential children who are bearers of a 'risk gene', however the latter is identified" (2). Broderick and Ne'eman express fear that increased knowledge of genetic markers for autism, during an era in which commentators align autism with disease, "may lead to prenatal testing for autism, thereby reducing the number of births of autistic individuals" (474). Genetic screening, offering people the chance to determine whether certain forms of life are meaningful, has the potential to redefine health. Organizations and institutions may not actively suggest encouraging research so that people may terminate pregnancies based on the results of genetic tests. However, the language of a global epidemic invites comparisons between autism and disease that could enable individuals and policy-makers to continue to characterize autism as a burden, silencing the undesirable behaviour that can be reframed as communication. Baggs, in her film, provides a counter-eugenic logic that demonstrates the importance of disability as a meaningful form of human relation. I will argue next that there are alternative ways of understanding autism in a global context.

## 4. Autistic Self Advocacy in a Global Context

One of the conventions of what Melanie Yergeau has named the "typical autism essay" is an opening sentence that cites the American Centre for Disease Control's statistic concerning the prevalence of autism (Yergeau). As I have noted, according to many organizations, charities, and government bodies, autism is an international health crisis. Autism charities and organizations are encouraging the importance of thinking globally. Autism Speaks now operates in partnership

with the World Health Organization through their Global Autism Public Health (GAPH) team, leading training efforts, promoting treatment centres, and disseminating knowledge in many different countries. Some individual projects have included the Parent-Mediated Intervention for Autism Spectrum Disorders (ASD) in South Asia (PASS), the Comprehensive Parent-Mediated Intervention for Children with Autism in Southern Taiwan, and the Heat + Project on increasing autism awareness in Ethiopia. The organizational materials collected on the Autism Speaks website describe the importance of respecting local knowledge about disability, and position their efforts as collaborative as opposed to hierarchical efforts to impose western treatment methods. Their associate director of public health research and scientific review, reflecting on how much autism research and advocacy has changed since the U.N. passed the World Autism Awareness Day resolution, suggests that South Asia is leading the way through action and government support (Rosanoff). Their materials demonstrate a public acknowledgment that western approaches to caring for and educating individuals with autism may need to be modified to fit other cultures. Yet these materials also do not discuss international consultation with autistic people, who are crucial stakeholders in discussions concerning autism and public health.

One of the efforts of the GAPH initiative is the Global Advocacy Leadership Network (ALN), which annually brings together health officials from around the world to discuss research and awareness. An article describing the second annual two-day conference meeting in 2014 notes that participants included "Autism Speaks Co-founders Suzanne and Bob Wright, representatives from the World Health Organization, the United Nations Convention on the Rights of Persons with Disabilities and ALN members and stakeholder organizations from around the world" ("Global Advocacy Leadership Network"). The crucial absence from this list is autistic people. While it is possible that representatives from stakeholder organizations may

themselves be autistic, the presence of autistic people is not specifically noted. <sup>88</sup> While parents, health care providers, and educators can be important allies, historically, Autism Speaks has deemphasized individual expression, and has not responded to autistic individuals who have repeatedly pointed out the insensitivity of many of their awareness efforts. <sup>89</sup> Yet despite their absence from major global knowledge sharing networks, autistic people interested in recognition and acceptance acknowledge the significance of forging global connections too.

With this context in mind, I would like to consider how Gerardine Wurzburg's documentary film *Wretches & Jabberers*, starring Vermont autism activists Larry Bissonnette and Tracy Thresher, responds to the imperative to think about autism and advocacy on a global scale. The 2011 film follows Thresher and Bissonnette as they develop connections with autistic writers in Sri Lanka, Japan, and Finland. At the time that this film appeared, a major focus in global autism discourse, as reflected through the 2011 United Nations official statement, was early intervention and treatment for young children. Although the main problem surrounding autism in popular media was then and in many ways remains the prevalence of diagnosis, in the film, Thresher and Bissonnette reframe the main issue to one of social attitudes. Furthermore, *Wretches & Jabberers* positions autistic people themselves as experts on the difficulties that they face. It differs from many popular autism documentaries, which tend to exclude the perspectives of autistic people and focus instead on family members and professionals. <sup>90</sup> Many such films about autism tend toward the sentimental, encouraging viewers to occupy the gaze of a parent, professional, or other onlooker who occupies a degree of distance from disability. *Wretches &* 

<sup>&</sup>lt;sup>88</sup> In other words, perhaps some autistic people would have attended as 'stakeholders', but the organizational material does not emphasize the importance of people with disabilities being involved in these events.

<sup>&</sup>lt;sup>89</sup> One of these efforts is the "I am Autism" public service announcement video that personified autism as a villain Much of the rhetoric in this awareness video replicates that of the New York University Child Center's "Ransom Notes" campaign, which personified autism as a hostage-taker. Joseph F. Kras argues that this affair created momentum for the neurodiversity movement.

<sup>&</sup>lt;sup>90</sup> Some examples include *The Autism Enigma*, *Sounding the Alarm*, and *Autism Every Day*.

Jabberers does not evoke the sentimental mode that has been associated with pity, but instead challenges its audience to reconsider their understandings of intelligence, ability, and personhood, and to confront any assumptions they may harbour. The individuals featured in the field come to occupy spaces of learning - such as universities, conferences, classrooms - and become educators. In a review of the film, Estée Klar, founder of the Autism Acceptance Project points out that while most films about autism "never show autistic people speaking for themselves or as experts of their own experience," this film is notable for presupposing "autistic competence" (120). Allowing autistic people to guide the discussion, Wretches & Jabberers reconfigures expertise. Wurzburg, the film's director, is a social justice filmmaker known for the films, Educating Peter (1992), Graduating Peter (2001), Autism is a World (2004), and Wretches & Jabberers (2010). Her film Autism is a World, released in 2005, starred an autistic woman named Sue Rubin who, like Bissonnette and Thresher, uses facilitated communication, or supported typing. Both films highlight the efforts of autistic people to change popular perceptions about autism, disability, intelligence, and effective communication.

One of the points that *Wretches & Jabberers* shows is that sharing messages of autism acceptance involves fostering a dialogue. Its stars, Tracy Thresher and Larry Bissonnette, travel to Sri Lanka, Japan, and Finland not only to share their message, but to strengthen and develop it through meetings with other communicators who type to talk. Thresher, Bissonnette, and the other autistic people that they meet in this film communicate through supported typing, which means that they require physical support to stabilize their bodies while typing, as well as emotional support from the facilitators who assist them. Together, Bissonnette, Thresher and the other autistic people that they encounter on their trip emphasize the importance of presuming competence and challenging assumptions about intelligence. The film commences with Thresher

and Bissonnette's arrival in Colombo, Sri Lanka, where they visit Chandima "Chammi" Rajapatirana, co-founder of the E.A.S.E. Network with his mother. The second stop on their tour is Kimitsu, Japan for a meeting with sixteen year old Naoki Higashida, a burgeoning activist and writer. They complete their tour in Helsinki, Finland, where they meet with twenty-one year old Antti Lappalainen and twenty-three year old Henna Laulainen, who are both eager to share their ideas. In addition to important, face-to-face conversations with other people with autism who type to talk, their tour stops also involve meetings with journalists, students, teachers, and conference attendees. While Bissonnette and Thresher take on a mentorship role to the younger autistic adults that they encounter on their trip, when they describe their experiences to audiences in other countries, they present with autistic people from these countries who can speak to experiential similarities, as well as more specific local challenges.

Interspersed in the footage of these international meetings are segments that follow Bissonnette and Thresher in their daily lives in Vermont. While the main objective of the trip is to connect with communicators in other parts of the world, the two also take this opportunity to contemplate the purpose of their lives. During a meeting with Monk Hogen at the Mitsuzoin Temple in Japan, Thresher confides, "my greatest anguish [is] not having a purpose in life" (Wretches & Jabberers). While searching the world to discover one's purpose is a familiar story, appearing in many genres, it is particularly charged in this context because, as the film makes clear in documenting the ordinary lives of many of the individuals whose stories are featured, autistic people, and particularly those who communicate differently, are not encouraged to find their purpose, and are not encouraged to make major decisions about their own living

<sup>&</sup>lt;sup>91</sup> E.A.S.E. stands for "educate, advocate, support, empower." Rajapatirana and his mother offer communication training for people with autism in Sri Lanka.

<sup>&</sup>lt;sup>92</sup> Since appearing in the film, Higashida has published a memoir entitled *The Reason I Jump*, which was translated into English by British novelist David Mitchell.

arrangements and daily activities. Following his meeting with Monk Hogen, Thresher announces, with renewed passion, that his purpose is "to show that people like me are intelligent" (*Wretches & Jabberers*). The film itself plays a role in enabling Thresher to act in fulfillment of this purpose, as it demonstrates the communication practices of autistic adults who need support from others to be able to converse and articulate their needs, thoughts, opinions, feelings, and aims for the future.

Facilitated communication, the form of augmentative and alternative communication (AAC) that Thresher and Bissonnette use, was first developed in Australia by Rosemary Crossley. This method involves providing emotional and physical support for individuals who type to talk, in the form of physical closeness and a light touch from a supporter that is ideally faded over time. Crossley worked with children diagnosed with severe cerebral palsy who were not able to speak orally. She taught them to communicate using a letter board, and was greatly able to further their education in St. Nicholas Hospital, where it had been presumed that they did not understand any conversations that took place between nurses and other staff. While many individuals were impressed with Crossley's innovations, others believed that she was unintentionally directing her students to point to specific letters. Her student Anne McDonald went before a judge to argue for her right to be able to leave the hospital and live with Crossley. As recounted in their co-authored memoir, Annie's Coming Out (1980), and the film adaptation of the same title, McDonald was able to demonstrate to the judge that she herself was communicating by pointing to a secret word that Crossley did not know. Crossley's method was later developed by Douglas Biklen at Syracuse University, whose guiding principle is "the presumption of competence," or the idea that even people who cannot speak are "thinking people with ideas about their lives and their relationship to the world" (1). Despite McDonald's victory

in Australia, the use of facilitated communication to support autistic adults has met with controversy since the 1990s. Some critics claim that facilitators inadvertently direct the individuals that they support to the letters, in what has been referred to as a "Clever Hans" or "Ouija Board effect" (Walters 220). In the face of such criticisms, many supporters of facilitated communication adopt Douglas Biklen's 'presumption of competence,' and his philosophy that individual differences can often require creative forms of support (73).

Erevelles examines the centrality of questions of competence in the debates concerning autistic adults who type by connecting anxiety surrounding facilitated communication to anxieties surrounding subjectivity. Skeptics of facilitated communication depend upon humanist understandings of a cohesive subject to argue that individuals who do not demonstrate competence in oral communication are not capable of further competence in written communication (25). Yet, as Erevelles points out, Biklen and other defenders of facilitated communication are also dependent on humanist ideas as they argue for the independent authorship of the communicators who depend upon facilitation to express themselves, but are nonetheless independent (27). Erevelles argues that the debates surrounding facilitated communication bear similarities with debates in critical theory surrounding the definitions of an author, and how these definitions affect our analysis of written texts. According to postmodern theory, she explains, the subject does not simply use language, but is an effect of language itself (19). Foucault and others declare the death of the author, meaning that theorists can analyze a text independently of knowing the author's intention. For postmodernists, the issue of who is writing the text becomes decentralized in literary criticism.

However, even as Erevelles cautions that humanist understandings of subjectivity limit possibilities for interrogating our understandings of autonomy, she insists that the question of

who is writing the words is important for individuals (29). When facilitated communication lost significant support in the 1990s because there were doubts surrounding whether individuals were composing their own thoughts, these individual communicators lost a valuable means of advocating for themselves and often returned to segregated environments (30). Erevelles suggests that the debates surrounding facilitated communicating can be best understood through a focus not only on how subjectivity is constituted in historical contexts, but on "why certain subjectivities are constituted in oppressive ways in those same historical contexts" (31). The words of those using facilitated communication meet with challenges in late capitalism, as their words call into question the systemic categorization of disabled people as part of a surplus population that supposedly lacks a certain skill set required for participation (31-32). 93 The debates surrounding facilitated communication are a context for Thresher and Bissonnette's film, even though the film does not explicitly recount the controversies surrounding supported typing. Thresher, Bissonnette and others do, however, call into question the categorization of disabled people as a surplus population in their search for a greater individual purpose to their lives, and present a clear challenge to the practice of segregation that occurs globally.

Thresher and Bissonnette receive support during their travels from their experienced facilitators, Harvey Lavoy and Pascal Cheng. The main goal of facilitated communication training, the form of communication that Thresher and Bissonnette use, is for the individual communicator to achieve as much independence as possible (Crossley 13). In *Facilitated Communication Training*, Crossley notes that facilitated communication is not an ideal method of communication, but a vital one for people who have exhausted all alternatives (7). However,

<sup>&</sup>lt;sup>93</sup> For another useful account of the controversies surrounding facilitated communication, please see Ralph James Savarese, who advocates for using best practices. Savarese argues that research showing the limitations of facilitated communication should not be dismissed, but he calls for additional research from researchers that will take into account "the complex needs of their research subjects" ("Anna Stubblefield and Facilitated Communication").

even as Crossley outlines the importance of greater independent communication, she also provides individual examples that demonstrate how a culture that emphasizes independence over interdependence still deserves critique. She notes that McDonald continues to communicate through facilitated communication by preference and quotes her explanation for why at length:

I communicate by spelling on an alphabet board, on which I can reach a top speed of 400 words an hour. I own a Canon Communicator...which I use with a headpointer...; a speech synthesizer...and a computer which...is the slowest to use of all my high-tech communication equipment....I can type at 10 words an hour, provided someone else sets up the computer...The gadgets enable me to do things I can't do without them, but they don't let me do them fast enough to make it worthwhile. If technology made me normal, it would be great; as it is it makes me slower and less efficient and reduces the time I would otherwise spend with non-disabled people. (Qtd. in Crossley)

In this passage, McDonald confronts an ideology of independence that values a technological solution to her communication difficulties over a solution that involves the supportive efforts of other people, who make communication a collective practice. She argues that in her case, the most technologically advanced solution is actually the most disabling because it increases her isolation, and limits her inclusion with non-disabled people. The amount of time it takes to communicate independently is not worth the tremendous social and emotional cost for her.

Yet as thinkers and practitioners like Biklen, Crossley, and Erevelles point out, there are other practical difficulties associated with facilitated communication, including the difficulty of continually needing to confront and challenge the belief that individuals who use it cannot possibly be able to have thoughts sophisticated enough as their on-screen writing would suggest. Thresher alludes to skeptical thinkers when he asks an education class in Japan what they think

of, "the paradox in front of [them], the peculiarities and typing of intelligent words" (Wretches & Jabberers). Thresher's question is one that demonstrates keen recognition of the assumptions that his audience might cultivate about those who lack oral speech. When a Japanese student supportively explains that he finds this paradox sad because he has never equated speaking with inner thoughts, Thresher agrees that "society has cloaked us with this paradox" (Wretches & Jabberers). Bissonnette in turn adds that, "Learning about autism requires storymaking about the human experience which is weird and offbeat like a primitive silent film" (Wretches & Jabberers). Like Baggs in "In My Language," Bissonnette points out that learning more about autism requires a different kind of storytelling and a different kind of listening - one that is open to touch in the sense of Baggs exploring an environment, or Bissonnette receiving support from a facilitator. Shannon Walters, author of *Rhetorical Touch*, suggests that this problem of skepticism and devaluation of the practice of touch used in facilitated communication stems from a lack of understanding of autistic people as potential rhetors. In the field of rhetoric, one of the ways of appealing to an audience is through *ethos*, or character formation. In traditional understandings of rhetoric, effective rhetors are able to construct an *ethos* that indicates that they can identify with their audiences and share their perspectives. The stereotype that autistic people are unable to connect with other people is a problem because it creates the impression that autistic people are not able to use rhetoric, or persuasive communication (Walters 112-117).

Within the traditional definitions of rhetoric that Walters outlines, Thresher, Bissonnette, Rajapatirana, Higashida, Laulainen, and Lappalainen, who have limited speech, would not be considered effective rhetors. And yet, working to change perceptions in a way that will allow autistic people to have more agency in their daily lives, regardless of where they live, is the ultimate point of the film project. When Finnish filmmaker Timo Viermaa asks Bissonnette and

Thresher about the purpose of their world tour, Thresher responds that their mission is "to move people's knowledge of disability to a positive place, seeing the intelligence rather than the inability" (Wurzburg). Thresher's goal is a persuasive one that involves education and the pursuit of social change. Walters, who argues that autistic people do think and write rhetorically, explores the significance of touch for autistic people, and specifically touch in facilitated communication. Walters looks to the Greek concept of *mētis*, which means "a way of knowing," to suggest that autistic writers form *ethos* and identify with their audiences through touch (112). She refers to touch as a dwelling place in which autistic people can form character, and points out that individuals who use facilitated communication, like Lucy Blackman, Tito Mukhopadhyay, and Sue Rubin, emphasize the importance of touch to their learning, communication, and composition processes (121). <sup>94</sup>

Walters points to these examples to show how people with autism resist the stereotype that they are not able to forge emotional connections with other people. The topic of touch is not one that receives direct attention in the film, although enabling greater access to communication supports like communication assistants and assistive technology does. Viewers see how the expression of this intelligence is enabled through touch, such as when Harvey supports Tracy during a difficult meeting with U.S. Senator Phil Scott. Focusing on this scene, Klar describes how "this method of support is tactile (that is the support of Tracy's forearm) as much as it is emotional; it suggests a relationship of trust and another body required to gain the momentum Tracy needs to continue typing his thoughts" (121). In documenting the typing process itself, the film exposes its audience of viewers to a new way of thinking, knowing, and being, demonstrating, as Tracy notes, the "perfect example of intelligence working itself out in a much

<sup>&</sup>lt;sup>94</sup> She also examines how touch is important to Temple Grandin and Dawn Prince-Hughes, who have both described how sensory experiences like touch facilitated their interactions with animals and people.

different way" (Wretches & Jabberers). The film allows for an expanded audience to witness the intelligence of "wretches," or non-speakers - an intelligence that has been ignored in favour of the intelligence of "jabberers," or speakers. 95 Like "In My Language," Wretches & Jabberers challenges the idea that individuals are incapable of the empathy that would allow them to imagine their audiences and be persuasive rhetors. Responses to interview questions demonstrate how this self-titled group of "wretches" empathize with each other. Reflecting on the trip and how the lives of the individuals that they have met differ from their own, Bissonnette describes his new friends, in an alliterative style that characterizes much of his communication, as "very like [Tracy and me] in their penchant for language as a loud spear for bursting bubbles of backwards thinking about people who don't get to speak normally" (Wretches & Jabberers). One of the rhetorical tools that they use through language is the expression and encouragement of empathy. When asked the most important thing that individuals should know about autism at a conference in Finland, Tracy encourages listeners to "think about what it would be like to not be able to talk and have to depend on whether people think you are intelligent or not and then remember these four brave souls in front of you today" (Wretches & Jabberers). When asked to offer his expertise on the most important aspect of autism, Thresher calls upon the audience to imagine what it might be like to have a more precarious relationship to communication, and to have bonds of support that are more immediately visible to others. His presence alongside Lappalainen and Laulainen reinforces that autistic people themselves belong at the centre of efforts to forge global connections, as new technological advances, medical discoveries, and increased knowledge of autism at a biological level are not the only ways to ameliorate the conditions of autistic people; understanding and acceptance are greatly needed now.

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<sup>&</sup>lt;sup>95</sup> Lappalainen transgressively reappropriates the term "wretch" to take ownership of his own intelligence as a non-speaking person. He invites his autistic friends to do the same (Wurzburg).

Critiques of the (mis)representation of autistic people in many genres, from public service announcements to Hollywood films, are common, with some suggesting that certain representations unfairly focus on the suffering of autism as opposed to the barriers imposed by society, while others suggest that representations that adhere too closely to a difference as opposed to disability model threaten to suggest that autistic people do not need any social support to be able to live meaningful lives. Autism is a term that describes a spectrum of conditions, but mainstream representations are often polarizing, either representing people as unintelligent and incapable of making decisions about their own lives, or too intelligent to require any social support to go about their daily lives. Wretches & Jabberers easily dispenses with this binary, as differences and similarities between the perceptions of those who type to talk and those who speak are paralleled by differences and similarities between those who speak English and those who speak Japanese, or Finnish. Through its exploration of communication across languages, the film demonstrates how communication for non-disabled individuals, as well as disabled people, is facilitated. 96 While versions of the DSM outline different ways that communication can be disordered, this documentary makes visible how communication is always mediated and contingent through its layer of facilitators. While Thresher and Bissonnette have their own facilitators, as they travel to other locations, their facilitators are in turn aided by interpreters who provide linguistic translations. The film represents Cheng and Lavoy as prosthetic creatures too; they depend on the translators to be able to navigate the new city spaces and to perform their work. 97 While Maho Suzuki, who performs English to Japanese and Japanese to English translations for the group in Japan is predominantly shown to complete her

<sup>&</sup>lt;sup>96</sup> To clarify, I am not suggesting that the film portrays Pascal and Harvey as disabled people too. Although the postmodern theoretical understandings of disability that I draw on perform important work in breaking down the binary between disability and ability in an ontological sense, the experience of disability as a specific social and political identity deserves acknowledgment too.

<sup>&</sup>lt;sup>17</sup>I am echoing how Wolfe and Wills both use the term "prosthetic" to describe language itself as a prosthetic.

translations very quickly, she stumbles over metaphor. When Bissonnette tells Higashida that orders for his art will come in "so like a meteor take off to lettered moonbeam night like neon lights lit in Tokyo," Lavoy jokes, "Good luck," to Suzuki, who exclaims, "Oh my goodness" (Wretches & Jabberers). Cheng offers ideas to Suzuki as to the main idea of the message.

Moments like this one demonstrate that instead of a dichotomy between the disabled person and facilitator, we see the facilitators and their actions as similarly unravelling the myth of the individual who exists completely independently. They too require aid to be able to take the trip.

Yet while Thresher and Bissonnette require aid to disseminate their message of autism acceptance, their words are not supplemented with the words of doctors, psychologists, or other professionals. The absence of these figures speaks to a distinction between this documentary and other documentaries about autism that I noted earlier, which is a distinction in how it defines expertise. Thresher, Bissonnette, and the allies that they visit are the experts of the film. While many documentary films depend on doctors and educators to tell the audience about autism, this film offers an insider's perspective. The presence of a doctor is something that is common to both memoir about autism and fictional films about autism; the doctor appears in such texts because he or she has explanatory authority. In my second chapter, I explained how doctors, psychologists, and other professionals assume explanatory authority in autistic memoir. The doctor mediates the autistic person's representation and lends a degree of authenticity to the person's writing; the doctor can verify that the diagnosis is true. Many representations of autism are now able to bypass this mediation. For example, The Loud Hands Project, a transmedia collection of the cultural production of autistic people, collects writings and essays into an anthology but does not include an external expert. Some individuals may still prefer to have an introduction to their works by an expert. Sometimes the expert also plays the role of editor and

allows for the dissemination of the text.<sup>98</sup> But it is becoming possible for autistic people to share their published works without necessarily needing to include a preface by an autism expert (and specifically a medical expert), and the decision to avoid doing so is often explicitly political.

Even amidst its celebration of autism expertise and the exciting world tour that Thresher and Bissonnette are able to make with their facilitators, the film captures painful and realistic footage as well. The two are very honest about the difficulties that they face as autistic adults. As I noted with respect to Baggs, many autistic people prefer the use of the term 'autistic person' to 'person with autism,' because the former term emphasizes that autism is an aspect of one's identity. Bissonnette and Thresher view their disabilities as integral parts of their identity, embracing Lappalainen's term 'wretches' to describe their own particular non-speaking brand of intelligence. <sup>99</sup> In their discussions, however, they sometimes refer to autism as an impairment, particularly with reference to their movement and sensory differences. Thresher admits to one questioner, "I have always been very angry about my autism," adding that he was not viewed as intelligent until after high school (Wretches & Jabberers). When he refers to his desire for communication before he learned to type, he refers to this desire as "trapped inside like a caged animal," and further characterizes this animal as "a beast" that was "tamed, [which] opene[ed] up the world with learning, advocacy, and purpose" (Wretches & Jabberers). Bissonnette similarly refers to coming into his own intelligence as a process including "powerful impulses toward growth and the beast disappearing" (Wretches & Jabberers). While the two aim to spread a message of acceptance, they are also honest about how the challenges of living with disability affect their lives, which extends to their use of metaphor to describe their feelings of repression.

<sup>&</sup>lt;sup>98</sup> Douglas Biklen's anthology, *Autism and the Myth of the Person Alone*, is one such example.

<sup>&</sup>lt;sup>99</sup> Bissonnette, however, calls himself both a wretch and a jabberer, since he does communicate some thoughts through oral speech.

Similarly, even as the film celebrates the great distances that the two traverse, it also alludes to the many unwanted travels that take place in the lives of many autistic people. Its soundtrack is predominantly upbeat and celebratory, as Bissonnette and Thresher connect with their friends in person and forge an international network to further their mission of demonstrating the intelligence of autistic people, giving it global reach. However, while the film and its stars celebrate the journey, they also challenge the idea that constant movement necessarily signals privilege. In his daily life, Thresher finds moving from place to place traumatic and stress-inducing. When asked about his living situation, he tells the audience, "I do not have a place to hang my hat" (Wretches & Jabberers). Unlike Bissonnette, who lives in a permanent home with his sister, Thresher receives temporary lodging through a centre for adults living in crisis. Sectioned in between Bissonnette and Thresher's trip to Sri Lanka and Japan is a segment on Tracy's life in Vermont, which also shows his visit to Senator Phil Scott to discuss the budget cuts to disability support systems. In addition to the film's showcasing of the new networks forged between autistic self-advocates, it also offers a narrative of Tracy's own journey toward what he defines as purpose. His personal quest for purpose, however, is central to the film's overall message about the need for support for autistic people. While basic survival needs like housing are not being met adequately, it is also clear that survival is not enough; people need to realize that autistic people are also looking for purpose and meaning in their lives as well. This theme is reiterated when Larry and Tracy meet their friends in Finland. While Antti Lappalainen is an aspiring writer, he is working in a centre for people with disabilities, completing chores like folding and shredding paper that do not challenge him in a meaningful way. Furthermore, the people who have assigned him to this program and supervise him do not seem to recognize his abilities; they make assumptions about his intelligence because he does not communicate in a traditional, recognizable way. Similarly, Higashida is a novelist who is not allowed to attend public school, and Laulainen wants more from her life than cooking, cleaning, and visiting her family's sauna. In the United States, Sri Lanka, Japan, and Finland alike, autistic people face exclusion. The film is in many ways about uniting purpose by traversing great distances, but it challenges any pretense that movement is always desirable or chosen.

The types of alliances forged in the film contrast markedly with the discourse surrounding the need for greater research for an autism crisis. While some of the film's stars are living in crisis situations, Wurzburg's film makes clear that the crisis is not autism in and of itself, but actually one of social attitudes. Or, as Bissonnette notes, "Lesson is autism is not abnormality of brain as much as abnormality of experience" (*Wretches & Jabberers*). The film reframes the idea that autism is a problem in a way that, I will argue in my next chapter, encourages people to question the assumptions that they usually make about autism and its relationship to global and environmental health. In particular, it goes a long way toward reframing the discourse surrounding autism, crisis, and epidemics.

## 5. Moving Beyond Awareness and Toward Autism Acceptance

One of the ways that Autism Speaks has attempted to raise awareness for autism on a global level is through the "Light it up Blue" campaign. On the United Nations Autism Awareness day, buildings around the world display a blue light to spread autism awareness. However, for a building to "light it up blue," they must also make a financial contribution to Autism Speaks, an organization that has traditionally prioritized funding for scientific research over efforts to help autistic people on a more immediate and personal level. In a recent documentary, Suzanne Wright explains that she chose the colour blue because the condition affects boys four to one

(Sounding the Alarm). While the choice of a particular colour may seem like a small concern, from a feminist perspective, the decision to represent autism through a colour that popularly connotes male experience downplays the concerns of autistic women, a group that has been marginalized within some autism communities. An alternative to blue has arisen in response to the designation of April as Autism Awareness Month. Autism Acceptance Month, which was spearheaded by Paula Durbin Westby, who organized the first celebrations, now provides an alternative for people who are interested in supporting autistic people without stigmatizing them or pushing for a cure (Autism Acceptance Month). Similarly, direct alternatives to the Light it Up Blue Campaign exist. In 2015, The Autistic Network for Community Achievement, an international organization, encouraged individuals to "Light it Up GOLD!" instead (Naturally Autistic). Other alternatives include the "Tone it Down Taupe" and "Light It Up Red" campaigns. The colours and the specific taglines differ from one campaign to the next, but these initiatives share a critique of mainstream discourse, and advocate for recognition that not all awareness necessarily leads to acceptance.

A counterargument that one might present against acceptance campaigns and their implicit critique of the medical model is that some individuals may desire medical interventions and procedures. For instance, while the vast majority of autistic activists strongly speak out against curative research, Sue Rubin, an autistic writer and activist who communicates through typing, has written favourably about medical research and even the concept of a cure (Wilson 94). Disability studies scholar Alison Kafer discusses the tension surrounding cure in disability studies. While she is critical of the assumption, in the medical model and society at large, that all disabled people long for medical cures, she cautions that excluding those who desire medical

<sup>&</sup>lt;sup>100</sup> The Autism Acceptance Month official webpage notes that the concept of autism acceptance predates autism acceptance month, originating in Jim Sinclair's essay "Don't Mourn for Us" and popularized by Estee Klar's The Autism Acceptance Project.

disability futures involves acknowledging the different and sometimes contentious relationships that people have to their own disability identities, while at the same time refusing to view the presence of disability as a sign of a failed future. I would argue that the model of autism acceptance that "In My Language" and *Wretches & Jabberers* both outline is one that rejects the presumption of suffering, but also one that allows autistic people to articulate their own feelings about their disability that may at times be confusing or contentious. Acceptance allows for individuals to take pride in a disability identity that has been policed and stigmatized.

Furthermore, cultural works that advocate for greater autism acceptance adopt a politicized discourse that the awareness model avoids. Autism awareness discourse, and its mandate to increase knowledge of autism, avoids questions of ethics, representation, and identity that acceptance discourse addresses directly. The awareness discourse surrounding autism, I would argue, shares commonalities with the discourse of tolerance that political theorist Wendy Brown defines as normative and depoliticized (4). Autism awareness discourse presumes an audience of non-autistic people, using metaphors of illness, contagion, entrapment, and death to advocate for greater efforts. In contrast, acceptance efforts address autistic people directly, encouraging both acceptance from non-autistic people, and also working to create a climate in which autistic people themselves are able to embrace autistic culture and identity. Acceptance is not only an issue of allowing for greater community inclusion, participation in the workforce, and self-appreciation, however; it is all of these things, but it is also about basic survival. As I have discussed elsewhere, the desperate search for a cure or methods or prevention has had, and continues to have, devastating repercussions. Misinformation surrounding the MMR vaccine has led to decreased rates of vaccination and rising rates of the measles. Children are given harmful

"cures" like chlorine dioxide/Miracle Mineral Solution. Autistic people constantly confront the belief that their lives as disabled people are less valuable, a form of discrimination that has limited their ability to receive medical care ("Learning from Autistic Adults"). These and other examples are evidence of issues for which awareness efforts are inadequate.

As well, awareness without acceptance might also be framed as what Nixon refers to as a form of slow violence. Autism awareness efforts mobilize the discourse of crisis and violence by highlighting the short time frame during which global diagnosis rates have increased, and by emphasizing the necessity of early intervention for autistic children. However, autistic adults have been living in a protracted crisis that has gone unnoticed by the general public and health communities. Earlier, I pointed out that Broderick and Ne'eman emphasize that autism is not a health crisis (468). They are certainly right, in the sense that autism is not a life-threatening diagnosis. However, autistic people do tend to live shorter lives. An alarming study published by the research charity Autistica in 2016 concluded that the average life span of an autistic person in the United Kingdom is 18 years shorter than a non-autistic person, with epilepsy and suicide listed as two of the major causes of premature death (4). While the study is limited to the United Kingdom, the findings have implications for autistic people in other countries as well. The report notes that these statistics concerning autism and premature death have gone unnoticed for a long time because much of the research to date has focused on autism in young children (Autistica 7). In addition to advocating for greater medical research concerning the prevalence of epilepsy in autistic adults, Autistica also calls for greater attention to the needs and perspectives of autistic adults. These findings suggest how a system that emphasizes researching issues surrounding children at the expense of excluding both the physical and mental health challenges of autistic adults is a form of slow violence with a clear representational challenge.

Wretches & Jabberers and "In My Language" offer alternatives to awareness efforts like those of the United Nations, Autism Speaks, and other organizations. They reframe what has been understood as an epidemic of individuals with defective communication and social skills as a different crisis of communication - a crisis characterized by a lack of access to communication aids, and an inadequate dialogue surrounding how autism affects autistic individuals themselves. As Clare Barker indicates in her book at the intersection of disability studies and postcolonial studies, one of the assumptions that has troubled disability studies is the idea that the western rights-centric model of disability activism is preferable to models from other countries that may focus more strongly on interdependence (22-23). These two works move away from a western medical model, as well as a model of disability that focuses solely on rights and independence; interdependence and networks of support and understanding are central to these works. They both begin an international dialogue on acceptance along multiple axes amongst people who may have similar experiences of marginalization within their diverse cultures and societies.

My next chapter explores further connections between disability studies and environmental movements that feed into the concept of critical ecologies of embodiment. As I argued in my introduction, critical ecologies of embodiment acknowledge that environmental change plays a role in human health. Artistic and literary works can creatively manipulate narrative time to show governments, companies, and other organizations have created disabling environments that create pain for certain bodies, and that these effects are not evenly distributed. In this sense, disability studies can draw from theory in the environmental humanities to offer a social, rather than medical, understanding of the relationship between environments and health. Examining critical ecologies of embodiment allows us to recognize and appreciate the generative difference that disability makes on an aesthetic and political level without suggesting that the

conditions that lead to these experiences of pain are acceptable. This mode of analysis continues in the tradition of disability studies in recognizing the rhetorical dimension of scientific knowledge. When disability is understood as evidence of worsening environmental health, individuals become the targets of stigma and blame, when larger, and more systemic issues deserve attention and critique. In my next chapter, I will look at how when we are determining whether or not an environment contributes to disability, we need to look at the rhetorical dimensions of scientific knowledge. In this case, we need to examine scientific knowledge translation about autism, and interrogate what kind of audience investments are present in the belief that autism is a problem. This next chapter will move toward a recognition of autism as a significant form of biological diversity, as opposed to a set of biological deficits.

## **Chapter Four**

Alternative Futurities: Neurological Difference and Environmental Diversity

## 1. Outlining Pathology versus Embracing Neurological Diversity

In "Don't Mourn for Us," a letter to parents of autistic children, Jim Sinclair, an autistic writer and activist, contests the belief that autism is the barrier behind which lies a 'normal' child. Sinclair encourages parents to rethink their belief that autism is an 'impenetrable wall' that prevents them from communicating with their normal child. He invites them to stop mourning for a child who is very much alive, and to accept that autism is an integral part of that child's personality. Disability studies scholar Stuart Murray, who also addresses the popular belief that individuals host their autism, critiques the detrimental impact of this "autism-inside-the-person" model (Representing Autism 30-31). The perception that autism involves a sort of parasitic relationship with the individual acting as a host has underpinned many theories about autism that position it as a disease as opposed to a set of neurological differences. As Murray suggests, many theories foster the belief that autism must be cured when "all serious research into autism acknowledges that it is a lifelong condition that is built into the fabric of the person who has it" and "as such, it cannot be cured" (Autism 89-90). Many writers contest the belief that a cure is possible or desirable, even while acknowledging the difficulties of living with autism (Baggs; Broderick and Ne'eman; Brown; Murray; Sinclair: Yergeau). Yet, as I discuss in my previous chapter, despite increasing interest in neurodiversity, many believe that we are living amidst an autism epidemic, and are hesitant to embrace neurological difference across the autism spectrum.

In this chapter, I build on my earlier discussion of the discourse surrounding an autism epidemic to discuss how proponents appeal to popularized environmentalist sentiments by

linking rising diagnoses to undesirable changes in our environments. While demonstrating how environmental degradation affects human health and ability is an important aspect of environmental justice, a disconnect exists between the concern that environmentalists express for rising diagnoses of autism, and the importance of equal rights that has been the focus of autistic self-advocates and their supporters. To examine the connection between autism discourse and environmentalist discourse, I use Ray's formulation of the 'ecological other,' which I have discussed in earlier chapters. Ray, who argues for the importance of considering intersections between disability studies and the environmental humanities, explains that mainstream environmentalism has contributed to the exclusion of disabled people in American culture, and shows how, "the figure of the disabled body is the quintessential symbol of humanity's alienation from nature," as, "environmentalism played a significant role in constructing the disabled body, a historical legacy that continues to shape the corporeal bases for its various forms of exclusion" (6). Ray's concept is useful for considering how the language of threat surrounding autism is bolstered by a belief that its development represents the toxic effects of biotechnology companies and consumptive practices. As with other disabilities, autism has become a symbol of humanity's alienation from nature. Crucially, it is not just specific environmental thinkers who make this association, but also a general public that is continually presented with metaphorical associations between disability and degradation, and between symptoms and pollution. In these discourses, autism is often an ominous sign for the future.

Many thinkers in disability studies have looked at how disability has been associated with a lack of futurity. Much of this work has taken place because of effective collaborations between disability theory and queer theory. As discussed in my previous chapters, Robert McRuer, who examines compulsory heterosexuality and compulsory able-bodiedness under capitalism, looks at

how the old adage that anyone who lives long enough will become disabled is not necessarily unifying, as it is frightening for people who associate disability with a lack of futurity (207). Alison Kafer similarly examines the relationship between disability and futurity in her intersectional study of disability studies, queer theory, and feminism. She critiques queer theorist Lee Edelman, who calls on those working in queer theory to 'fuck the future,' or, in other words, to reject heteronormative visions of the future – specifically, a future centering on biological reproduction and the figure of the child. Kafer notes that Edelman's critique is valuable for those who face pressure to project themselves into the future, but she points out that disabled people are never encouraged to project themselves into the future, and are often actively discouraged from reproducing (31). Kafer argues that 'fucking the future' is not a viable option for disabled people, who are actually tasked with carving out space for themselves in such visions. Her work highlights how disabled people often confront the perception that futures containing disability are failed futures, in which disability remains a problem.

Academic and artist Ju Gosling makes similar claims to Kafer in her advancement of a scientific model of disability. Gosling argues for a scientific model of disability as an alternative to the medical model. She suggests that the general public has been trained to put their trust in the power of science to eventually cure disabilities. In order to critique this perspective, Gosling turns to the history of scientific thought and research. In particular, she points out that with the invention of cures for various conditions, new forms of disability will continue to assert themselves. Writing in response to utopian visions of a future where disability is cured, Gosling points out that those who have such faith in science should note that the history of science itself reveals that such claims are exaggerated (173). New technologies can affect human ability and our definitions of it in myriad ways, which suggests the need for imagining spaces, communities,

and social practices that welcome disability. <sup>101</sup> Studies of disability and emerging technologies also look at the exclusion of disability in discourses about the future. Kathryn Allan and other thinkers in the *Disability in Science Fiction* anthology look at the tense relationship that disability has with science fiction; while science fiction demonstrates how our understanding of what constitutes a disability is always changing and is dependent on our environments, some science fiction stories clearly imagine away disability to signal a more desirable future.

Disability, then, often functions as a sign of a failed future. <sup>102</sup>

Similarly, James C. Wilson, examining scientific discourse and knowledge translation surrounding the human genome project, critiques how the project codes disability as a textual error. He laments that the field of genomics might "permanently stigmatize disability as the genetic Other," as the field, as its currently constituted, positions scientists as editors removing textual errors from a definitive source text (28). Conscious of the importance of genetic research and medical technologies that have saved the lives of many disabled people, Wilson suggests that genomics might play an alternative, important role in promoting disability acceptance through emphasizing that variation is natural. Wilson's work suggests one way autistic people are othered, as genetic others. One of the possibilities that genetic research looks toward is

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<sup>&</sup>lt;sup>101</sup> An example relevant to Gosling's case is the example of Thalidomide that I discussed in my introduction.
<sup>102</sup> In an analysis of the novels *Blindsight* by Peter Watts and *River of Gods* by Ian McDonald, Netty Mattar argues that, "while mainstream representations of prostheticized disabled bodies have tended toward the reassertion of normativity, SF challenges these ideas by exploring how science and technology unsettles the assumed limits of the human body" (76). Elsewhere, I discuss how the interaction between narrative and play in the computer game *Deus Ex: Human Revolution* (2011) emphasizes how what we consider an able body in a science fiction game setting differs substantially from our definitions of an able body in the present time, which in turn illustrates how definitions of disability change across culture and over time ("Playing for Transcendence").

However, the erasure of disability in science fiction is also very prominent. For example, the protagonist of the film *Avatar* (2009) is a wheelchair user who manages to escape his disabled body at the end of the film by transporting his consciousness into an alien avatar. When disability is more prominent in science fiction, it often signals a dystopian future. In the conclusion to this work, I discuss the film *Mad Max: Fury Road* (2015), and tensions surrounding its simultaneous celebration of disability and use of disability to signal a bleak future.

103 Although Wilson acknowledges the importance of genetic research, he also critiques how much money is directed toward research when comparatively little is given to people living with the impairments and diseases that science promises to help (33).

prenatal screening technology to determine if a fetus is autistic. Discussions around these technological possibilities concern how one might alter the genetic makeup of a fetus before it becomes autistic. One of the ethical issues that such a technology presents is the question of selective abortion. Many believe that screening technologies would problematically assist in efforts to terminate autistic people, arguments that can be supported by looking at how screening technology has decreased the birth rate of children born with Down's syndrome. <sup>104</sup>

One could make the counterargument, however, that autism is associated with the future, and with human progress. After all, many retrospective diagnoses now circulate, as the practice of diagnosing historical figures with autism based on biographical information has become popular. Paul Heilker points out that many speculative lists of famous autistic people appear on the internet, with such inclusions as Marie Curie, Leonardo Da Vinci, James Joyce, Nicola Tesla, and Alan Turing. As these individuals are celebrated for furthering human progress through achievements in science and art, looking back to their accomplishments is also a means of looking forward, and a way of showing how autistic people have made meaningful contributions to human civilization. Neil Patrick Shepard similarly notes that in a cultural moment that celebrates "geek chic," Asperger's syndrome has been associated with technological progress, and cultural acceptance is ripe in some areas. However, he points out that many representations of Asperger's syndrome "are problematic in the way that they uphold traditional normativity in terms of gender, race and class, as well as reifying stigma toward other points on the autism spectrum" (ii). Heilker points out that some within the autism community push even further to suggest that autistic neurology is an improvement over 'normal' neurology, and marks the next

<sup>&</sup>lt;sup>104</sup> Joan K. Morris and Eva Alberman note that between 1989 and 2008 in England and Wales, the number of live births with Down's syndrome dropped by 1% due to antenatal screening and subsequent abortions. If such screening had not been available, the number of infants born with Down's syndrome would have increased by 48% (Morris and Alberman 1).

phase of human evolution; here, he notes that the discourse uncomfortably echoes that of racial supremacists (Heilker). While autism is sometimes aligned with the future in popular perceptions and within some autism communities, it is often only with reference to specific autistic people who demonstrate skills in science, technology, engineering, and mathematics (STEM) fields associated with technological innovation, progress, and the future. Although the popularity of the diagnosis has made representations of autism more common in popular culture, the predominant autistic figure that features most often is white and male. In awareness advertisements, this figure is usually a child, as many organizations are still invested in presenting autism as a childhood disability for which we may find a cure in the future. Such investments indicate a continued struggle to imagine a future that includes autistic people who do not necessarily fit within the favourable cultural scripts about autism – autistic people who may not work in STEM fields, who may not communicate orally, who may occupy other marginalized identity positions, and who may require significant daily support and assistance.

This chapter focuses on writers for whom imagining alternative, inclusive futures is vital, in an age of risk in which, from an environmental standpoint, imagining the future is often a bleak exercise. My aim is to survey the ways that autism has become associated with environmental degradation and a corresponding lack of futurity in the public imagination, and to turn to writers who argue instead for the role of autistic people as activists. In doing so, I advocate an intersectional approach to thinking about environmentalism by drawing on feminist ecocritical writings, including those of Ray, Alaimo, Banu Subramaniam, and Giovanna Di Chiro. I explain how these scholars show how we can look at the relationship between people and their environments to complicate traditional understandings of the borders between nature and culture, while also emphasizing the importance of how individuals frame these relationships

themselves. In this respect, I seek to contribute to the conversation surrounding connections between disability studies and the environmental humanities by considering the agency of autistic people in their own writings compared to how they are characterized in those of environmental, charitable, and research organizations. In my earlier chapters, I explained the significance of disabling environments by looking how Alaimo's work responds to the struggle of individuals with MCS for recognition. My work pursues a different question of recognition; I engage with the political struggles of autistic adults, whose concerns are often absent from environmental writings that discuss autism along the same lines as disease, when the concerns and the discourses surrounding them are very different. Although more recent work in disability studies troubles strict distinctions between disability and illness by pointing out that diagnoses like chronic illness blur these categories, the extent to which a strong identity movement has emerged surrounding autism has complicated the push toward a cure that is less controversial in research surrounding cancer, ALS, and other conditions that are known to be life threatening. While autistic people may experience significant health challenges, many still reject the perception that, given the choice, they would want to be normal. However, writings that link autism to environmental change often do not engage with distinctions in how this diagnosis has been framed by those who have received it and by their allies.

In my next section, I use Ray's concept of the 'ecological other' to examine a selection of environmentalist articles, blogs, and materials from autism organizations. I examine the language used to articulate connections between autism and our changing environments in these artifacts. I do not engage with the question of whether or to what extent autism has environmental causes,

and I do not argue that all research on this topic is ableist. 105 Rather, I examine the knowledge translation of research on environmental factors to the general public. Showing how the discourse surrounding autism often draws problematic comparisons between the changes represented by ecological devastation and the changing condition of human neurology, I suggest that hypotheses linking environmental toxins and autism tend to be expressed in ways that validate a medical model that frames autism as unnatural and that discounts autistic subjectivity. As I point out in my third chapter, Broderick and Ne'eman argue that characterizing autism as a health crisis "draws upon a medicalized disease discourse in which people who have labels of autism are constituted not as neurologically different, nor even as disabled, but rather as diseased, not healthy, or ill" (468). The disease model appears in environmentalist works that position autism as a sign of our worsening ecological condition. I argue that autistic individuals are positioned as ecological others when autism is held up as an example of the toxicity of our contemporary society, and I emphasize the importance of pursuing efforts to link disability rights and environmental justice in a more nuanced way. In my third section, I investigate a future that champions preventing autism by looking at the knowledge translation of autism research in two documentary films. In my fourth section, I examine a second, inclusive future represented by the efforts of technology companies, and discuss both the possibilities and limits of this future. In my final section, I examine the writings of autistic adults and their creative engagement with these ideas, including how they resist dominant metaphors about autism by creating new ones that carve out a space for autism in the future, and emphasize how variation is natural.

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<sup>&</sup>lt;sup>105</sup> Here, I echo Scott Michael Robertson, as I would argue that while scientific research into autism can yield important insights, research into the specific challenges that face autistic adults in their daily lives, such as housing and communication support, need to be prioritized. Causation research will not be able to help autistic adults now. <sup>106</sup> This is not to suggest that autism as an embodied reality should be ignored. Douglas Biklen points out that "the person labeled autistic has been known to complain about an unruly body that will not always comply with intention" (66). Some people have co-occurring conditions and disabilities that are life-threatening. However, autism is not a life-threatening condition, which, as disability advocates point out, makes some comparisons to illness untenable and offensive.

## 2. Autism in the Popular Environmental Imagination

Bridging disability studies and the environmental humanities reveals how the medical model both shapes environmentalist perspectives on disability, and appropriates environmentalist discourse to exclude disabled people. Popular environmentalist organizations concerned with the detrimental effects of commercial chemicals and genetically modified foods will cite autism as one of many conditions on the rise because of the practices of unethical corporations like Monsanto. Cassady Sharp, writing for Greenpeace, lists a link between glyphosate in Monsanto's Roundup herbicide, and rising rates of autism, as one reason to join in an upcoming March Against Monsanto (2013). 107 The March Against Monsanto organization has also drawn attention to autism. In 2013, they posted an infographic on social media exhibiting a correlation between the rise in autism diagnoses and the rise in the production of genetically modified foods (March Against Monsanto). In 2014, The March Against Monsanto marked autism awareness month in April on social media by calling for a public outcry over the prevalence of autism, noting that the composition of the national food supply and the Centre for Disease Control's vaccine schedule have both changed in the time that rates of autism have increased. 108 While the majority of scientists do not support links between autism and vaccines, critical environmentalist thinkers who are accustomed to governments and corporations choosing to fund studies that minimize their accountability may, understandably, be difficult to convince. 109 However, while many of

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<sup>&</sup>lt;sup>107</sup> Many articles in the spring of 2013 that discuss the link between autism and Monsanto's herbicide reference Anthony Samsel and Stephanie Seneff's study, "Glyphosate's Suppression of Cytochrome P450 Enzymes and Amino Acid Biosynthesis by the Gut Microbiome: Pathways to Modern Diseases". This study links the consumption of glyphosate residues to gastrointestinal disorders, obesity, diabetes, heart disease, depression, autism, infertility, cancer, and Alzheimer's disease. Scientists have challenged the study's methodology, arguing that the claims in the article are extremely speculative (Goldstein 2014). While some of the critics are Monsanto supporters, environmentalists who critique Monsanto critiqued the article too (Haspel 2013).

<sup>&</sup>lt;sup>108</sup> Some users strongly objected to the suggested link between vaccines and autism in the comments section by emphasizing that readers have shown this connection to be false.

<sup>&</sup>lt;sup>109</sup> For example, as I have previously noted, chemical manufacturers fund research that deny MCS is an illness (Alaimo126). Fracking is another example of an industry in which companies are known to fund research indicating

these efforts on the part of environmentalists may be well-intentioned toward autistic people, this practice of attempting to unmask the environmental truths of embodiment distinguishes between those whose bodies are affected by toxicity and those whose bodies are not.<sup>110</sup>

Many environmentalist writers, who are justifiably concerned about connections between corporate practices and poor human health, continue to suggest that autism might be a form of mercury poisoning. For example, journalist Brita Belli calls for greater research into environmental factors by exploring connections between autism and neurological damage from mercury poisoning in her book, The Autism Puzzle: Connecting the Dots Between Environmental Toxins and Rising Autism Rates (2012). 111 Autism, in these accounts, becomes an additional argument for changing larger agricultural practices. Environmentalist thinkers have also linked autism to poor nutritional habits. People for the Ethical Treatment of Animals used autism to further their cause by using a "Got Autism?" campaign to promote veganism by suggesting a causation link between autism and cow's milk (PETA). Another example of efforts to link autism to poor health and unsustainable practices was celebrity chef Pete Evans's voicing of his belief that western consumptive practices are causing autism; Evans suggested that the Paleo diet could reverse symptoms of autism (Crane 2014). Many experts refuted Evans's claim, but his message was one of many moments in which autism was held up as an embodied sign of the damage of western agricultural practices. While critiques of Monsanto and other companies are

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that the controversial practice has a limited environmental impact. As Cary Nelson, former President of the American Association of University Professors, has noted, a key issue in this case is transparency. In 2013, he wrote that, "Frackademia constitutes a new institutional identity formed by a mixture of political and financial pressures, an identity that can compromise both the environment and academic research" (Nelson.)

Mel Chen makes a similar critique in her work as she breaks down the distinction between toxic and non-toxic bodies. She "engage[s] toxicity as a *condition*, one that is too complex to imagine as a property of one or another individual group or something that could itself be so easily bounded" (Chen 196).

<sup>&</sup>lt;sup>111</sup> Brita Belli is a former editor of *E-The Environmental Magazine*. Belli's book was reviewed by Brian Clark Howard of *National Geographic*, and Eleanor J. Bader of *AlterNet*, whose review was also featured in *Salon*.

necessary, we can also critique the way in which popular environmentalism uncritically refers to autism to strengthen its arguments without referring to the perspectives of autistic people.

However, some autistic people do express needs and preferences for particular diets, and my criticism of media discourse is not a wholesale dismissal of the way that people, both autistic and non-autistic, might feel more focused or energized by modifying their diets. Autism is experienced differently by many people, and some individuals may have accompanying conditions for which they might take supplements or might make significant changes to their consumptive habits. Donna Williams, for example, notes that she follows a special diet because she has food allergies to phenol and salicylate, which affect her anxiety levels, sensory perception, and impulses to self-abuse (78). While following special diets and avoiding contact with particular substances may ameliorate the daily lives of some autistic people, presentations of links between autism and genetically modified foods, agricultural pesticides, and cow's milk often, one, alienate autistic people through rhetoric that promotes fear; two, create the impression that with sufficient effort, autism can be cured and people can return to an original, normal state; and three, omit the voices of autistic people who might complicate these claims. The generalized metaphorical associations between autism and environmental degradation position autistic people as ecological others, as outsiders in a discourse that clearly concerns them.

However, it is also important to recognize that critiques of the rhetorical strategies of environmental organizations and journalists also proceed from within the environmental humanities as well. In my introduction, I discussed how Donna Haraway and Anne-Lise François critique how environmental discourse problematically draws on such terms as 'natural' and 'pure' to oppose advances in biotechnology. François is critical of the development of GMOS, but she argues that the popular trend of calling these products "Frankenfoods" betrays, "a

dangerous fetishization of purity and biological essence fueling the resistance to these newer technologies" (50). Similarly, Haraway, "cannot help but hear in the biotechnology debates the unintended tones of fear of the alien and suspicion of the mixed" (qtd. in François). Biologist Banu Subramaniam, who shares similar concerns, describes how strong parallels exist between the anxiety surrounding foreign plants and foreign people. She notes that, 'like the earlier germ panic surrounding immigration and immigrants, questions of hygiene and disease haunt exotic plants and animals," and outlines three similarities: firstly, both 'alien' (plants and people) are recognized as other; secondly, both are understood to be taking over everywhere; thirdly, they are silently growing in strength and number; fourthly, they are difficult to destroy and can withstand extreme situations; five, they are predators who reproduce rapidly; and finally, six, they never look back upon gaining territory: "like human immigrants, the greatest focus is on their economic costs because it is believed that they consume resources and return nothing" (30). As I will show, the similarities that Subramaniam notes here pertain to media discourse about autistic people, as such discourse often depends on the use of fear to demand public attention.

The imagined differences between humans and extraterrestrial life have often been used as a metaphor for the differences between autistic people and neurotypical people. Some within the autism community have embraced this metaphor, including Alex Plank, creator of the website *Wrong Planet*, which serves as a forum for individuals with autism, Asperger's Syndrome, ADHD, PDDs and other neurological differences, as well as their parents and interested professionals. Anthropologist Dawn Prince-Hughes, in her memoir of living with autism called *Songs of the Gorilla Nation*, describes how she identified with the character of Seven of Nine from *Star Trek*, a part-machine and part-human woman who was assimilated by an alien species called the Borg. Prince-Hughes notes, "like Seven of Nine, I find that I am only

<sup>112</sup> For an extended analysis of this topic, please see Ian Hacking's article, "Humans, Aliens, & Autism."

part "human" and very much something altogether different; I am overwhelmed by the social demands of "normal life"; and I am lonely" (85). For Prince-Hughes, who recognizes that she often feels "othered" by the people with whom she is surrounded, identifying with a character that is similarly understood as an "other" is comforting. However, while the alien metaphor may be empowering for people to use to describe themselves and validate their own differences, it takes on a more problematic valence when a neurotypical audience appropriates this metaphor. For example, psychologist Oliver Sacks used Temple Grandin's quotation that she often feels like "an anthropologist on Mars" in her interactions with non-autistic people as the title for his popular book on cognitive difference. As Dolmage points out, Sacks appropriates Grandin's metaphor for himself; although Grandin had characterized herself as a human visiting an alien world, Sacks turns the metaphor around to describe himself as a human amongst alien personalities (8). 113 While identifying oneself as having landed on the wrong planet may serve to show how disability changes in different social contexts, this same metaphor has also been used to categorize and catalogue difference in ways that focus on deficit. In particular, characterizations of autism itself as a parasitic alien align difference with disease.

Some awareness documents use prevalence statistics to suggest that on a global scale, we should fear how autism is taking over normal children. Such documents suggest that an invasion of sorts is taking place. One example is Suzanne Wright's "Call for Action" in November 2013, which prompted the memoirist John Elder Robison to cut ties with the organization. Wright intersperses her message for the nation to take further action with the refrain, "This is autism," to

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<sup>&</sup>lt;sup>113</sup> Ralph James Savarese critiques Sacks for the authority that he maintains in his book even as he draws very empathetic portraits of his patients:

His shifting metaphors and anachronistic fantasy work to humanize the scientific authority required to tell these stories, but the authority itself is never renounced, nor is its connection to a pathologizing impulse. Indeed, both remain in the kinder, gentler figure of the physician or anthropologist. Apparently oblivious to the oppressive history of anthropological endeavour, Sacks, for example, reinscribes the center/margin binary that makes colonialism possible, exactly as he would have us believe in his folksy goodwill. (273-274)

describe how parents and other family members feel depleted by the everyday challenges of disability (Wright). Wright's comparison of the prevalence of autistic people to a situation in which three million children in the United States went missing or became ill reiterated many of the harmful metaphors to which Robison had objected. While Wright's call to action does not call for violence against autistic people, her suggestion that autism is a problem that will cost the nation over 137 billion dollars has been perceived as threatening by those who celebrate neurological difference and those who are more interested in accessible environments, improved health care, and more opportunities to speak for themselves than in efforts to make them more like "normal" people. 114 115 What Wright's approach and some environmental approaches seem to share is an understanding of autism as something that is hosted, and extrinsic to one's identity. Such approaches, and their corresponding attempts to pathologize and change autistic difference, trouble Prince-Hughes. Speaking to her lived experience as an autistic woman, she laments the objectification of the character Seven of Nine:

Neurotypical humans, I have learned, have a deep fascination with, and an attraction/repulsion to, the kind of figure I presented...People seemed to want to conquer the very parts of me that made me initially appealing to them. For people to fantasize about toppling and ravaging the very qualities that make a person such as me or Seven truly beautiful seems irrational. Like Seven's character must have felt, I have many times seen no end in sight to the eternal drifting through cold space in a ship out of control, without the comfort of a living mirror for my soul or the warmth of a companion who loves me because she understands me from the inside of my body out. (86)

Here, we might see comparisons with Subramaniam's account of how the focus on foreign plants and foreign people is on economic costs; similarly, the call to action suggests that autistic people "consume resources and return nothing" (30).

<sup>&</sup>lt;sup>115</sup> For example, autistic people, like other disabled people, have consistently faced barriers to accessing life-saving medical treatment like organ transplantation procedures (Ne'eman, Knapp, and Narby).

Describing how the alien metaphor can be both empowering and limiting may seem paradoxical, but I would argue that the reflections that Prince-Hughes offers here reveal the hidden and unintentional violence of attempting to make autistic people look and behave 'normally'. As evident from her discussion of reactions to the character of Seven, the problem that she faces is not that she is recognized as in many ways different from the people with whom she is surrounded, but that this difference is not something that is understood to be able to peacefully coexist in the neurotypical world. Instead, difference is something that must be recognized, targeted, and conquered as the individual is assimilated.

While appreciation for the talents of autistic people is more common now than it was at the beginning of the twenty-first century, many parents remain instructed to fear autism as a potential risk factor, as something that threatens to affect the original plan for their child's development. The belief that autism is a form of mercury poisoning, which still has adherents despite significant research disproving it, is rooted in the idea that autism is hosted by a normal body. Although the MMR vaccine is understood within the medical profession as important to protecting public health, some people refuse vaccination for their children on the grounds that the vaccine contains harmful, toxic substances that have the potential to make a person autistic. Attention to the vaccine controversy surrounding Andrew Wakefield's research increased in 2015, as many American celebrities and politicians, such as Jim Carrey, Robert F. Kennedy Jr., Jenny McCarthy, and Donald Trump continue to advocate for the right to refuse vaccination or modify the vaccine schedule for one's child. Many journalists and public figures have been drawing attention to the vaccine debate on the other side, and assuring individuals that vaccines do not cause autism. In doing so, many are pointing toward the expertise of doctors, insisting that

people should pay more attention to those with professional knowledge. The key emphasis, for many in favour of vaccination, is that vaccines do not cause autism. The vaccine debate puts many disability rights advocates and autistic people in an unusual position of defending medical expertise in order to speak out against the ableism that has defined the anti-vaccine movement.

After all, defending the authority of doctors may be unusual for disability studies scholars, as the field encourages an alternative discourse about the body to that of established medical paradigms. Scholars have deliberately challenged the idea that only health professionals are qualified to speak about disability. In addition to its strong activist foundation, the development of the field is indebted to the insights of Michel Foucault, who critiques the objective status of professional knowledge and its relationship to truth in *The Birth of the Clinic*. Disability studies scholar Licia Carlson points out that Foucault's work is central to disability studies because it "problematizes what is taken to be self-evident with respect to institutions, power, and certain classifications of individuals" (133). In a chapter on "Seeing and Knowing" in The Birth of the Clinic, Foucault discusses the establishment of the space of the clinic and its production of the medical gaze as one able to see and know the truth of bodies. In order to address the ableism present in the claims of those who link autism to vaccination, many have turned to the explanatory authority of the vast majority doctors, who assert that links between autism and vaccination are untenable. While the opinions of doctors and researchers on this matter deserve recognition, the extent to which medical paradigms naturally code difference as deficit still merit attention. On this point, Murray cautions, "medicine is, it appears, our best guide for understanding autism at any given moment in time..." but he also notes that our faith in

<sup>&</sup>lt;sup>116</sup> One popular example of a popular critique of individuals who have chosen not to vaccinate their children was that of American comedian Jimmy Kimmel, who played a recorded clip of doctors on his show in an effort to encourage viewers to consult medical knowledge, as opposed to the experiential knowledge of parents and celebrities.

medical knowledge needs to be tempered by recognition of the limitations of that knowledge (*Autism* 2). While many have been quick to supportively echo the claims of doctors that vaccines do not cause autism, does such recognition legitimately constitute an erasure of the fear surrounding autism, or merely a displacement of that fear? In other words, while those in the medical profession and their supporters may dismiss links between vaccines and autism, they may not necessarily be accepting of autistic difference. While anti-vaccination discourse may be entrenched with ableism, those who advocate vaccination sometimes use ableist language to characterize people who refuse vaccinations for their children.

Many individuals who critique people who have been dubbed "anti-vaxxers" represent them as unintelligent conspiracy theorists, and suggest that these people should pay attention to medical authorities as opposed to vocal celebrities who oppose vaccination. While it may be inadvisable to take medical advice from celebrities, ableism also attends the critique of individuals who question medical authority on vaccines. Writers have uncritically applied ableist terms such as "crazy", "stupid", and "moron" to those who would question medical authority. In an article for *New Republic*, journalist Rachel Hills speaks to this issue. She argues that the best way to increase vaccination rates is to avoid accusations and insults, and instead attempt to understand the group labelled "anti-vaxxers" (Hills). Her argument draws on Jennifer A. Reisch's sociological research into the gendered nature of vaccine refusal. Reisch connects vaccine refusal to practices of neoliberal mothering:

As managers of risk and good choice-makers, some women who embrace the tenets of neoliberal ideologies find that the centrality of the mothering role translates into an

<sup>&</sup>lt;sup>117</sup> For example, in an article in the *New York Daily News*, Dr. Dyan Hes, the medical director at Gramercy Pediatrics, describes her experience with an individual skeptical of vaccination as follows: "I just spent the last half-hour Facebooking with some crazy anti-vaxxer. Convincing (them) is difficult" (Engel). Another example of such ableist characterizations of people who question the merit of vaccination is a blog post by obstetrician Dr. Amy Tuteur, which is a response to journalist Rachel Hills titled, "Sorry, but anti-vax advocates are idiots and crazies."

individualistic experience of accomplishment and expertise, even as their perceived options are facilitated by access to resources. (682)

Reisch points out that many women's health movements emphasize the importance of individual choice, and women's decisions to refuse vaccines for their children thus demonstrate their exercise of individual choice in a manner that is consistent with other advocates. When one considers the connection between women's health movements and disability studies, as well as the barriers to accessing medical knowledge, vaccine refusal may be, not more justified, but more understandable. The argument that people should simply listen to doctors with respect to autism is perhaps not nuanced enough, as it lacks attention to the critique of medical knowledge that disability studies and women's health movements have put forward.

With this critique in mind, perhaps what deserves more attention in discussions of vaccines is not the question of causation, but the implicit risk assessment that leads some individuals to believe that being autistic is worse than contracting the measles. While medical knowledge and its dissemination has helped to dispel widespread public belief that the MMR vaccine might cause autism, not all recent efforts to dispel these beliefs are necessarily directly working toward autism acceptance, although they might be in some cases. Although increasing vocal support for vaccination is in many ways productive and will help autistic advocacy, such efforts can also be coupled with an acknowledgment that researchers who perform medical research surrounding autism are often guided by ableist assumptions that inform their interpretation of research findings. <sup>118</sup> In an article in *Medium*, Sarah Kurchak addresses the issue

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As I discuss in a book review, Murray makes an important contribution to critical autism studies by acknowledging how the diagnostic criteria of autism forms a dominant narrative that is predominantly negative:

Although Murray summarizes key facts about autism, he emphasizes the provisional nature of medical knowledge, and highlights our ultimate lack of knowledge. He focuses on significant absences and definitions as he criticizes how the sensory experience of autism receives little attention in diagnostic manuals despite its centrality to individuals, and clarifies that neurological difference does not imply poor health. Most significantly, Murray supports his call to read the construction of autism as a narrative by

that the media focus has not been on accepting autism, but on reassuring the public that vaccines do not cause it. She shifts the question to ask if those who believe in causation really believe that being autistic is worse than dying from the measles (Kurchak). Kurchak offers an alternative perspective for tackling the anti-vaccination movement, which, rather than suggesting the infallibility of doctors, calls upon those engaged in the debate to make use of the expertise of autistic people, who can assure individuals that while autism may be disabling in many ways, the stigma generated by vaccine controversies is part of that disabling experience. As individuals who refuse vaccination often frame it as a choice for healthier, natural, and environmentally conscious way of living, vaccine refusal is also part of the ecological othering of autistic people.

Ray explains that the concept of the ecological other is about cultural disgust; one's physical form becomes evidence of one's allegiance to or disregard for environmental politics. Popular environmentalism presents the body as "the site of negotiation of and resistance to industrial food production" (Ray 2). In the fight to 'combat obesity', it is individual bodies, as opposed to systems of production and distribution, that are recognized as targets. While one's weight may be interpreted as evidence of one's commitment to environmentalist values, one's way of interacting with the world has been taken up by an environmentalist lens too. Popular environmentalism may not blame autistic people for disregarding the environment in the same manner in which it often blames heavier people for unsustainable practices, but it exhibits

explaining how the diagnostic process is evaluative in the absence of clear biological markers. The diagnostic process often supplies the 'patient story' (particularly for non-verbal individuals), and frames autism as a problem. For example, researcher Simon Baron-Cohen suggests that in order to receive a diagnosis of autism, there must be evidence that the individual in question is suffering. While Murray does not suggest that suffering never accompanies autism, he does highlight how other life experiences, such as poverty, cause suffering but do not necessitate the creation of individual diagnostic criteria. He argues that understanding autism as a form of suffering, "produces a working version of the condition that has an assumed negativity and a normalized value-judgment built into its medical/diagnostic baseline" (21). (170).

John Duffy and Rebecca Dorner make similar claims about Theory of Mind (ToM), arguing that "despite its foundations in the language of cognitive psychology, [ToM] is a discourse of affect and values or a rhetoric of scientific sadness in which autistic people are mourned even as they are ostensibly explained" (201).

cultural disgust toward autism as a condition through a practice of abstraction. Ray also explains that her concept of the ecological other depends upon Mary Douglas's argument that the environment "is as much a disciplining discourse as it is a material object" (Ray 18) as, to quote Douglas, society "produces its own selected view of the natural environment" and its accompanying risks (qtd. in Ray 18). Ray clarifies that, "those in power are in charge not only of defining the environmental risks, but also of identifying people who are 'risks to nature'" (18). In many popular environmentalist accounts, autism is affiliated with the worst offences of biotechnology companies, corporate agriculture, and individual consumptive practices. For this reason, popular environmentalist takes on autism echo the same goals of prevention and cure articulated by charity organizations, which are characteristic of scientific research directions toward autism. The ecological othering of autistic people is made possible by the abstraction that comes with characterizing autism as a disease, and through the use of militaristic metaphors.

Although the cultural representation of autism is different from the cultural representation of obesity, issues of blame and stigma arise in conversations about autism as well. While professionals in the mid twentieth century blamed mothers for autism, suggesting that the parenting styles of 'refrigerator mothers' were responsible for their children's behaviours, in the twenty-first century, in some circles blame has shifted to mothers who do not engage in holistic efforts to recover their children. Jordynn Jack explains that the memoirs of self-titled autism mothers like that of American actress Jenny McCarthy suggest that the dedicated parent of an autistic child is one who works hard to eradicate the signs and symptoms of autism through healthy living (63). In these memoirs, if autistic bodies are the "site of negotiation of and resistance to industrial food production," the mothers are the warriors fighting on the battleground (Ray 2). In Steve Silberman's *Neuro Tribes*, a history of autism and the

neurodiversity movement, he offers a sympathetic portrait of the Rosa family, who contended with blame and stigma. Craig and Shannon Rosa were nearly pressured into giving their son, Leo Rosa, chelation therapy before they made peace with his diagnosis. In this account, Silberman notes that Shannon Rosa was chastised by other parents in the blogging community for giving up on her son's recovery when she and her husband decided that discovering their son's strengths was more important than "dwelling on the cause of his autism or pitying him as the hapless victim of a Big Pharma conspiracy" (77). Jack and Silberman both explore the deep-seated feelings of blame and responsibility that lead parents to pursue cures for their children, and the lack of support that they receive to accept their children's diagnoses and develop their strengths.

The environmentalist rhetoric present in both the accounts of parents who aim to recover their children from autism, and charitable efforts to cure autism, position the diagnosis as a disease in need of eradication. Considering the implications of the goal of the eradication of autism, I chart the absence of the perspectives of autistic people in two documentary films that discuss potential environmental triggers for autism, which are *Sounding the Alarm: Battling the Autism Epidemic*, which was produced by Autism Speaks, and "The Autism Enigma," which was an episode of *The Nature of Things* with David Suzuki. Many environmental organizations express similar concerns to the charity Autism Speaks, in the sense that their materials also reflect a belief that autism is necessarily a problem. In contrast to ASAN, which understands autism as a form of neurological difference, and suggests that its status as a disability be understood along social lines, Autism Speaks understands autism through a medical lens as a series of deficits (ASAN). By examining how awareness efforts that are interested in curing and

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<sup>&</sup>lt;sup>119</sup> Additionally, Autism Speaks funds research into environmental causation of autism. The organization supports environmental research into how "environmental influences interact with genetic susceptibility ("Environmental Factors in Autism Initiative"). While I would not suggest that the practice of investigating environmental influences is inherently ableist, when Autism Speaks disseminates research findings, their reputation as an organization that highlights the negative aspects of autism contributes to the practice of ecological othering.

preventing autism co-opt the discourse of environmentalism to create a sense of urgency, I suggest that scholars in the environmental humanities and in disability studies can together be critical of these discourses of ecological othering, and reposition autistic people as ecological subjects. Before attempting to rescue individuals from autism, concerned environmental thinkers can consider whether autistic people are expressing an immediate need for the prevention that research into environmental triggers for autism promises.

## 3. Autism and Documentary Films: The Disablism of a Future Without Autism

Sounding the Alarm: Battling the Autism Epidemic, a documentary exploring the rising rates of diagnoses in the United States, was released in 2014. It profiles several families, including Bob and Suzanne Wright, who co-founded Autism Speaks for their grandson. <sup>120</sup> As Lei Wiley-Mydske notes in her review of the film, the title uses a troubling military metaphor to encourage awareness. It also, she points out, echoes concern surrounding the financial cost of autism. It addresses the issue of inclusion through the story of Kent, who leaves high school and faces the limited prospects available to autistic adults, and John, who opens a car wash to ensure employment for his autistic son and other adults. However, its persistent focus on research makes clear that inclusion is a temporary step; the ideal vision of the future promoted by the film is one in which autism and its inherent suffering can be prevented. This is a future characterized by disablism, a process which Disability studies scholar Fiona Kumari Campbell describes as a "set of assumptions promoting the differential or unequal treatment of people because of actual or presumed disabilities" (152). In particular, the metaphors used to describe autism and autistic people in this film promote viewing them through a disablist lens.

<sup>&</sup>lt;sup>120</sup> Bob Wright is a former Chairman of NBC Universal, credentials which contribute to the popularity of Autism Speaks. Wright's charity embraces neoliberal tactics and functions more like a corporation than a disability advocacy organization (Broderick).

Unlike the film Wretches & Jabberers that I discussed in my previous chapter, which positions autistic people themselves as autism experts, Sounding the Alarm depends upon the explanatory authority of medical researchers. Toward the film's close, Dr. Christopher McDougle, director of the Lurie Center for Autism, reiterates that discovering the cause of autism is also important from an economic perspective. He tells the audience, "If we don't begin to find out how to identify the cause and begin to prevent this disorder, or at least intervene earlier in life so we can alter the lifetime course, it's going to cost society a tremendous more amount of money than it's going to cost by being proactive and addressing it now" (Sounding the Alarm). The film's lack of acknowledgment of autistic people who strongly object to the normalizing message that autism must be cured undermines the efforts toward inclusion that the film attempts to illustrate. It presents a vision of the eradication of the ecological other, a future that has eliminated autistic people through cure and treatment. 121 Its message is that greater inclusion is needed until there is a research breakthrough, which is a different message from ASAN and its international partner organizations that present autism acceptance as an end goal in its own right. The militaristic logic of Sounding the Alarm is that accepting autism denotes passivity and complacency. The film operates through abstraction; while autistic children and young adults are present, very few autistic people speak for themselves in this film. 122 Instead, fear operates as a rhetorical strategy to encourage attention and raise awareness.

Lori Unumb, the vice president for state government affairs at Autism Speaks, invokes fear in her descriptions to viewers in her segments of the film. She calls the rise in autism

<sup>&</sup>lt;sup>121</sup> One potential technology explored in the film is the use of maternal screening for antibodies that might contribute to the development of autism, with the expressed purpose of making those antibodies non-functional. The researchers interviewed do not discuss the ethical implications of this technology, such as whether parents might choose to abort a fetus based on the results of the screening (*Sounding the Alarm*).

<sup>&</sup>lt;sup>122</sup> Many autistic adults argue that Autism Speaks does not represent their interests (Ne'eman; Sequeniza, Wiley-Mysdke; Yergeau).

diagnoses, "an unseen and unprovoked medical disaster" (Sounding the Alarm). She also compares autism to a tsunami, warning American viewers that, "there is a huge autism tsunami that is going to hit the state budgets of all our states" (Sounding the Alarm). Here, Unumb's strategy for raising autism awareness positions autism itself as a spectacular natural disaster, a form of sensational violence that, if individuals have not experienced, they have witnessed via news channels. Abstracting autism to characterize it as a disaster, then, is a rhetorical strategy designed to bring attention to prevention research. Unumb's characterization of autism as a looming disaster shapes the film's call for research into environmental causation. Wright articulates her belief that while the majority of research about autism points to genetic markers, there must also be an environmental trigger. She argues that environment must play a role in causing autism because "there's no such thing as a genetic epidemic and we have an epidemic now" (Sounding the Alarm). The film visits the offices of autism researchers that describe potential environmental influences. Dr. David Amaral suggests that environmental chemicals, such as flame retardants and packing materials like BPA, might affect human DNA and increase the risk of autism. Similarly, Dr. Irva Hertz-Picciotto emphasizes that research should examine environmental triggers, explaining, "We need to be looking at maternal nutrition. We need to be looking at air pollution, pesticides. We encounter these kinds of exposures in our everyday lives through what we eat, what we breathe, what medications we take" (Sounding the Alarm). By featuring the voices of scientists alongside militaristic calls to action, the film employs similar rhetorical strategies to that of environmentalist discourse that focuses on maintaining purity.

The discourse in the film encourages concern surrounding the proliferation of toxicities in the contemporary era, and presents autistic bodies as those which are most polluted by these toxicities. Di Chiro, who works at the intersection of queer theory and the environmental

humanities, points out that references to toxicity often appeal to normalizing sentiments. She suggests, however, that an alternative, more inclusive discourse is possible and imperative:

What are the toxic residues of unrecognized or unacknowledged polluted politics that continue to reassert the normalized body and the naturalized environment and therefore impede the potential for forging coalition politics that move us toward a more just, green, and sustainable future? Can we imagine environmental-feminist coalitions that can forge a critical normative environmental politics (we *all* should live in a clean environment; we *all* should have the right to healthy bodies) that resist appeals to normativity? (Di Chiro 203)

Di Chiro's caution that concerns surrounding toxins promote the outdated concept of a pure human body provides insight into how the discourse of this film erects a barrier between those whose bodies are interpreted as evidence of the destruction of our environments, and those whose bodies are impermeable. The co-opting of environmentalist discourse results in a call to action against autism itself, which problematically aligns neurological difference with pollution and impurity. The idea that autism is an aspect of a person's identity is not explored; it is clear that autistic people themselves are not part of the intended audience of this film.

Many scholars have already skillfully critiqued the awareness efforts and research priorities of Autism Speaks, which produced this documentary (Broderick; Broderick and Ne'eman; Sequenzia; Yergeau). The organization has deployed its ideas "through its corporate-style, neoliberal, market approach to cultural and political rhetoric, deploying its rhetorical tactics and strategies more as a powerful corporate lobbying machine than as a traditional disability advocacy organization" (Broderick). My contention is not only that Autism Speaks engages in the practice of ecological othering, but that the rhetorical strategies of organizations

like Autism Speaks are echoed in environmentalist works that characterize autism as a disease. Canadian environmentalist David Suzuki's documentary series *The Nature of Things* dedicated an episode to exploring potential environmental triggers for autism. The episode, entitled "The Autism Enigma" first aired in 2011, and re-aired on CBC TV in both September 2014 and September 2015. "The Autism Enigma" considers rising rates of autism among new Canadians, the impact of dietary interventions, and research into gut bacteria. When compared to *Sounding the Alarm*, Suzuki's documentary is more measured and less offensive. However, it similarly minimizes autistic presence through its near exclusive focus on parents and professionals. As it profiles multiple families, this documentary presents their situations as tragic not because of the lack of support that they receive, but, problematically, because autism takes children away; throughout the film, interviewees assert that they lost their children to autism. While one mother comments of her son, "It's like he's not even there," another holds up a photograph of her son as a child and states, "This is where he's gone" ("The Autism Enigma").

Suzuki is a well-respected environmentalist who is known for educating the public in environmental sciences and for criticizing government inaction on climate change, sustainability, and other issues. These credentials suggest that his discussion of autism in relation to environmental conditions carries greater weight with a mainstream public than many other environmental figures who might posit similar claims. Since 1979, he has hosted *The Nature of Things*, a series of documentaries exploring topics in environmental science. He is a reputable international source on environmental issues, whose environmental perspective on autism has the potential to be influential. The question that guides the documentary, which Suzuki poses, is "could a change in our microbes affect our bodies and contribute to diseases like autism?" ("The Autism Enigma"). His question, however, assumes that autism *is* a disease, a perspective that

both scientists and activists question. Although disability and illness are often related, the disease model of autism does not take into account how autistic people have identified with the condition by embracing it as opposed to pushing for its eradication, even while facing the challenges of other health conditions. While many people who develop life-threatening illnesses later in life do not see the eradication of their illnesses as a eugenic effort, many autistic people who do not believe their lives are at risk from their diagnoses view the movement to prevent autism as a form of eugenics that suggests that their lives are not valuable.

The idea that autism research should move toward prevention is one that the documentary presents without an exploration of alternative perspectives. In the episode, a representative from the Autism Canada Foundation tells viewers "we have to look at environment now because we know that environment influences our gene expression and we know that if we understand what environmental triggers are influencing autism we can avoid these and maybe consequently reduce the amount of autism that we're seeing ("The Autism Enigma"). 123 In this linguistic construction, autism is separated from autistic people. The Foundation's goal is not stated as reducing amount of autistic people, but the goal of prevention has been understood this way by those who see autism as inherent to the individual. As Sinclair argues, "It is not possible to separate autism from the person – and if it were possible, the person you'd have left would not be the same person you started with." He encourages parents to question whether autism itself is their child's problem, or whether the problem is located outside the individual. Canadian autism researcher Michelle Dawson has similarly objected to the characterization of autism as a problem. In her collaborative work on autism and intelligence, Dawson has shown that researchers have erroneously deemed autistic people unintelligent because they have measured

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<sup>&</sup>lt;sup>123</sup> When this episode was filmed, the organization's vision, as expressed on their website, was, "a world in which autism is preventable and treatable" (Autism Canada Foundation 2011). The Autism Canada Foundation has since merged with Autism Society Canada (ASC).

them by neurotypical standards (Dawson, Soulières, Gernsbacher, and Mottron 2007; Gernsbacher, Dawson, and Mottron 2006). Her research partner Laurent Mottron believes that scholars should move beyond cataloguing autistic deficits; he argues that "by emphasizing the abilities and strengths of people with autism, deciphering how autistics learn and succeed in natural settings, and avoiding language that frames autism as a defect to be corrected, [scientists] can help shape the entire discussion" (35). While *Sounding the Alarm* and "The Autism Enigma" focus on the loss than autism represents, voices like those of Sinclair, Dawson, and Mottron suggest what would be lost in a vision of the future in which autism does not figure.

While the stories of autistic people who require the support of their families and experts to be able to advocate for their needs deserve attention, the documentary does not feature the perspectives of autistic people and their supporters who might argue for a recognition of the challenges that autistic people face at a social, as opposed to a biological level. In a review of the documentary, Kitaygorodsky, Percy, Schormans, and Brown praise certain aspects of its coverage, but they critique its exclusion of autistic voices (100). While both documentaries criticize the lack of attention to the environment in autism research, many disability studies scholars criticize instead the lack of attention to quality of life research in this field; as the majority of research is oriented toward producing a world without autism, the daily challenges of autistic adults are often forgotten. Scott Michael Robertson argues that research should focus on issues like access to augmentative and alternative communication, compatible employment opportunities, and social acceptance. 124 Melanie Yergeau critiques research into causation that

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<sup>&</sup>lt;sup>124</sup> The complicated relationship that disability studies scholars, and particularly critical autism scholars, have with medical research resembles that which many critical race theorists have with scientific research. Entire colonial civilizations served as experimentation ground for medical research, and yet scientific research was eventually able to show that there is no biological proof of different races. Similarly, disabled people have been abused in scientific and medical research studies, and yet many of these studies have resulted in the development of technologies that enable disabled people greater access to public spaces that are disabling. As Haraway points out, disabled people are often the first to use new technologies (313-314). Scientific research into autism has helped to dispel many

focuses on prevention. She explains that according to the typical autism essay, "the world's population is slowly heading the way of neurological disfigurement – because of vaccines, because of genetics, because of excessive television watching, because of airborne pollutants, because of gluten and casein and artificial sweeteners, because of, quite literally, your mom" (Yergeau). Her parodic list derides the sense of fear invoked by contemporary discourse on autism. While we can find a certain humour in watching members of the public and experts alike leap to causation theories by correlating autism with everything that we associate with the degeneration of society, from, to repeat the examples listed above, excessive television watching to airborne pollutants, what critics like Yergeau also point toward is the tragic consequences of many of these beliefs, as many purported cures for autism have actually led to fatalities.

While some 'autism cures' may seem inauthentic but harmless, administering others would constitute abuse or even torture. Autistic children have died as a result of the administration of supposed cures such as chelation therapy and chlorine dioxide/Miracle Mineral Solution (CD/MMS). Chelation therapy, which is sometimes used to treat individuals who have received heavy metal poisoning, involves the administration of products that claim to cleanse an individual's body of toxins and heavy metals. The use of chelation therapy for autistic individuals can be life-threatening, as such products can strip the body of essential minerals.

assumptions about autism, such as the belief that autism is purely psychological in nature. Many of these concerns surrounding the place of the body in scientific discourse are taken up by McKittrick, in an examination of the afterlife of Sarah Baartman, a South African woman whose body was exhibited in London as a curiosity both before and after her death. McKittrick notes:

Baartman's life story reveals that the weight of historic scientific narratives are substantial: she not only embodies the biased racial-sexual discourse of her day (the evolutionary tables, the taxonomic ranks, the statistics, and the exacting measurements that hierarchically organize humans according to racial-sexual markers, she also demonstrates how our *present* system of knowledge (the tables, the ranks, the statistics, the measurements) continue to be informed by such discourses. (115)

McKittrick's critical discussion of how scientific study remains implicated in colonialism, when considered with respect to autism discourse, suggests an important caveat that even progressive scientific research is still part of a body of knowledge that is often complicit in other forms of ableism. As McKittrick shows in her article, science and creative practice are intertwined and often influence each other; science has incredible potential, but its limits deserve consideration too.

CD/MMS, another purported cure for autism, combines sodium chlorite and citric acid, which together form bleach. Individuals promoting the use of CD/MMS have encouraged parents to administer the solution through enemas as a means of cleansing the body of toxins and so healing what homeopath Kerri Rivera calls the symptoms of autism in her book, *Healing the Symptoms Known As Autism* (2013). In 2014, the United States Food and Drug Administration released a health information report warning consumers of misleading and dangerous autism treatments like chelation therapy and CD/MMS (FDA). Autism Speaks directs readers to this report, noting that autism cures do not yet exist; the organization does not support the use of alternative therapies like CD/MMS or chelation therapy to treat autism. However, Vancouver-based autism activist Amethyst Schaber makes an important point that the narrative of pity and suffering that many charity organizations construct about autism is one that inspires desperation in parents, and it is out of desperation that parents turn to drastic measures to attempt to cure their children. Promoting autism acceptance, she concludes, can play a role in curbing desperate and violent attempts to cure children of their autism (Schaber).

Many of the treatments for autism suggest that the condition is a result of the proliferation of toxins in the body. In Murray's *Autism*, he describes how looking at autism as a toxin affects how individuals value it, and consequently how individuals value autistic people in society. In the first section of my dissertation, I explored fictional works and their representative strategies for drawing attention to communities of people whose health has been disregarded, whose combined experiences of colonization, poverty, disability, and illness have led to their erasure. Examining the different cures for autism and their accompanying philosophies can allow for another turn to slow violence from Rob Nixon, a concept that helped to shape my own work. Nixon, who explores human corporeality as evidence of environmental suffering, argues that the

persistent illnesses of individuals who experience the effects of environmental racism demand that we redefine the temporality of violence. Considering the prolonged health effects of the Gulf War, he asks, "after an official victory has been declared, how do we track the persistence of unofficial hostilities in the cellular domain, the untidy, attritional lethality that moves through the tissue, blood, and bones of combatants and noncombatants alike, moving through as well the living body of the land itself?" (Nixon 200). One interpretation of efforts to cure individuals of autism is that these individuals understand autism itself as a violence against the body, and autistic individuals as people whose rights to accessible environments have been violated.

Some thinkers influenced by popular environmental discourse may believe that autistic people are victims of slow violence because of potential links that some researchers cite between changing environmental conditions and changes in human neurology. However, the 'cures' devised for autism, from bleach enemas that can prove fatal to children to abstaining from vaccination, which can lead to an outbreak of the measles, are another type of slow violence that deserves consideration, and it is this slow violence that results from the ecological othering of autistic people, who have spoken out against efforts to cure them. Scientific research has been imperative in dispelling the beliefs that efforts like chelation therapy, CD/MMS, and other treatments can eliminate autism. However, while many medical professionals would stress vaccination and caution against the dangers of running bleach through a child's intestinal tract, the medical model of autism is still implicated in the practice of categorizing autistic deficits, an approach that has led many people to hope for cure as opposed to greater acceptance, greater accessibility, and greater access to enabling technologies for those with sensory and communication differences. What I am calling the parasite model of autism – a model prompted by Murray's idea of hosting – is prominent amongst individuals who believe autism can be

cured. Those who believe in cure suggest that there is a true person behind the autism, a condition that acts like a parasite that inflicts harm upon its host. In Murray's biocultural history of autism, he critiques the belief that, "autism somehow inhabits a body that is not autistic, and that the two might be prised apart in some way, with the non-autistic, 'real,' self saved from the disability" (49). This is a similar critique to that leveled by Sinclair, who calls parents to stop mourning autistic children in the passage that I used to open this chapter. Like members of the communities that I discuss in Chapter One and Chapter Two, autistic individuals assert proudly that while they may be disabled, they are very much present; efforts to cure them are not, they clarify, efforts to help them, but efforts to suppress their unique way of being in the world.

In many ways, understanding autism as a symptom that masks a true self can be linked to humanist ideas about subjectivity that understand the individual as a singular rational and independent entity. In *How We Became Posthuman*, N. Katherine Hayles critiques this model of subjectivity with recourse to a notion of distributed cognition; while we may act as though we are a single "I," many different systems of our body are working at the same time, and conflicting with one another. Hayles suggests that revising our understanding of consciousness and control in this way helps to ground the body in its materiality (6). Similarly, an understanding of autism as part of the material presence of the individual, rather than external to the subject in this way, can help shift the focus away from cure and toward enabling the individual as he or she exists in the present. What we might call the parasite model of autism is also very tied to the idea that autism affects children, and that one can excise it with diligent treatment. While Murray states a preference to maintain a degree of distance in his account of the history of autism, he remains critical of curative thinking:

Where those that champion curing are definitely in the wrong is in their idea that somehow the autistic and the human can be kept apart, and that to eradicate the former is to liberate the latter. This is one of the worst by-products of the notion that the condition is some kind of toxin or malign 'visitation'. It is nothing of the sort, and that is a fact that will have to be accepted. (101)

As Murray points out, much of the discourse that focuses on curing autism and recovering children ignores the presence and intelligence of autistic people. Sometimes, the act of purifying the autistic body has been understood in religious terms, in which the condition becomes problematically aligned, inadvertently or not, with sin. The idea that the biological reality of autism itself is a form of violence, as opposed to the treatment of autistic people, is one that deserves much greater interrogation in conversations surrounding autism and the natural world.

## 4. Autistic Productivity: The Ableism of Co-opting Neurodiversity

While many turn to health to bolster arguments against industrial practices and companies that ecocritics have similarly criticized, positioning the body as a site of environmental injustice can be detrimental when doing so denies the subjectivity of the persons in question. Characterizing autistic people as aberrations upholds a problematic idea of natural purity, an idea that ecocritics point out has been used to justify discrimination and exclusion based on race, gender, and

<sup>&</sup>lt;sup>125</sup> Murray cites the Son-Rise program as an example of one autism cure that positions the return to a normal, non-autistic self as a form of religious resurrection. He explains:

Curing autism, it seems, invites miracles. One of the most well-known, longstanding, and public processes of treating the condition is the Son-Rise program, established by Barry and Samahria Kaufman, and run out of the Autism Treatment Center of America in Massachusetts. Son-Rise, for all that its origins lie in the treatment the Kaufmans developed for their own son Raun, makes the notion of resurrection clear through its very title. (*Autism* 92)

sexuality (Clark 75). 126 Neurodiversity, the term used to shift the conversation about autism away from deficits, often appears in media discussions about cognitive difference and the successful employment of many autistic adults in the technology sector. In this section, I suggest that popular discourse about autism has equated neurodiversity with neuro-exceptionality in ways that unnecessarily divide autism communities, and I attempt to resituate neurodiversity through the writings of autistic adults, whose creative works show how environmental diversity might be more central to discussions of neurological diversity. Although efforts to increase employment rates are important, writers offer other reasons for valuing and respecting autism outside of its much purported competitive advantage in the capitalist marketplace. And although the history of characterizing autism as a disease has led to easy correlations between autism and unsustainable environmental practices, perhaps considering neurodiversity from an environmental justice perspective can lead to greater acceptance with more attention to the voices of autistic people. While it is important to recognize the ways that environmental health affects human health, disability studies instructs us that we must also be aware of the very political meanings of "health". 127 Greater engagement between these two fields could allow for greater communication that to be autistic and healthy is not a paradox.

While celebrations of autistic difference are becoming more common, they are also divisive, as some suggest that autistic individuals who are able to speak are not representative of non-speaking autistic people who may not be able to work independently or communicate without significant assistance. I would argue that one of the reasons why discussions of autism

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<sup>&</sup>lt;sup>126</sup> In the introduction to this work, I discussed how Clark explains that in an age of ecological risk, calls to respect the natural world are occurring at the same time as resistance to problematic calls to uphold human nature, an idea that has been used to support exclusionary practices (Clark 75).

<sup>&</sup>lt;sup>127</sup> As Ne'eman and Broderick point out, not all autistic people experience health problems (468). Those who do, such as those who need organ transplants, or other life saving medical procedures, are placed in a precarious position because their lives are not considered liveable.

and neurodiversity become so polarizing is because of the co-opting of the concept of neurodiversity to mean superiority or neurological exceptionality. As I pointed out in Chapter Three, according to Ari Ne'eman, the current president of the Autistic Self Advocacy Network, neurodiversity is, "the idea that the paradigm of acceptance extended toward racial, religious, and other similar differences should apply to neurology as well" (qtd. in Broderick and Ne'eman 470). Ne'eman's definition emphasizes that respecting neurodiversity involves respecting difference; rather than drawing a distinction between those who are neurodiverse and those who are normal, Ne'eman's definition suggests that neurological differences of any kind deserve respect. However, many popular discussions have departed from this definition in ways that have enhanced existing divisions between parents and autistic people. I began this chapter with a discussion of autism and futurity. Here, I would posit that there are two dominant visions of autism's future that self-activists challenge, and both futures consider the place of autistic people in the social context of neoliberal capitalism as an economic and political system.

American writer Elizabeth Moon's science fiction novel, *The Speed of Dark*, published in 2002, offers one sketch of a potential autism future. The novel follows the story of Lou Arrendale, a bioinformatics specialist with a diagnosis of autism. Lou is a member of section A, a special division of autistic workers who are easily able to recognize and analyze patterns.

Toward the end of the novel, Lou decides to undergo a fictional experimental treatment from his company that effectively cures his autism, which allows him to pursue an alternative career.

Michael Bérubé notes that many readers have critiqued Moon's novel for its adherence to what disability studies scholars identify as the 'cure or kill' narrative formula for disability. I refer to the novel in this context because its representation of disability in the competitive workplace introduces the concerns of this section of my chapter. Lou and the other members of his work

section have accommodations, including access to a private gym with trampolines, private parking, and various stimuli for their desks. In the acknowledgments section of the book, Moon notes that this setting resulted from her conversation with an employment law attorney, who helped her design a near-future business and legal climate as it related to disability (ix). The novel's fictional company invests in the development of an autism cure, however, because its new manager views the accessibility provisions for section A as expenses that limit the company's profit. In contrast, the immediate supervisor of section A argues that these provisions are economical because the workers of section A are more efficient than their fellow employees. I will refer back to these characters – the manager who views disability as costly and the supervisor who views his employees as particularly productive – as I consider how economic paradigms inform the language that we use to discuss autism and other disabilities.

In replacing a medical model of disability with a social one, many scholars show how definitions of disability are not objective or transhistorical, but are intimately connected to the economic systems and political ideologies that structure our lives. In "Constructing Normalcy," Leonard Davis links the invention of the disabled body to industrialization and the creation of statistics as a discipline. He argues that, "this belief combined with an industrial mentality that saw workers as interchangeable and therefore sought to create a universal worker whose physical characteristics would be uniform, as would be the result of their labours – a uniform product" (3). In the contemporary era, the logic of the market and its need for efficiency influence perceptions of a disability. As Robert McRuer explains in *Crip Theory*, neoliberal capitalism

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<sup>&</sup>lt;sup>128</sup> Joshua St. Pierre discusses one example of how neoliberal capitalism constructs disability in his article, "The Construction of the Disabled Speaker: Locating Stuttering in Disability Studies". He explains:

The stutterer finds and defines herself in a context dominated by expectations of efficiency. Welded to notions of success and productivity within capitalism, expediency of both labour and communication sets the terms for participation in our socio-economic system while also enforcing the production of the sorts of subjects it requires...In failing to conform to the expectations of expediency, the stutterer *herself* is constructed as a faulty instrument that is inefficient and less useful. From this angle, the stutterer feels the

is the system in which and against which embodied identities have been shaped over the past twenty-five years. However, he also notes that an expansive notion of access is not present in many anti-capitalist movements because, for those who oppose capitalism and corporate globalization, disability is "the object against which an imagined future world is shaped" (3). As we have seen, tensions exist between a model of disability that embraces bodily difference and popular critiques of how unsustainable practices are creating disabling environments - critiques that point to how xenobiotic chemicals are negatively affecting human health, and to how exporting the risks of industrial development contributes to disproportionate experiences of painful disability in developing countries.

The extent to which autism is understood as a disability is also connected to ideas of workplace competency, as bolstered through the popular use of functioning labels to divide the spectrum. Employment values of efficiency and expediency inform popular representations of autistic people and the quality of life that they experience. While this idea is intimated in other disability studies work that shows how capitalism shape all embodied identities, the ways that autism is understood in relation to capitalism are important because they relate to two different futures. The first future, connected to a medical model of disability, in which disability is an individual or bodily deficit, is one in which autism, an expensive disability, is treatable and preventable – in which disability is "the object against which the future world is shaped" (McRuer 3). Articles involving the knowledge translation of research linking autism and environmental factors in the popular imagination invoke this future, using autism to bolster arguments against the environmental excesses of contemporary capitalism. These critiques, however, are approached from a standpoint that connects rising diagnoses to environmental

pressure of pace from *within*, the pressure to be the sort of efficient subject valued and required for participation. (12)

toxins, and that represents autism as a disruption of the natural. As we have seen, a future of prevention and treatment is a terrifying vision for many autistic people, who see the movement toward preventing autism as a form of eugenics that suggests that their way of being is not worthwhile. The second, hopeful future, represented by the Section A supervisor, relates to acceptance of neurological diversity and the growing suggestion that autistic individuals are naturally suited to particular careers. Articles that focus on hiring efforts suggest that recognizing the value of autism in the global marketplace can provide an avenue for social acceptance. As autistic people are uniquely able to embody the corporate values of efficiency and productivity, these articles claim, autism can be re-coded as productive. Self-advocates, however, present alternative possibilities to both the abstractions invoked by the fear-filled language of cure and the celebratory discourse of efficiency; these works challenge how we understand intelligence, disability, and the functioning labels ascribed to individuals with autism and other disabilities.

The descriptions "high-functioning" and "low-functioning" are often used to describe the spectrum, serving as labels that reference an imaginary standard as opposed to the abilities or disabilities of an individual in context. As disability studies scholar Tanya Titchkosky notes, ideological assumptions are embedded in what we consider a functional problem. She writes:

To think about disability is to think of some individuals with a functional problem; it is not to think about how the notion 'functional' is a socially organized term with a highly contingent usage that presupposes a rather mechanical version of the body and is sometimes even used to imagine embodiment as somehow separate from the socio politico milieu within which bodies always appear. (Titchkosky 55-56)

In the context of autism, the idea that an individual may need help with tasks, such as communicating through augmentative and alternative communication, affects perceptions of

intelligence. The term high-functioning is often used to describe individuals who are able to work, or extremely popular autistic figures who are well-known to the public for their accomplishments. While many activists specifically contest the term "low-functioning," others suggest that "high-functioning" also perpetuates a stigma. In a blog post entitled, "High Functioning is an Insult, Too," one popular autism blogger writing under the alias Autistic Bitch from Hell demonstrates that high-functioning is insulting by performing a bias test that involves using the term to describe other marginalized people. She produces such statements as "she is a high functioning woman" and "he is high functioning for a black man" to show how the use of high-functioning inscribes limitations upon the people that it describes. She strips away other identity categories to say, "He is a high functioning person" and then asks, "what does that mean? Is he well educated? Rich? Popular? Imaginative? Healthy? Friendly? Intelligent? Optimistic? Hardworking?" (Autistic Bitch from Hell). As she illustrates, the recourse to functioning labels suggests a teleology that is not ascribed to a non-disabled person. Evaluation in terms of success or failure proceeds unquestioned because functioning is seen as internal to the person as opposed to a product of external possibilities and constraints.

Increasingly, organizations and public figures are recognizing the significance of creating more accessible environments for autistic people. One organization working to reduce the stigma associated with autism is the Danish company Specialisterne, which has recently expanded its operations to other global locations, including the U.S. and Canada. The company is a consulting firm that hires autistic employees for technology companies. The consultants carry out specialized tasks as testers, programmers, and data-entry workers. Specialisterne's company philosophy is similar to that of the supervisor in Moon's novel, in the sense that the company maintains that autistic people are not only able to perform these jobs, but that they may be the

best people for them. Specialisterne describes its approach to managing high-functioning people as the dandelion model on its website:

Most people view this plant as a weed, a nuisance, something to be rooted out and eliminated. But did you know that, when cultivated, the dandelion is a valuable herb with healing qualities, and is cultivated for its wide number of pharmacologically active compounds. Weed or herb? You decide. (Specialist People Foundation)

Specialisterne's dandelion model, like the social model of disability, emphasizes that disability is not an inherent problem rooted within an individual, but is shaped by environments and attitudes. Here, we can recall Subramaniam's discussion of panic surrounding the rampant growth of foreign plants and its parallels with panic concerning the supposed invasion of foreign people. The dandelion model suggests an important alternative way of understanding autistic people outside the discourse of panic that pervades media reporting on autism. The company's movement from understanding autistic people as having deficits to having assets aims to change mainstream conversations surrounding autism as a disorder to offer a different future. Other companies are adopting similar hiring practices. However, while these practical efforts to secure employment for autism are important considering the discrimination that individuals have often faced in the workplace, news coverage of the efforts that these companies undertake often offers an alternative meaning to neurodiversity than that advanced by advocates, suggesting that individuals possess neuroexceptionalities that make them ideal employees.

Gareth Cook, in the *New York Times*, explains of Specialisterne founder Thorkil Sonne, "it is Sonne's ultimate goal to change how 'neurotypicals' see people with autism, and the best way to do it, he has decided, is to prove their value in the marketplace". Similarly, an article in the Harvard Business Review by Michael Schrage begins, "talk about turning a bug into a

feature," and proceeds to describe the software company SAP's plan to hire autistic workers. Schrage considers how viewing autism as a profitable disorder makes understanding goals for professional development and individual well-being difficult. Imagining a scenario like Moon's, he asks, "If drugs and/or medical intervention effectively treat the awkwardness and dysfunction associated with autism, might they also undermine the cognitive skills and abilities that originally got those autistics hired by SAP and other IT firms? Would autistics feel compelled to cling to their disabilities for fear of losing their jobs?...Ironically, a cure for autism likely obliterates the disorder's competitive advantage in the global marketplace" (Schrage). The idea that autism is a competitive advantage, an idea distilled from the concept of neurodiversity, has the potential to perpetuate ideas of autistic sameness that draw on stereotypes, like the belief that autism is always paired with savantism. While this second future is more promising for disability rights, at the same time, acceptance based on economic productivity suggests an idea of tolerance that co-opts, domesticates, and incorporates autism by abstracting it into an economic advantage.

In this sense, approaches reflect, as McRuer outlines by drawing on Emily Martin's discursive study of 'flexibility,' how neoliberalism embraces diversity through the trope of flexibility. While many organizations claim to be flexible, flexibility more accurately refers to the attribute of individuals, who perform subjective wholeness to manage crisis (McRuer 17). Autistic individuals who are able to perform the work of coding, referred to in news articles on autism as 'meaningful work' are treated as flexible bodies, plugged into an imperfect economic system. The discursive celebration of the value of autism in the global marketplace exists in a strange tension; the discourse that constructs the practice of coding as meaningful work and that constructs autism as an economically productive disability leaves an approach to understanding the body solely for its utility unquestioned. The presentation of autistic neurology as a

specialized way of thinking that makes individuals valuable in the marketplace differs from the concept of neurodiversity as a paradigm of acceptance toward neurological difference, a paradigm that emphasizes the importance of rights to accommodations in all professions, as well as acceptance for individuals who are not able to prove their economic utility but are nonetheless included as part of the neurodiversity movement. While Ne'eman, for example, has stated that recruiting efforts for autistic people are long overdue, he also noted that while most of the firms expressing interest in workers are science, technology, engineering, and mathematics fields, other possibilities should be available, stating, "many of us can and do succeed in a variety of professions. I, for instance, am an autistic person working in politics and public policy, which is certainly not a stereotypical field" (qtd. in Kelland). Although finding employment that is a good fit for an individual is a prime concern of organizations interested in increasing employment opportunities for autistic people, Ne'eman makes an important point that widespread accessibility to diverse areas of employment should be the ultimate goal of such efforts. 129

The practical efforts of companies like Specialisterne to move away from the deficit model and provide employment for people who deserve fair consideration are important and instructive, and my point is not to critique the practice of job creation in itself. Rather, my point is that the implications of using market success as evidence for the value of autism acceptance deserves critical consideration, and that this strategy might prescribe unnecessary limits on the potential of neurodiversity. While the neurodiversity movement is not an anti-capitalist movement, many news stories that describe neurodivergence as profitable avoid capturing the

<sup>&</sup>lt;sup>129</sup> The media attention that Specialisterne garners was critiqued in 2009 in *Whose Planet is it Anyway?* The Autistic Bitch from Hell writes that providing accommodation in the workplace should be a standard practice of any inclusive society. She asks, "should it simply be seen as a fabulous, wow-inducing event when an employer simply obeys the law by giving fair consideration to, and then hiring, a qualified applicant with a disability?" (Autistic Bitch from Hell"). Her concern is with the separate but equal ethos of hiring practices that might further limit what autistic people can do.

movement's disruptive potential. The use of phrases like 'meaningful work' and 'contributing to society' that are found in these stories suggest that quality of life depends upon being part of a country's labour pool, which many disability advocates contest. Sunaura Taylor, an artist and advocate, believes that people with disabilities should have the right to work and workplace accommodations, but she also defends her right "not to work," arguing that Western culture has a limited notion of social contribution. Disability studies scholar Kelly Fritsch similarly criticizes the discourse surrounding disability and employment, pointing out that news stories about the successful employment of disabled people often suggest that the labour market is more inclusive than it actually is in practice. She writes:

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. (Fritsch 29)

As Fritsch points out here, it is worth being cautious when celebrating the extension of jobs to disabled people as an end goal in itself. Some individuals may not perform paid labour, but this should not disqualify them as citizens and as human beings. The act of interpreting neurodivergence as neuro-exceptionality has been polarizing, leading many parents to suggest that neurodiversity does not apply to their children who are not able to perform paid work. For example, writer Amy S. F. Lutz, who questions the veracity of the words of autistic people who talk to type, suggests that a true autism rights movement would recognize that people all have very different levels of brain functioning instead of "implying that we are all the same, with

'intact minds' that just need to be accessed." However, Ne'eman's definition of the paradigm of neurodiversity, which has been foundational to the neurodiversity movement, does not suggest that individuals all have the same kinds of minds, but that people should have their rights and beliefs accepted and respected regardless of how they think. Philosopher Ian Hacking makes a similar point, insisting that autistic self-activists reject a reified idea of neuro-normality. He explains: "I have noticed that when I say 'neurotypical' in mixed or neurotypical company, many neurotypicals say 'neuro-normal' back to me. That's *exactly* to miss the point. The neurodiversity movement rejects the idea that there is neuro-normality" (46). Neurodiversity does not refer to only a select population of autistic people. While it is important to recognize the ability of many autistic people to be part of the labour market, acceptance should not proceed on the grounds of productivity alone; if neurodiversity only referred to autistic people who were capable of being employed, its utility as a concept would be incredibly limited.

## 5. Autism and the Environmental Imagination: From Ecological Others to Ecological Subjects

One conversation featured in the documentary *Wretches & Jabberers*, discussed in my last chapter, begins with a question from Naoki Higashida to Larry Bissonnette and Tracy Thresher. He asks: "I've been thinking about the meaning our lives with autism. Why do you think people like us were made, were born?" (*Wretches & Jabberers*). Bissonnette types in response, "Mankind expresses itself finely in variety. We are one branch of a long, lots of leaves, diverse and wonderful beauty tree" (*Wretches & Jabberers*). Pleased with this answer, Higashida then turns to what this analogy means on a political level, explaining, "I know that each leaf has a value and meaning to the life of itself, so our mission is to prove it. We have launched out of the

door. I am wondering and looking forward to what the door outside looks like" (Wretches & Jabberers). While neurological diversity is associated with technological affinities and with the useful analogy of autistic people running a different operating system than neurotypical people, environmental metaphors that contrast with the metaphors of devastation expressed in media discourse can also be productive. Thinking about the shared goals of environmentalists and disability rights activists to have difference recognized as valuable suggests a political alliance that can frame neurological diversity along the lines of biodiversity, a framing that emphasizes the role of autistic people as subjects.

One of my contentions throughout this chapter has been that the environmental humanities has not yet been attentive to the writings of autistic activists, who are often very invested in environmental issues, even as they have called for the conversation about autism to be shifted away from causation and cure and toward issues of acceptance and inclusion. In the next section of this chapter, I turn once more to the cultural work of autistic writers and activists, this time with respect to their engagement with natural metaphors and ecological issues. I argue the body of literature by autistic self-advocates sampled here is an important addition to cultural conversations about intersections and tensions between disability studies and the environmental humanities. Even as these writers express criticism for efforts to recover autistic people and make them more whole as opposed to recognizing the intelligence and creativity of autistic people, they offer suggestions for how neurodiversity might be reframed in a way that allows autism to be linked to environmental health as opposed to devastation.

Bridging theory from the environmental humanities and disability studies can helpfully open up possibilities for the potential of the term neurodiversity – possibilities that autistic writers are already exploring. One counterargument to my perspective might be that not all

autistic people are environmental activists, and to characterize them in this way is actually a disservice. It is certainly true that not all autistic people would express interest in nature or characterize themselves as environmental justice activists. My intention is not to use the recurrence of environmental themes and metaphors in the writings of autistic activists to suggest that autistic people are somehow innately and essentially more attuned to the natural world. As I pointed out in Chapter One, Ray addresses a similar issue in her work on Indigenous literature, noting that claims that Indigenous people are automatically connected to nature can draw on stereotypes, when many Indigenous people care about environments because they experience environmental racism (85). Similarly, disability scholars have shown why environmental issues are of interest to disabled people on a political level. For people with multiple chemical sensitivities, people working in harsh industrial conditions, or people living in areas of mass disablement, environmental questions are central.

But individuals with disabilities that are not specifically caused by environmental pollution may still feel affinities with environmental movements, in a similar manner to how feminist thinkers have noted that their allegiance to environmental movements is linked to feminism. In her studies of both the eco-feminist tradition and the tradition of cyborg feminism first championed by Haraway, Alaimo arrives at a position in between these two poles that nonetheless asserts a powerful allegiance between feminism and environmentalism. In order to discuss her work's relevance to disability studies and autism advocacy in particular, I quote her article at length:

On the one hand, Mother Earth and ecofeminist glorification of nature play into the pockets of patriarchal capitalism; on the other hand, cyborgs forsake alliances between women and nature and may bolster a destructive technophilia. Articulating women and

nature as agents in a mutual struggle, however, could strengthen environmental feminism's political impetus while opposing the appropriation of nature as a passive resource. (Alaimo 133).

Alaimo thus distinguishes between grounding politics in affinity, and grounding affinity in politics (150). She explains that to ground politics in affinity suggests essential connections between women and nature, connections which can play into an environmental ethos that blames female consumers for unsustainable domestic environmental practices, while disregarding the larger practices of corporations in perpetrating environmental crimes. Her critique speaks to how charity organizations and companies can use environmental discourses that draw on the natural to limit the agency of autistic people. Instead, an affinity grounded in politics emphasizes how autistic people and the natural world are both oppressed by ideologies that emphasize conquering the natural world and the body itself for instrumental purposes. Disability studies scholar Zach Richter's insights in "(Re)wilding the Stutter," an entry in the Did I Stutter Project blog, speak to this difference between a politics grounded in affinity and an affinity grounded in politics. He compares what he names "embodiment conservation" and environmental conservation, noting that both are efforts to look at the value of difference in non-monetary terms. Attending to how autistic writers compare neurological diversity to biological diversity in order to make a shared politics apparent can allow for similar connections.

Prince-Hughes, for example, shows how remaining critical of the anthropocentrism that has characterized our disregard for natural environments can translate into greater acceptance. Her memoir, *Songs of the Gorilla Nation*, weaves together her life story with the stories of the gorillas that she worked with as an anthropologist. She clarifies that the emergence that the gorillas facilitated for her was not a recovery from autism:

When I speak of emergence from the darkness of autism, I do not mean that I offer a success story neatly wrapped and finished with a "cure." I and the others who are autistic do not want to be cured. What I mean when I say "emergence" is that my soul was lifted from the context of my earlier autism and became autistic in another context, one filled with wonder and discovery and full of the feelings that so poetically inform each human life. (Prince-Hughes 3)

Prince-Hughes demonstrates how she does not have to overcome her autism to be able to succeed as an anthropologist. She does not suggest the need for a cure; instead, she articulates a hope that autistic people "will be perceived as being as whole as the worlds they sense" (224). Her work offers insight into how critiques of our own anthropocentric attitudes can proceed alongside appreciation for neurological difference. As Prince-Hughes explores both the cyborg character of Seven of Nine and the gorillas she works with as both central to conceptualizing identity, she offers an intriguing and important vision of the possibilities of technology alongside the preservation and conservation of environments.

Others have similarly drawn attention to the importance of recognizing neurological difference in ways that are particularly amenable to thinking about other forms of justice as well. For example, Mel Baggs, in the YouTube performance piece "In My Language" discussed in Chapter Three, compares the lack of acceptance that others show toward hir way of being to the way that a child who is not speaking in a dominant language is understood. Sie explains that hir language is about being in a conversation with hir environment ("In My Language"). Alison

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<sup>&</sup>lt;sup>130</sup> An interesting and perhaps controversial aspect of Prince-Hughes's text is her agreement with Elisabeth and Niko Tinbergen, whom she identifies as rarely cited researchers who argue that, "modern life, with its unnatural living conditions, chemicals, broken-down social systems, and chronic stress, overstimulates and assaults the human animal, causing some to manifest the biological and psychological matrix we call autism" (Prince-Hughes 223). I am not suggesting that the Tinbergen research theory that Prince-Hughes articulates is necessarily accurate but rather that her willingness to consider how environments affect people while still embracing autistic identity provides a counter-discourse to that surrounding an 'autism epidemic'.

Kafer has argued that while the piece is not explicitly about nature, it challenges "implicit assumptions that nature only exists 'out there' as opposed to in the everyday spaces that surround us" (144). Rather than claiming hir performance is specifically about autism, Baggs describes hir message as, "a strong statement on the existence and value of many different kinds of thinking and interaction in a world where how close you can appear to a specific one of them determines whether you are seen as a real person or an adult or an intelligent person" ("In My Language"). Accepting and celebrating difference, Baggs argues, involves recognizing and celebrating myriad different thought processes instead of asking people to pass as neurotypical.

Another writer who, like Bissonnette, tends toward natural metaphors, suggesting an appreciation for natural environments and what Richter terms "embodiment conservation," or the desire to communicate and interact in the world in one's preferred way, is Tito Mukhopadhyay. Mukhopadhyay uses strong natural imagery in his essays and poetry that assert the value of his words despite his communication differences. The organization Cure Autism Now (CAN), which later amalgamated with Autism Speaks, sponsored Mukhopadhyay and his mother to move from India to the United States before the two "broke with their sponsor over the aggressive cure agenda" (Savarese 275). His story *The Mind Tree* is a series of vignettes interspersed with poetic quatrains that describe visits the narrator, a mind tree, receives from ants, passing humans, and other creatures. His characterization of himself as a mind tree, an individual who has an active intellectual life even while appearing stoic and unmoving to the outside world, allows for a consideration of the importance of a natural world that is often framed as passive, and standing on reserve for humanity's use. In a vignette of *The Mind Tree* called, "The Heart of the Earth," Mukhopadhyay notes:

Hence I could tell that the great heart of the earth beats very slowly. To realise this, it took a long time. I had to wait for the vibrations in succession, keeping my roots alert even to pick up the slightest ripple. (181)

Mukhopadhyay's extended metaphor of the mind tree here displays parallels with his life story in "The Voice of Silence" and "Beyond the Silence," which preface *The Mind Tree* vignettes. In this story, he praises the efforts of his mother, who accepts his differences and displays patience in teaching him using techniques that she devised herself. Her efforts to understand him parallel his efforts to understand the earth, over time, in *The Mind Tree*. Mukhopadhyay's dream, expressed in this book, is that "we can grow in a matured society where nobody would be 'normal or abnormal' but just human beings – accepting any other human being – ready to grow together" (90). Rather than expressing hope for a cure, like the sponsoring organization that initially brought him to the United States, he longs for acceptance of his difference.

As the poems zero in on different modes of being in the world, they offer an aesthetic and politics that values biological difference. Ralph James Savarese, who has studied Mukhopadhyay's work extensively, characterizes his way of perceiving the world as a "postcolonial neurology," describing him as "a neuro-cosmopolitan armed with metaphor in a world that is often quite hostile to the neurological other" (273). While critics would suggest that describing autistic experience as postcolonial experience is appropriative, Savarese counters that, "it is worth conceiving of autism in postcolonial terms because it allows us to see the current struggle for self-determination being waged by autistics as a kind of neuro-nationalist uprising and because it also frames the encounter of autistics and neurotypicals (NTs) in cosmopolitan terms" (274). The analogy that Savarese crafts is also useful for thinking about the way in

<sup>&</sup>lt;sup>131</sup> Savarese further elucidates that, "terms such as 'left hemisphere,' 'right hemisphere,' and 'left hemispheric dominance' suggest a geo-politics of the brain, as if the history of colonialism had been mapped onto it" (275).

which Mukhopadhyay resists ordering the world around him in *The Mind Tree* through a non-hierarchical mode that intrinsically values difference.

The tree metaphor that Mukhopadhyay uses to characterize his own autistic experience is similar to that which poetry editor N. I. Nicholson employs. Nicholson, an autistic self-advocate, is the founder of the poetry journal Barking Sycamores, which was launched in 2014. 132 This journal publishes neurodiverse writers who have labels such as autism, attention deficit disorder, bipolar disorder, and synaesthesia. They explain that one of the reasons why they chose this name is because, "the American Sycamore tree sheds its bark in larger chunks than other trees, which often leaves this tree with a pale, skinless appearance. Similarly, autistic people can often feel like the world – in both sensory and emotional data – invades our being, as if we have no skin to protect us" (Nicholson). By comparing the shared sensitivity of autistic people with the sycamore tree, Nicholson invokes a similar sense of vulnerability to that seen earlier. However, Nicholson does not use this sensitivity to suggest that autistic people need to be fixed in some way. Instead, with this analogy, they suggest how such experiences are generative at an aesthetic level. Experiencing sound, taste, and touch in heightened ways may be overwhelming, but it can also be exhilarating and inspiring for those inclined to creative pursuits. Like the Specialisterne website, Nicholson uses an analogy between autistic people and nature. Yet while Specialisterne indicates that a dandelion may be useful despite its perception as a weed, Nicholson speaks to aesthetics and sensations – the experience as valuable in its own right. The two sites have very different mandates - one is ushering autistic people into a competitive workplace, while the other is soliciting poetry submissions. Nicholson's analogy, however, offers insight into how autistic self-activists can still have powerful affinities with environmental justice movements.

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<sup>&</sup>lt;sup>132</sup> I use the pronoun "they" to refer to Nicholson because this pronoun usage is consistent with that present on the *Barking Sycamores* journal website.

However, Nicholson offers a second reason for the choice of the name 'sycamores'; he notes that a high definition fiber tracking (HDFT) brain scan of Temple Grandin, the famous professor of animal science, appears "very tree-like, with her neurological connections reaching higher and farther like branches – so it's easy to picture a tree of nerves growing in one's brain" (Nicholson). Turning to Nicholson's discussion of Grandin makes evident a gap in my own discussion so far, in that I have not discussed her work even though she is one of the most prominent thinkers on how autistic cognition differs from neurotypical cognition, as she argues that autistic people share with non-human animals intense powers of observation (Grandin 8). In fact, one might use Grandin to suggest a counterargument that autistic bodies are sometimes positioned not against nature, but as being in greater harmony with it. In Cary Wolfe's What is *Posthumanism?*, he discusses how Grandin's writings challenge how we have historically defined and understood human thought processes and patterns of communication (127). While Grandin's corpus is robust in its discussion of autism and affinities for the nonhuman world, I have not discussed her at length because I want to differentiate my argument from her scientific one. I am not disagreeing with Grandin's insights, however. Grandin's work has been pioneering in making people rethink the value of autistic people and their patterns of thinking. She has encouraged people to rethink their perceptions about intelligence and consider the value and importance of visual modes of learning and thinking. But rather attempting to categorize characteristics that animals and autists share, I consider the similarities in attitudes that governments and corporations adopt toward environments and toward people with disabilities, and the parallel struggles of environmental justice activists and neurodiversity activists.

## 6. Alternative Futurities: Welcoming Autistic Difference

In closing this chapter, I would like to shift my focus away from the present to consider how disability might be perceived and included in the future, by providing a reading of the young adult science fiction novel On the Edge of Gone by Corinne Duyvis. Duyvis's near future novel takes place in the year 2035, and imagines that the global population is anxiously preparing shelters as a large comet is on course to hit earth. The *novum* (a term coined by science fiction scholar Darko Suvin that refers to a new idea or invention) that Duyvis introduces is the idea of generation ships capable of sustaining small populations, which promise that human life can continue outside of Earth. The novel is told from the perspective of a sixteen year old Dutch and Surinamese teenager named Denise, who, like the author herself, is autistic. As Denise explains, while many global governments and private citizens construct generation ships, not everyone is lucky enough to secure a spot. Denise and her mother are travelling to their shelter when they are diverted and discover that a generation ship, the Nassau, has not departed due to maintenance issues. Although the two are given temporary refuge in the ship for the impact, they are told that they must eventually leave and fend for themselves in the dangerous world outside. On the Edge of Gone tells the story of Denise's efforts to secure places on the generation ship for her, her mother, and her missing sister Iris, by proving that she can be useful.

On the Edge of Gone is Duyvis's second novel. She is also the author of Otherbound (2014), a fantasy novel for young adults that won a Bisexual Book Award in the speculative fiction category, and was longlisted for the James Triptree Jr. Award. Duyvis is also a co-founder of the website Disability in Kidlit, founded in 2013, which features articles, reviews, and discussions about the portrayal of disability in fiction for children in young adults. All of the contributors, writers, and editors of the website are themselves disabled, espousing the disability

rights principle of 'Nothing about us, without us.' Among other aims, the site hopes to advise writers on how to create respectful disabled characters, help librarians and teachers find positive representations of disability for young people, and to give disabled people a space to discuss how writers portray disabled characters in their favourite genres (Disability in Kidlit). In On the Edge of Gone, Duyvis explores the conventions of science fiction to imagine alternative futurities that welcome disability through her representation of an autistic character. She has written about her intentions of countering a dearth of representations of disability in science fiction very directly, noting, in an opinion piece in *The Guardian*, "I've seen disabled readers or viewers ask about the potential for disabled characters in their favorite genre or series, only to be disparagingly told that it wouldn't be realistic for them to survive" ("Fiction, like life, tells disabled people their lives have less value"). I would argue that what is particularly significant about Duyvis's On the Edge of Gone, however, is how the novel carves out space for autism in the future a nuanced way that does not simply suggest that only certain forms of autistic difference aligned with contemporary beliefs about genius are worth preserving. In this respect, the novel offers an expansive vision of human community that moves beyond the utilitarianism championed by other works of science fiction that focus on bare survival, and its brutal, dehumanizing costs.

Although Denise is autistic, contending with her autism is not the plot of the novel in and of itself. At the same time, Denise, as the narrator, does not ignore the fact that she is autistic, or deny the way that it informs the way that she experiences the world and shapes her social interactions. Her diagnosis is first disclosed to the reader shortly after the impact of the comet, as Denise and her mother have found temporary safety aboard the *Nassau*. Her mother tells their guide aboard the ship that she is autistic, a practice that Denise later notes that she dislikes, after she herself reveals her label to her former teacher. She confides to the reader, "I don't want to be

like Mom, pushing my limits in everyone's face and demanding sympathy" (59). The novel explores some of the implications of disclosing in this way, and the stigma that Denise experiences. When she is uncomfortable during a random check upon her room after a theft of supplies has taken place and she asks to lift her sheets and mattress herself, the brother of the *Nassau*'s captain surmises, "She's just being difficult. Have you *seen* an autistic kid?" (316). The implication that Denise is too capable to be autistic is one that she herself struggles with internally, despite the fact that her parents worried that she would be institutionalized (210). Although she recalls her childhood history during her narration to the reader, explaining that she "barely said a word between the ages of four and six" and has a class photo in which her "face is covered in scratches from when [she] latched onto a particularly bad stim," she is not immune to self-doubt influenced by the disbelief of others (210).

However, Denise's struggles to have her diagnosis recognized as real are not only related to her ability to be able to pass as neurotypical in many situations. Her identity as an autistic young woman also intersects with her identity as a young Black woman, as she is of mixed Dutch and Surinamese heritage. Reflecting on her late diagnosis, Denise notes in a narrative passage, "At the time, I thought the diagnosis was delayed because I was bad at being autistic, the same way I was bad at everything else; it took me years to realize that since I wasn't only Black, but a Black girl, it's like the DSM shrank to a handful of options, and many psychologists were loath to even consider those" (210). Denise's fictional struggles reflect the reality of racial disparities in diagnoses, an area that researchers have studied. For example, Begeer et al. noted that pediatricians were more likely to discuss autism with reference to Dutch people as majority cases than Moroccan or Turkish people as minority cases, speculating that, "Pediatricians may be more inclined to attribute social and communicative problems of children from non-European

minority groups to their ethnic origin, while they would possibly attribute the same problems to autistic disorders in children from majority groups" (146). In the novel, clinical experts are not the only ones who do not recognize Denise as autistic. When Denise finally discloses to her former teacher on the *Nassau*, so that she will refrain from touching her, Els responds, "Of course you are," explaining that the diagnosis never occurred to her before because, "I just thought you were..." (59). Els does not finish her sentence, but Denise fills in the blank internally, thinking, "*Difficult* is what she's thinking, just like a dozen teachers and psychologists before her. *Just another maladjusted Black girl from the Bijlmer*" (59-60). Although Denise encounters one therapist or teacher who thinks that she just needs "structure and a gluten-free diet," she is not subjected to many normalizing therapies or purported cures because she is not viewed as disabled; rather, she is pathologized based on her racial identity (210).

While the novel's jacket offers the impression that the novel is about Denise's efforts to convince other people on the generation ship that she is useful, in spite of her diagnosis, the story inside is more complex. Denise is the first member of her family to receive a place on the ship, as she manages to recover a missing barrel of supplies. Her high school teacher Els is also a passenger on the *Nassau* generation ship, and shortly after she discovers that her former pupil is autistic, she offers her a job. When Denise asks Els, why she offered her a job, Els explains:

I had autistic colleagues at the university. They were accommodated, and they *thrived*. One researcher came in earlier than everyone else and would stay the longest. I saw the same strengths in you once I knew to look for them. You're punctual, you're precise, you're trustworthy. When you don't know something, you either figure it out or you ask, and either way, you get it right. I wanted to give you the same chance my colleagues had,

and that other *Nassau* passengers got. One of the doctors is autistic – did you know? (282)

Denise, far from the only disabled character in the novel, is also not the only passenger on the generation ship who is autistic. Els, who knows other autistic people, is aware that Denise may learn differently, but she strongly believes that her former student is capable of contributing to the future society in her own unique way. And yet a plot twist reveals that Els has been hiding barrels of supplies to create a false sense of scarcity that will discourage the ship's captain from taking on new passengers. Els may believe that Denise is useful, but she is less inclined to believe that Denise's mother, who struggles with addiction, is worth saving.

Duyvis's novel is set in a future where humans have the capability to travel to other planets, but the resource disparity that it portrays in this future crisis reflects existing inequalities. Sociologist Ulrich Beck, in his theory of world risk society, suggests that large-scale problems like environmental degradation can become unifying, and as "risk-based difference increasingly overlays, aggravates, or replaces the old class division as the original and intrinsic form of inequality" (142). In *On the Edge of Gone*, the discovery of the comet catapults research and construction forward; NASA, in this future, had discovered twin planets a decade before but their planned missions had been "alternately held back by lack of funding, and spurred on by more and more bad news about climate change and waning natural resources" (105) Denise notes that when the comet was discovered, "funding rolled in" (105). The slow progression of environmental disaster does not garner sufficient urgency to seriously explore leaving the planet, but the catastrophic urgency of the comet leads to the creation of generation ships. Government ships selected the majority of passengers based on skill or lottery. Captain Van Zand of the *Nassau*, an owner of multiple factories and refineries, received a ship written off as unusable

permanent shelters on earth. Another passenger explains to Denise that in looking for people to fill particular jobs on the ship, "'[The captain] spread the word in the right circles, but kept the ship's location hush-hush" (73). While ostensibly individuals are selected for survival based on their utility, as opposed to other differences, individuals who have desirable skill sets are typically well-educated, with enough financial capital to have acquired their knowledge. Individuals are in many ways dependent on one another for their survival, but the novel quickly shows how this future can also be divisive, as 'productivity wars' emerge on the ship as individuals hope that proving their worth will lead to their family members filling new spots.

Although the comet's impending impact propels the first chapters of the novel, the initial disaster is the inciting event of the story, rather than its climax, as it focuses on the aftermath of a major disaster. Shelters have been designed to withstand the initial impact itself, allowing individuals to live through the disaster itself, but the slow crisis of the environmental consequences of the impact and waning resources will make survival challenging. Denise notes that, "there were predictions of the ozone layer going, of dust and debris blocking the sun, and disaster piling on top of disaster worldwide. Earth would take years or decades to be remotely habitable again, generations to recover fully. And how many people would survive to see that happen?" (105). Through the travels of Denise, who leaves the *Nassau* daily to search for her sister, the novel contrasts the situation of the individuals residing in the tranquility of the cloaked ship, who are able to reliably eat three meals a day at the cafeteria and reside in spacious quarters, with those outside who scrounge for food and supplies. The word 'Nassau' derives from the German word *nass*, meaning 'wet,' which aptly describes the setting as a tsunami is one of the first disasters that Denise, who subsequently travels by water scooter, is confronted with

on Earth's surface. However, it also evokes the capital of the Bahamas, an area known for jarring wealth disparity between Paradise Island and Downtown Nassau. The disparities that Denise faces in this post-apocalyptic setting may be the result of a fictional disaster, but they reflect existing realities of environmental racism, as disasters that seemingly do not discriminate disproportionately affect poor, racialized communities. Individuals who are already disabled or sick are also strongly affected by the disaster, as health is one metric for evaluating candidates for ships. Denise's sister Iris, upon viewing individuals housed in a temporary shelters, reflects, "I saw more melanin, wrinkles, and wheelchairs in that one room than on the entire *Nassau*" (357). Faced with these realities, proving 'useful' is the only means by which many individuals are able to find safe passage away from Earth, and the channels for being able to do so are also difficult to access when the location of the ship is kept secret.

The idea of utility that *On the Edge of Gone* explores was also a key issue in *The Speed of Dark*. While Moon's novel complicates the deficit paradigm of autism through its presentation of the Section A workers, it still limits its discussion to a cost-benefit analysis that takes the form of a debate between the manager who views accessibility provisions as costly, and the supervisor who view his employees as particularly productive in the competitive workplace. Denise, who is not particularly skilled in pattern recognition or other skills typically associated with autism, struggles with her own feelings of inadequacy compared to the other passengers. Before the comet, Denise worked at an animal shelter, and studied feline anatomy in her spare time. As ships carrying animals have already departed, Denise is unsure of how her skills will translate to this new environment, and worries that certain habits, like avoiding particular kinds of fruit and repeating the phrases of others, will make people question her value. However, while Denise manages to prove herself useful to the *Nassau* and its many passengers, the novel offers a strong

critique of an outlook that focuses on utility, even in the post-apocalyptic scenario of a dying planet. As Denise voices her own feelings to her sister Iris, telling her, "I don't think I'm built for the end of the world," her sister responds, "Whether someone is useful only matters if you value people by their use" (447). Iris's statement is instructive for thinking about the ways in which disability is often understood in contemporary culture, and within a neoliberal paradigm, which emphasizes the necessity of work. The *Nassau*, it is worth noting here, is more inclusive of disability than other generation ships; wheelchair users who have valuable skills are given positions on the ship when others would not give them places on board. Denise, however, gains enough confidence to declare, finally, that this is not enough – that the ship can do more for those still on Earth by sending engineers to repair their boats, and providing signal boosters for them to communicate across large distances. After having convinced the Captain to delay the launch to help survivors, as the book closes, she is attempting to convince him to stay in Earth's biosphere, insisting that "Other planets will wait" (452).

Denise's survival as a disabled young woman is a powerful conclusion to the novel, given the prevalence of the 'cure or kill' narrative trope for disability, as well as the common associations between disability and a lack of futurity. Canadian disability studies scholar Derek Newman-Stille points out that the apocalyptic subgenre of science fiction in particular, "tends to evoke the horror of the end of humanity by first showing it twisted in the form of disabled bodies" (221). Not all readers would see the persistence of disability into the future as desirable; Robert McRuer, for example, notes that social movements that oppose disabling global politics have not been as quick to ally themselves with disability because they position disability as, "the object against which an imagined future world is shaped" (3). Certainly, the idea of welcoming disability into the future can be a difficult prospect when, based on political, economic, and

environmental policy, the future seems bleak for everyone. Duyvis explores this concept in her book, as science fiction becomes a useful site for reconciling both the futurity that disability rights activists so desperately want to build with the futurity that environmental thinkers would have us recognize as increasingly precarious. *On the Edge of Gone* commences with the bleak statement, "The first time my future vanished was July 19, 2034," as the comet is announced (1). It proceeds with Denise's admission, "This is the second time my future vanishes: it's January 29, 2035, and I give up" (3). As the novel closes, once Denise has procured a spot on the ship and has managed to help with the survivors in the ways she can, she concludes, "We welcome our future, whatever it may be" (456). The future may be bleak, but disability has not been erased from it, nor is it used to make the future appear worse. It is, simply, an ordinary aspect of human diversity that will be, to use Rosemarie Garland-Thomson's term, conserved. While this novel explores environmental catastrophe, while also representing the experience of disability, the text does not position individuals with disabilities as ecological others.

Although autism has been "othered" under the guise of environmentalism, nuanced approaches to environmental issues can be amenable to the concerns of autistic people.

Borrowing ideas from other groups concerned with environmental racism provides insight into thinking about how neurological diversity and conservationists interested in preserving biodiversity might have commonalities. Rather than attempting to critique existing totalizing descriptions of autism by inserting new totalizing descriptions that are more amenable to environmental advocacy, I suggest that there are parallels in desires to view cognitive environments and natural environments along instrumental lines. In the first section of my dissertation, I explore the urgency of making connections between environmental justice movements and disability politics by looking at creative works representing the experiences of

communities of mass illness and disablement, whose health has been affected by the use of their environments on the part of governments and corporations. I also explore how these works move beyond narratives of pity, asserting the subjectivity of disabled people and the value of their lives even while asserting that the conditions that led to the acquisition of their disabilities were unacceptable. In this section, I explore potential tensions between the environmental humanities and disability studies by examining the use of environmentalist discourse. However, I ultimately argue that while environmentalist discourse has been appropriated, thinkers in the environmental humanities could greatly enhance and nuance their projects by considering the insights of autistic writers. In my conclusion, I return to the concept of critical ecologies of embodiment with which I began, and explain how it might function in disability studies, postcolonial studies, and ecocritical studies based on the case studies that I have explored throughout this dissertation.

# **Toward Critical Ecologies of Embodiment: Concluding Remarks**

"So when the woody stems first appeared, they were deviations merely, not improvements. They were abnormalities, freaks. In those days, though, there was no one around to propose therapeutic intervention. So they remained...It was deviation in development that produced this grove, this landscape, this living planet. What is good is that the world remain ever open to deviation."

#### - Ladelle McWhorter

"If my nightmare is a culture inhabited by posthumans who regard their bodies as fashion accessories rather than the ground of being, my dream is a version of the posthuman that embraces the possibilities of information technologies without being seduced by fantasies of unlimited power and disembodied immortality, that recognizes and celebrates being human as a condition of human being, and that understands that human life is embedded in a material world of great complexity, one on which we depend for our continued survival." – N. Katherine Hayles

"Of course, one cannot think without metaphors. But that doesn't mean there aren't some metaphors we might well abstain from or try to retire."

-Susan Sontag

## **Reiterating Connections**

Throughout my dissertation, I have been introducing a discussion of the *critical ecologies of embodiment*. In this conclusion, I will review aspects of this concept by showing how each chapter of the work contributes to its meaning. I will also show how developing critical frameworks that investigate how cultural works contribute to our knowledge of the ecologies of embodiment is a process that depends upon harnessing new metaphors and associations. These are metaphors that I have identified by examining literary and popular writings about disability because, as I assert throughout this dissertation, the ways that we talk about disability, and the ways that we tell stories through disability, matter. Many disability studies scholars identify the problematic metaphors that we use to discuss disability. My dissertation has certainly contributed to this catalogue. It is true that a considerable quantity of scholarship in disability studies suggests that we look at the materiality of disability as it appears in the stories that we tell, as opposed to how disability serves as a metaphor for other experiences, feelings, and beliefs.

However, while it is important to recognize the materiality of the body, I agree with many other disability studies scholars that moving away from the use of metaphorical language is not only improbable - metaphors are how we think – but ultimately undesirable. <sup>133</sup>

I have created a chart that compares what I call dominant metaphors to what I call generative metaphors. The dominant metaphors are the automatic ones – metaphors that reveal the ways that we are accustomed to thinking about disability, and that may even be instinctive for us many of us, whether we identify as disabled or not. The generative metaphors, on the other hand, offer a new way of thinking about disability. They are not intended to be fixed metaphors, and the way that I present them here is not intended to suggest that all disabled people are in agreement about how we should write disability, or that I think we need to pin down the meaning of disability definitively. But they are metaphors that I have seen in my examination of writing about disability, and ones that stand out from the metaphors that we are accustomed to seeing. In addition to explaining which part of my dissertation these metaphors derive from, I also discuss popular examples from literature, comics, film, and other creative projects. As I discuss these examples, while I may suggest that some works have the potential to produce more generative understandings of disability than others in the sense that they offer new understandings that are readily apparent, I argue that if we approach all of them as careful readers we can generate important, and sometimes resistant meanings from them. The method that I employ in this conclusion borrows from Jay Dolmage's concept of mētis from Disability Rhetoric. Mētis is a form of embodied thinking that, unlike logic, which always implies forward momentum, encourages thinking sideways and backwards (Disability Rhetoric 5). By chronicling the

<sup>&</sup>lt;sup>133</sup> For example, as I noted in Chapter Two, Clare Barker argues that materiality and metaphor do not necessarily need to be opposed (20). Jay Dolmage also argues that while metaphors in scientific writing have often objectified people with disabilities, new metaphors "can and are being used to offer a more inclusive view of human experience" ("Between the Valley and the Field" 108).

representation of disability in these examples, I am not looking to suggest that disability has one meaning in these texts, but that we as readers can play a part in deriving different meanings from them.<sup>134</sup> In large part, embracing these new metaphors involves shifting our understanding of the body as a tool that we possess, to understanding the body as "the ground of being" (Hayles 5).

My concept of critical ecologies of embodiment is designed to address what I suggest is a problem of environmental inaccessibility. My dissertation in this respect draws on how theorists in disability studies and the environmental humanities have redefined the terms 'accessible' and 'ecology,' and seeks to bring this theoretical work into dialogue. According to the Oxford English Dictionary, the term "accessible" has these meanings:

- 1. a. Capable of being entered or approached; easy of access; readily reached or got hold of. Also with *to*.
- b. Of a person; readily and willingly available *to* others. Also (without construction): approachable, friendly.
- c. Able to be received, acquired, or made use of; open or available (to *a* particular class of person).
- d. Able to be (readily) understood or appreciated.
- e. With to. Open to the influence of; capable of accepting; willing to receive.
- 2. a Capable of being used as an access; affording entrance or a means of approach. Also in figurative contexts.
- b. Orig. *U.S.* Capable of being conveniently used or accessed by people with disabilities; of or designating goods, services, or facilities designed to meet the needs of the disabled.

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<sup>&</sup>lt;sup>134</sup> In *Disability Rhetoric*, Dolmage explains that "even if a text actually does want to represent disability in a purely negative, simplistic manner or use disability as a tool of dissimulation, in many ways it will fail" (51). I would argue that reading with an eye to identifying the new metaphors of critical ecologies of embodiment often involves looking for these imperfect representations and their corresponding disruptions in meaning.

In bureaucratic discussions, making a place accessible can refer to following a particular code of guidelines regarding best design practice. In this respect, our understandings of the relationship between disability and accessibility typically hinge on definition 2B. However, disability studies thinkers have pointed out that access encompasses more than design, as they challenge other thinkers to consider how our understandings of this concept might be expanded.

For example, philosopher Tanya Titchkosky asks that readers think of access not as something measurable, but as "a complex form of perception that organizes socio-political relations between people in social space" (ix). Other thinkers have discussed how understandings of access might be reframed to consider how education can be made more accessible for disabled people, not only with respect to the physical design of campuses and cities, but with respect to the actual delivery of educational content. Margaret Price calls for a more expansive understanding of access in *Mad at School*, in which she addresses the idea that even scholarly work on the disabled body still tends to presume an able mind (6). She notes that in addition to chronicling the "violence of exclusion" within the academy, her work also celebrates, "new forms of access and cooperation, a gradual reshaping of what academe is and might be" (7). Dolmage also argues that educators might learn from disability access, pointing out that the steep steps that characterize inaccessible buildings can serve as a metaphor for exclusion from bodies of knowledge, whereas universal design can signify enabling practices within the classroom ("Mapping Composition" 14). Crucial to the thinking of these scholars is the idea that 'access' must expand beyond physical referents and policy documents, which means that its temporal and spatial borders should be more expansive. To return to the definition of accessible from the OED that I introduced, while the final definition of accessible - "Capable of being conveniently used or accessed by people with disabilities; of or designating goods, services, or facilities

designed to meet the needs of the disabled" - may appear to be the most relevant for thinking about accessibility for people with disabilities, attending to the insights of thinkers like Dolmage, Price, and Titchkosky would seem to call that we pay attention to other aspects of the definition that may initially seem less pertinent (OED). Titchkosky's reframing of access as a form of perception would seem to suggest that access involves being "open to the influence of; capable of accepting; willing to receive" people with disabilities (OED).

Others have considered how the meanings of access shift from one cultural location to another. Clare Barker, for example, suggests that the implementation of access may have different connotations in postcolonial contexts. In her literary analysis of Patricia Grace's novel Potiki, which tells the story of a Māori community in New Zealand and their struggles with land developers, Barker points out that access is framed as a more communal practice, as individual needs are compatible with communal needs, even if a philosophy of individualism is not (43). 135 In addition to showing how a disability studies lens can inform analyses of postcolonial texts, Barker also illustrates how the understandings of community present in postcolonial novels about disability encourage a rethinking of the idea that disability is a burden. Instead, access for people with disabilities is understood to help everyone. Although Stacy Alaimo's primary field of study is environmental criticism, as opposed to postcolonial studies, her work offers a similar rethinking of access. As Alaimo examines the experiences of people with multiple chemical sensitivities (MCS), she points out that "making public spaces accessible for chemically reactive people would benefit everyone" (124). She understands, of course, that to do so is not an easy task, requiring, "a radical overhaul of industrial, consumer, and everyday practices, as well as a

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<sup>&</sup>lt;sup>135</sup> Barker explains that when the community in the novel rebuilds their wharenui, or communal meeting house, following an arson attack on the part of the land developers, they construct a ramp to accommodate the needs of a central character who is disabled. She notes that in this representation of a Māori community, "the individual's needs are inextricable from the wellbeing of the group, and such accommodations are presented not as exceptional adjustments but as organic and vital elements of community life" (43)

drastic departure from both philosophical and commonsensical conceptions of an enclosed, impervious, human subject" (139). However, Alaimo's point that we are all somewhere on a continuum of sensitivity to our environments suggests that we need to expand temporal and spatial understandings of 'access' to consider how political decisions that seem detached from questions of access actually have bearing on human health and ability.

Alaimo's expansive understanding of what it means for a society to be accessible is the framing of access that I borrow from most in this work, but the others inform my thinking as well because they point out that access, like disability itself, is not a clear state, but a process. One of the lessons that we can learn from disability scholars and activists who have contributed to our understandings of what it means to be 'accessible' is that while universal access is something that we should always be striving to achieve, making a space accessible in practice is always about contingency. 136 This is not to say that there should not be clear practices in place that people should observe, or guidelines that people can follow. It is to say, however, that even when best practices are followed, the materiality of different bodies meeting in different spaces at different times will always be unpredictable, requiring some openness and improvisation. As disability studies becomes more expansive in its purview, acknowledging the presence of neurological differences, chemical sensitivities, chronic illnesses, and other invisible disabilities, the complex access needs of some may even conflict with those of others. For example, one of the chemicals that many people with MCS are sensitive to is cigarette smoke, meaning that accessible environments are smoke-free environments. However, many people who are addicted to cigarette smoke are often stigmatized due to persistent ideologies that equate health and morality, and may consequently avoid places where opportunities to smoke are infrequent or

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<sup>&</sup>lt;sup>136</sup>Acknowledging this contingency was an important stage in the conceptualization of this project, and this contingency is one of the reasons why I investigate the critical ecologies of embodiment, as opposed to offering an outline of accessible ecologies, as I had at one time planned.

denied. Another example is that a form of self-stimulation or "stimming" that may be calming for one autistic person could be anxiety-inducing for another person. Such emergent differences in terms of how people experience disability require flexible thinking and openness that moves beyond official guidelines for accessibility that are designed to clearly outline responsibilities.

Yet even when guidelines are in place, they are often de-prioritized or ignored. We often hear apologies after the fact when things are not accessible, as well as attempts to shift blame from one party to another. One recent international example of a lack of accessibility that garnered significant attention was that of the lack of appropriate sign language interpretation at Nelson Mandela's funeral in South Africa on December 15, 2013. Officials had intended the event to be accessible to Deaf listeners, and had acquired a South African Sign Language (SASL) interpreter to translate the ceremony. However, it quickly became apparent to Deaf viewers, both in South Africa and abroad, that the interpreter was not actually using recognizable SASL signs. News coverage of the event revealed that the interpreter in question, Thamsanqa Jantjie, had been critiqued for his inaccurate interpretations in the past, and for his lack of use of SASL, and potential lack of knowledge of the language. 137 Accusations of blame for why the event was not properly accessible to Deaf viewers - or, in other words, why an interpreter with a history of inaccurate translations was chosen for the event - were passed back and forth in the wake of the news coverage. The Deaf Federation of South Africa (DEAFSA) indicated to media outlets that they had warned the African National Congress about Jantjie's unacceptable work well in advance of the ceremony. Representatives from the government indicated that the South African Broadcasting Corporation (SABC) had acquired the services of the interpreter. Yet SABC indicated that they had their own interpreters in studio, and would not require the services

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<sup>&</sup>lt;sup>137</sup> News coverage of the event was further complicated by Jantjie's disclosure that he was taking medication for Schizophrenia and was hearing voices during the ceremony. For further consideration of this complexity, please see Jonathan Hsy's informative blog post, "Signs Taken as Wonders: Žižek and the Apparent Interpreter."

of another one (Bornman, Nair, and Molatlhwa). In the wake of outrage on the part of both international and domestic viewers, a clear apology was impossible to find.

Such controversies of course occur in Canada as well. One fairly recent Canadian controversy surrounding a lack of accessibility on the part of the government took place in July, 2013. The offices of several Conservative Members of Parliament (MP), including Ryan Leef, Shelly Glover, Lawrence Toet, Dean Del Mastro, and John Baird sent out pamphlets entitled, "Supporting Jobs for All Canadians" (CBC News). The pamphlet was designed to inform Canadians of the steps that the Harper Government was taking to remove workplace barriers for people with disabilities. While the pamphlet featured Braille lettering underneath the title, it did not feature embossed text that would actually enable blind or visually impaired people to read it, rendering the flyer completely inaccessible to this community. Doreen Demas, a visually impaired woman residing in Glover's riding, made the point that the flyer not only did not include actual Braille, but did not include any information concerning where a person with a visual impairment would even be able to access the text from the pamphlet. In response to the controversy, Glover defended the flyer by pointing out that the Braille was only intended as a visual representation. In an email to the Canadian Broadcasting Corporation (CBC), she explained: "Like the other graphics on the mailer, it signifies a group of Canadians who may face challenges in obtaining employment. Our Conservative government is committed to supporting all Canadians in finding work, and is proud of renewing our support for the Enabling Accessibility Fund" (Qtd. in CBC News). While Demas was dissatisfied with the government's action, she told the CBC that instead of an apology, she would "like to see the government take real steps toward helping people with disabilities land jobs" (Qtd. in CBC News). The message

that Demas articulates here is similar to one that significantly informed my discussions in Chapter One, in which I discussed apologies that have been offered to Indigenous people.

While an official apology and the assumption of responsibility may be a step toward acknowledging the injustices of the past, such apologies often do not go far enough. Although we might hope that an apology is the beginning of a conversation with respect to issues of accessibility or Indigenous sovereignty, it is often the end of one. In Chapter One, I discussed the ethics of apology with respect to Indigenous groups in the United States as well as Canada. I noted that reparations in Navajo culture involve offering *nalyeeh*. It is worth quoting again at length for considering its applicability to issues surrounding accessibility as well:

*Nalyeeh* is 'enough that there will be no hard feelings'. It insists on good intentions to undo the harm and restore order and safety. Those good intentions must become plans, and those plans must be executed. The parties must then think about the evil that was addressed and the way it was overcome, and reconsider how everyone must live in the future. (Brugge, Benally, and Yazzie-Lewis)

An apology, understood in this way, is not only concerned with the events of the past, but with plans for the future; an apology is not a single event, but an ongoing process. An ethics of access may have a sense of apology with it, but it should also be accompanied by a promise for the future - a promise for better efforts, and a plan for them. The creators that I investigate in this dissertation all suggest that we need to move beyond the act of apologizing, and toward action - moving from an ethics of apology to an ethics of access and acceptance. Places like Bhopal, Déline, and others are often explained away by referring to the past. People living in multiple regions are told that today's governments and corporations are more responsible. We do, however, still see the offloading of environmental risk onto neo-colonial areas. But, we also

know that these are not just events - these are ongoing catastrophes, instances of what Rob Nixon calls 'slow violence'. Although responsibility may be difficult to assign within existing legal and political realms, these issues should be central to disability discussions. As disability studies scholars, we recognize that disablement is a process, but the temporality of this process needs greater consideration. Considering the definition of 'accessible' alongside that of the definition of 'ecology' therefore helps clarify the possibilities of critical ecologies of embodiment.

The second major concept that I draw on in this work is that of ecology. According to the *Oxford English Dictionary*, the term ecology has multiple definitions:

- 1.a. The branch of biology that deals with the relationships between human beings and their environment. Also: the relationships themselves, esp. those *of* a specified organism. But this is how theorists have defined it....
- b. Chiefly *Sociol*. The study of the relationships between people, social groups, and their environment; (also) the system of such relationships in an area of human settlement.

  Freq. with modifying word, as cultural ecology, social ecology, urban ecology.
- c. In extended use: the interrelationship between any system and its environment; the product of this.
- 2. The study of or concern for the effect of human activity on the environment; advocacy of restrictions on industrial and agricultural development as a political movement; (also) a political movement dedicated to this.

As disability scholars have worked to expand our understandings of access beyond traditional definitions, critics in the environmental humanities similarly have sought to offer multiple definitions of ecology. One of the aspects of this project of defining ecology has been, as I have discussed previously, an interrogation of what is known as the divide between nature and culture.

While earlier work in environmental criticism set its scope to investigating nature writing, the discipline has expanded to consider the representation of nature in other forms of literature as well, as part of the recognition that nature is not something that exists in a paradisiacal space outside of culture, but is part of urban environments as well.

Environmental criticism, like disability studies, critiques many of the epistemologies of modernity. Ursula Heise explains that for ecocritics, ecologies represent an alternative to modernity's scientific and economic approaches to nature. She notes that these alternatives range from deep ecology to social ecology, and offers succinct definitions of the two:

Deep ecology foregrounds the value of nature in and of itself, the equal rights of other species, and the importance of small communities. Social ecology, by contrast, tends to value nature primarily in its human uses and has affinities with political philosophies ranging from anarchism and socialism to feminism. (507)

Heise notes that while deep ecology approaches were popular in early environmental criticism, current work tends to draw more heavily on the paradigm of social ecology, taking into consideration environmental justice approaches that consider how factors like race and class affect people's exposure to environmental pollution and catastrophe. <sup>139</sup> In part, she notes, this is because environmental criticism, as it emerged in the United States, has been influenced by both international perspectives, as well as by African American, Chicano, and Indigenous

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<sup>&</sup>lt;sup>138</sup> Heise explains ecocriticism's critique of modernity as follows:

Environmentalism and ecocriticism aim their critique of modernity at its presumption to know the natural world scientifically, to manipulate it technologically and exploit it economically, and thereby ultimately to create a human sphere apart from it in a historical process that is usually labeled "progress." This domination strips nature of any value other than as a material resource and commodity and leads to a gradual destruction that may in the end deprive humanity of its basis for subsistence. Such domination empties human life of the significance it had derived from living in and with nature and alienates individuals and communities from their rootedness in place. (507)

<sup>&</sup>lt;sup>139</sup> While social ecology approaches would seem to have more in common with disability studies than deep ecology approaches, it is worth noting that many scholars have taken up the issues of speciesism and ableism in conjunction. For more on this topic, see Alice Crary, Sunaura Taylor, and Cary Wolfe.

perspectives within the United States; many people writing from these alternative perspectives are less inclined to romanticize landscapes that are untouched by human civilization. <sup>140</sup> The way in which social ecology critiques the nature/culture divide by focusing on representations of the environment outside of explicitly environmental texts and with reference to urban landscapes speaks to how disability studies has critiqued the divide between disability and ability by exploring the representation of the body in texts that are not always intended as specific explorations of disability. The divide between nature and culture and ability and disability is also relevant to the framing of disabled bodies as bodies that are not fit to be in nature (Ray 35). A recurring trope of disability in popular culture is that of disability preventing meaningful connections with the natural world, a trope that depends upon the kinds of binaries between nature and culture that environmental critics are already working to critique.

Developing critical ecologies of embodiment involves examining how some bodies have come to represent the dependencies and artificialities of the contemporary era, while others are shown to thrive in landscapes that open themselves up for exploration. Tobin Siebers discusses this tendency in reference to a controversy surrounding the lack of accessibility at the Galehead hut in the Appalachian Mountains. The United States Forestry Service required that the lodge be compatible with the ADA, to which the Appalachian Mountain Club protested, arguing that a wheelchair ramp to the hut was not necessary because wheelchair users would not visit the lodge (30-31). Siebers notes that media largely sympathized with owners of the hut, who believed that its patrons would not be wheelchair users. When wheelchair users did make the trek, the media pointed out that if they were capable of the journey, they should not need an accessible entrance. Siebers, pointing out that able-bodied people are not expected to crawl through the windows to

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<sup>&</sup>lt;sup>140</sup> For example, Heise notes that scholars have shown how African American authors tend to associate wide open natural spaces with the forced labour of slavery, eschewing pastoral imaginary (508).

access the hut, attributes this line of thinking to an aspect of what he calls the 'ideology of ability' – technologies are often celebrated, but when a technology is specifically defined as assistive it becomes viewed negatively (31). Disability studies scholar Alison Kafer notes a similar tendency to cast disabled bodies outside of nature, pointing out that while the public is often happy to create trails in natural areas, wheelchair accessible trails are presented as an affront to the natural landscape (136-137). Critical approaches to ecology call for nuanced understandings of the relationship between bodies and environments that recognize that the natural world is home to many different kinds of bodies, and that being in tune with nature does not need to involve bodily displays of mastery over nature.

I began my dissertation with an introduction to the three main fields that I draw on: disability studies, environmental studies, and postcolonial studies. It may appear as though, in offering these definitions, I am engaging more so with the former two. However, postcolonial studies is central to this inquiry because the colonial practices that the discipline positions itself against are both so disabling and so unsustainable that the stories of formerly colonized and neocolonized people deserve critical attention. It is also forms of resistance against the colonizing of bodies and landscapes that produces the metaphors that I now introduce. The chart on the following page sets out the four central metaphors that I am working with in this dissertation, and the sections that follow discuss them with reference to popular works:

Dominant Metaphors	Generative Metaphors
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Disability = Degradation	Bodily Difference = Biodiversity
Symptoms = Pollution	Communication = Pollination
Disabled Life = Alienation	Disability Culture =
	Conservation
Cure = Rebirth	Cure = Techno-Fix

### Disability as Degradation/Disability as Biodiversity

The first of these metaphors is disability as a metaphor for environmental degradation. One of the ways that we signal that environmental conditions are intolerable is by showing the pain that humans experience in these environments. After all, while we may insist upon the importance of preserving nature for its own sake, one clear strategy for drawing attention to environmental issues is showing how people are affected by them. For many well-intentioned thinkers, disability becomes a tangible reality for pointing toward the need for environmental mediation and intervention. In part, this is such a common metaphor because of the reality that disabling environments produce disabled bodies. One example of where we can see this idea of disability as degradation played out is in the popular Hollywood film Mad Max: Fury Road (2015), directed by George Miller, which received six academy awards in technical categories for its immersive and terrifying vision of a post-apocalyptic future. <sup>141</sup> The film begins with a shot of Max, the titular character (though arguably not the protagonist) surveying the desert before him. Next to him on the ground is a lizard; when the lizard turns to the camera, the audience can see that it has two heads. Max, played by actor Tom Hardy, spears the lizard and begins to eat it raw, immediately signifying to viewers how polluted this world has become. 142 While Max himself is relatively healthy, becoming a human blood donation bag for a group of young men known as "half-life" warboys because they have been exposed to so much radiation that they will only live half of an average human life span, the film features many disabled characters. Actress Charlize

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<sup>&</sup>lt;sup>141</sup> Jenny Beavan, who won an Oscar for her work on costume design for this film, described how *Mad Max* speaks to contemporary environmental issues in her acceptance speech: "I've been thinking about this a lot, but actually, it could be horribly prophetic, *Mad Max*, if we're not kinder to each other, and if we don't stop polluting our atmosphere…" (gtd. in Wong)

<sup>&</sup>lt;sup>142</sup> Disability studies scholar Ellen Samuels is currently investigating the representation of conjoinment in popular culture, and considering the ethics of using conjoined twins to draw attention to slow violence. While her work focuses on conjoinment in humans, her critical observation that conjoinment has become a potent means of signifying environmental injustice would seem to apply in this incidence as well.

Theron plays the role of Imperator Furiosa, a disabled woman who uses a prosthetic arm. <sup>143</sup> Meanwhile, the villain Immortan Joe is first introduced facing away from viewers, allowing audiences to see the numerous tumors that line his back. Later in the film, he uses an intimidating chrome respirator mask decorated with horse teeth to breathe. One of his sons carries an oxygen tank on his back, and his other son is of very small stature. And finally, while Max himself is a healthy, capable donor, he is nonetheless a disabled character. In addition to wearing a leg brace, the title *Mad Max* and the various unexplained flashbacks that the character experiences suggest that he is 'mad' because he is experiencing post-traumatic stress.

Viewers celebrated *Mad Max* for its representation of disability, in particular with its casting of Charlize Theron as a disabled woman who is the film's strongest hero. Hero. And yet, while this recognition of narrative inclusion is significant, I would insist that one of the reasons why *Mad Max*, as opposed to other Hollywood films, features so many disabled characters is because it is in many ways a depiction of the absolute worst of all possible futures — an irradiated desert world of ruthless scavengers, rampant misogyny, and life-threatening disabilities. The politics of using disability to signify a bad future is an issue that is absent from many analyses of the film. As well, while the trope of disability as a sign of evil is complicated through the presentation of Imperator Furiosa as a disabled hero, the film's heroic characters are largely disabled from the hardships they have faced, as opposed to being disabled from birth. It is also

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<sup>&</sup>lt;sup>143</sup> It is common practice for Hollywood to cast non-disabled actors in the roles of disabled characters. For more on the issue of casting in Hollywood and beyond, please see "A Clarion Call to Non-Disabled Actors to Refuse to Play Disabled Characters" by Lennard Davis or "Casting a Non-Autistic Christopher in The Curious Incident of the Dog in the Night-Time" by Stiofan MacAmhalghaidh Âû.

<sup>&</sup>lt;sup>144</sup> For examples, please see Tauriq Moosa's "Your Body isn't your world: The heroes of *Mad Max* and disability", Brent Walter Cline's "Power and Disability in *Mad Max: Fury Road*", and Jorain Ng's "Disability in *Mad Max: Fury Road*."

<sup>&</sup>lt;sup>145</sup> However, while people praise the representation of disability in the film, others have noted that the lack of representation of people of colour in the film is troubling. This is particularly significant given the film's nomination for several Oscars in a year in which many celebrities and viewers boycotted the Oscars due to its lack of recognition of actors of colour.

notable that the representation of the sympathetic characters does not draw on the grotesque in the same way that it does for the villainous characters. Imperator Furiosa may use a prosthetic arm, but the dangers she continually faces suggest that this represents a loss or amputation, as opposed to an environmentally caused bodily difference. Similarly, Max's disabilities are acquired from his traumatic life. The only heroic character whose disability is clearly related to the harsh planetary conditions is Nux, a half-life who eventually sacrifices his life for Furiosoa's cause; while he begins to interrogate the beliefs of his community, he continues to believe in the ideology that it is better to die, and to be witnessed dying heroically, than to succumb to his own body. My reading is not, however, intended as an admonishment of the film, but perhaps a call. If a film about the worst possible future can feature people with disabilities, what about a film about the best possible future? After all, science fiction often questions eugenic practices and warns of the dangers of technologies that threaten to make us all the same. And yet some of these efforts stop short of questioning what Tobin Siebers defines as 'the ideology of ability,' as disability is continually associated with the kind of future no one wants.

However, perhaps there is another future that this film looks toward. The film's representation of disability is not without its tensions, and yet it concludes with a disabled woman who implicitly promises, not the return of the world that preceded this one, but a world founded on new ideologies. While they may never be able to fully remediate their environment, the community recognizes the mistakes of the past that led them to this predicament. Theron's character manages to free women who are used as "breeders" against their will, and lays claim to a citadel that had been under the control of a misogynist leader. Her promise of a different future is also grounded in a feminist ecocritical stance; the remaining female characters are left with seeds that represent the hope of a better future. Rather than a technological fix, enacted through

scientific reasoning, here, the promise would seem to be a new *ethos* - one that celebrates disabled women and their capacity for leadership, insisting that social change and political change is fundamental to ecological change. How then, does such a film, suggest that disability signifies biodiversity? It would be at best unconvincing and at worst cruel to suggest that radiation poisoning or painful tumours be immediately read as signs of biodiversity. However, what we see in the film is a shift from viewing disabled bodies as disposable lives to viewing them as part of the human community. Immortan Joe assembled an army of the "half-life" warboys, indoctrinating them to give their lives for a glorious afterlife as a means of excising them. With the shift in leadership comes the promise that respect will be given toward those whose bodies are affected by the environment, as they are recognized as bodies *worth inhabiting*.

All of the writers and artists that I have examined in this dissertation reiterate this message that all bodies are worth inhabiting, even if the conditions that led to their pain are not acceptable. In the case of the works explored in the first section of my dissertation, in which I discussed the relationship between disability and industry, this idea was borne out through a clear contestation of the inevitability of the deaths of Indigenous and formerly colonized populations living in rural areas. While the presence of disabled people in an environment has often been linked to environmental degradation, the presence, inclusion, and agency of disabled people can be a sign of a commitment to biological diversity, in terms of both the acceptance of all bodies, as well as in terms of a commitment toward environmental remediation that insists that all people have the right to health. In the second section of my dissertation, I looked at writers who contest the inevitability of poverty and alienation in the lives of people with neurological differences, who call upon us to recognize human diversity in the same way that we

recognize the value of difference in our environments. However, in practice they have often been presented as suffering victims of an environment, whose presence should be erased.

On this note, another text that offers insight into my means of complicating the idea that disability connotes degradation is Zoo City (2010) by South African writer Lauren Beukes. Beukes is also the author of the cyberpunk novel Moxyland (2008), which features both the slow violence of the ghettoization of impoverished 'rurals' who have higher rates of AIDS and reduced access to medical treatment, as well as the spectacular violence of a deadly virus released amongst protestors who can only receive the antidote by reporting to the police. Zoo City, in contrast, is not about disability in a traditional sense, and yet its message certainly speaks to how changes in one's embodied means of interacting with the world are stigmatized, and often interpreted as signs of ecological disaster. 146 Billed as a "muti (indigenous medicine) noir" novel, Zoo City imagines a future in which many people throughout the world have mysteriously acquired animal companions (Stobie 367). These humans, who are called aposymbiot individuals by professionals and 'zoos' by general society, are ghettoized in a separate area of Johannesburg. These companions, however, tend not to be of a domestic variety; instead, zoos are accompanied by mongeese, sloths, crocodiles, and other wild animals. Everyone who is 'animalled' receives, as well, a particular talent or *mashavi*, or talent. 147 The novel follows Zinzi December, a former journalist whose sloth familiar accompanies her as she uses her talent for finding lost things to investigate the disappearance of a young pop star, and continually faces the stigma associated with carrying a sloth on her shoulders.

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<sup>&</sup>lt;sup>146</sup> Fiona Kumari Campbell, writing on ableism, argues that we should "shift the gaze of contemporary scholarship away from the spotlight on disability to a more nuanced exploration of epistemologies and ontologies of ableism" (np). While a disability studies lens equips us to write critical works on the representation of disability, I would argue that exploring that ideologies surrounding the body and ability deserve critical attention even when disability appears to be absent from textual content because attending to this absence can be revelatory.

The term *mashavi* is a Shona word that translates to "alien spirits" (Shoko 59).

In the absence of any definitive, scientific answer to explain the presence of these unusual animal companions, theories emerge to explain their existence. The book presents many of these theories in the form of fictional excerpts from academic papers, documentary reviews, definitions, journal passages and other documents that precede individual chapters. As many of the individuals who have animals have committed crimes or carry large burdens of guilt, many perceive the animals as external embodiments of sin. One of the theories is that the aposymbiot phenomenon is a result of environmental degradation. In conversation with a therapist,

December notes that she prefers this Toxic Reincarnation Theory to the idea that the animals are a means of expelling sin, explaining:

It's very now. Global warming, pollution, toxins, BPA from plastics leaching into the environment has disrupted the spiritual realm or whatever you want to call it, so if you're Hindu, and you go through some terrible trauma, part of your spirit breaks away and you return as the animal you were going to be reincarnated as. (Beukes 187)

The theories that emerge to explain the existence of these animal companions showcase the tendency to associate difference with bad habits, from moral transgressions to disregard for the natural world. Critic Cheryl Stobie suggests that Beukes's corpus speaks to the realities of segregation in South Africa in the present, as it projects social divisions into the future to make present the persistent reality of these divides in the post-apartheid period (368). In contrast to the theories that it introduces to explain the presence of animals amongst the ghettoized population, the novel offers a more sympathetic portrait of the characters, complicating their association with sin by also exploring the individual talents that accompany their stigma.

To clarify, Beukes's characters certainly do not read as supercrips who overcome any individual barriers or receive redemption through channeling their talents. The novel's focus is

always on the ways in which society enacts barriers, such as by barring individuals from restaurants, preventing them from renting apartments in certain divisions of the city, and making employment difficult to come by. In addition to being looked upon with fear and disrespect, at other times, animalled individuals will attract individuals for the spectacle they present, as traveling with an animal becomes, in the eyes of some, an invitation to converse. And yet their talents, often organized around perception and being able to retrieve things that others are not able to find, suggest the particular situatedness of the zoos, and their specific insights. *Zoo City* draws attention to the harmful effects of poverty and stigma that the zoos experience, but also to the harmful effects of the proliferation of theories that read zoos as signs of the worst aspects of human nature and society, and in this sense, it mirrors much of the discourse surrounding disability and unknowability that I discuss in Chapter Four. But the idea that disability confers specific insight is one that I will explore in greater detail in my next section, in which I discuss how a disability studies perspective calls us to value alternative communicative practices.

### Symptoms as Pollution/Communication as Pollination

In Chapter Four, I described how scholarly and autobiographical writings about autism reframe autistic patterns of communication, often referred to as symptoms or behaviours, as forms of rhetoric in their own right. I explained how autistic bodies have often been framed as polluted bodies in need of purification. A metaphor that I see developing for ways of thinking of thinking and being that allow for the generation of dialogue, not only with respect to autistic experience, but for other experiences of disability as well, is that of disabled communication as a form of pollination that allows for new understanding and growth. The example that I would like to start with concerns communication amongst young adults in the 2014-2015 comic series *Ms. Marvel*,

written by G. Willow Wilson and illustrated by Adrian Alphona. The superhero Ms. Marvel in this series is Kamala Khan, a Pakistani-Muslim American teenage character co-created by Marvel editors Sana Amanat and Stephen Wacker. Khan acquires her superpowers when she is engulfed in a cloud of alien Terrigen Mist, becoming one of a community of individuals with hybrid human and alien DNA known as the Inhumans. In a presentation at TEDxRainier concerning her experience writing for *Ms. Marvel*, Wilson explains that she saw parallel forms of both anxiety and resistance in Muslim communities, and amongst the young generation of Millennials – groups that she notes are both misunderstood and maligned in mainstream media. She noted that when she set out to write *Ms. Marvel*, "I had in mind a saying attributed to the prophet Muhammad that seemed particularly relevant. If the hour of reckoning falls upon you and you are holding a seedling in your hand, plant the seedling" (TedxRainier). Wilson explained that her intention was to capture the growing sense amongst both Muslims and Millennials that even though the planet is dying and it may too late to undo the damage that human civilization has caused, the actions that we take today remain important.

One of the issues surrounding contemporary culture and education that Wilson's writing takes up is the experience of Millennial thinkers who are consistently targeted by media commentators with respect to their dependence on technology, and their fatalism - which is said to take the form of an obsession with stories about the end of the world. Rather than discuss the specific inclusion (or exclusion) of disabled characters in her work, or even how Kamala's power to transform into other people and alter the size of her body speaks to conflicts

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<sup>&</sup>lt;sup>148</sup> For example, Emory University Professor Mark Bauerlein argues that digital technology is preventing young people from developing writing skills and the ability to think critically in his book, *The Dumbest Generation: How the Digital Age Stupefies Young Americans, and Jeopardizes Our Future (Or, Don't Trust Anyone Under 30)*. Melissa Ames, taking up the concerns of Mark Bauerlein and other critics of adolescents, suggests that youth interest in dystopian fiction is evidence that they are engaged in political questions, and argues that educators can use these works to encourage students to become more politically engaged outside of fiction (3).

surrounding assimilation, I would like to consider how her stories speak to the characterization of an entire generation as less capable and less intelligent than the generation that preceded them. 149 Wilson's spoken defense of Millennials appeared shortly after Lily Eskelsen García, the head of the National Education Association in the United States, described looking after the "chronically tarded and medically annoying" as among the many responsibilities of teachers during her reception speech for a Progressive Champion Award (Campaign for America's Future). <sup>150</sup> Meanwhile, only months later in Canada, journalist Heather Mallick criticized the present generation of university students for their dependence on excessive accommodations with respect to a decision on behalf of the Ontario Human Rights Commission to allow students to receive accommodations at York University without having to declare a specific diagnosis. Ms. Marvel tackles pervasive beliefs surrounding the young generation of present high school and university students, and their learning practices. Shortly before an attack on Kamala's high school, she and her friend Nakia are approached by a teacher who asks them to share their thoughts on an article that they have read for class. Nakia admits that it insulted her because, "the writer said that teenagers are just parasites addicted to their smart phones who don't give back to society... how can you write off a whole generation before it's even had a chance to prove itself?", to which Kamala adds, "Well...giving up on the next generation is like giving up on the future, right? And...and sometimes the next generation has to deal with all the problems the last generation left for it to fix" (Wilson, Alphona, and Wyatt 63). Kamala and Nakia face pervasive

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<sup>&</sup>lt;sup>149</sup> For a fuller discussion of how Kamala's conflict surrounding how to use her powers speaks to her struggles with her identity, please see Miriam Kent's "Unveiling Marvels: Ms. Marvel and the Reception of the New Muslim Superheroine."

<sup>&</sup>lt;sup>150</sup>Eskelsen García has since apologized, admitting that her joke about "medically annoying" students was inconsiderate and misleading, but she claimed that she intended to say "chronically tardy," with respect to students who are late, as opposed to "tarded."

beliefs that their generation is not capable, intelligent, and altruistic enough to tackle large-scale global problems, and argue that this line of thinking has destructive implications for the future.

The core arc of the first ten issues of Wilson's Ms. Marvel confronts this issue, as it follows the protagonist's investigation of a mysterious figure called The Inventor, who has been using teenagers as human batteries in an effort to lessen the world's dependence on nonrenewable resources. While Khan pursues the suspect from the assumption that he has been abducting her school friends in order to accomplish this task, an unexpected twist reveals that he has only been using volunteers. The scientific plausibility of using human beings as power sources is not particularly significant in this storyline; rather, the decision to become the literal biological power on which the rest of society depends is symbolic of the guilt that this generation is made to feel. Astonished that her friends would agree to this arrangement, Khan probes for answers only to find out that her peers have volunteered because they have internalized the many angry screeds that describe her generation as worthless. One of the teenagers awaiting his fate as a battery explains to her, "If we could harness [the energy of teenagers], we wouldn't need to kill each other over oil and fry the planet and melt the ice caps and stuff. We're parasites, basically. Kids are, I mean. The planet is overpopulated. We're an extra generation – we shouldn't even be here" (Wilson, Alphona, and Wyatt 90). Another child explains, "the world is basically melting. Canvas bags and hybrid cars ain't gonna cut it. We've gotta do something drastic" (Wilson, Alphona, and Wyatt 101). Her peers are willing to devote their bodies to what they perceive to be the Inventor's environmental cause, becoming an alternative energy source to non-renewable resources. Ms. Marvel rejects this solution, equating it with giving up on the future, as she explains: "I get it. I do. The media hates us because we read on our *smartphones*. The economists hate us because we trade things instead of buying them...We're not the ones who

messed up the economy or the planet. Maybe they do think of us as *parasites*, but they're not the ones who are gonna have to live with this *mess*" (Wilson, Alphona, and Wyatt 91) Kamala continues to ask the other students what they did before they devoted their lives to the Inventor's cause, suggesting a particular niche for each one that will be more useful than giving up their lives (Wilson, Alphona, and Wyatt 101-102). While she agrees that drastic measures are needed in order to bring about large-scale change, she is unwilling to watch her classmates be used. Ms. Marvel's defence of her generation is one that Wilson herself has further clarified.

In Wilson's talk about her work at Rainier, she clarifies that Millennials are not as obsessed with despair as onlookers might think. She connects Millennial thinking to the Muhammad's call to plant the seedling, arguing that this generation of critical thinkers may enjoy reckoning with world's problems, preferring to confront painful realities:

They have rejected the cult of positive thinking that has dominated for so many decades: the idea that we can be saved by hard work and relentless optimism alone. This is a generation that prefers to know exactly how bad things are. Yet if you look at the majority of those stories I just mentioned, you see that the plurality are stories about hope, about survival, about ad-hoc families struggling to stay together. Sometimes the endings of these stories aren't happy; it's true. But they do suggest one thing that I think is critical to Millennial thinking, and which I try to incorporate into Ms. Marvel as well. Sometimes a mess stays a mess. There's not always a way out. But there is always a way forward. (TEDXRainier)

Wilson's descriptions of Millennial thinking speak back to a narrative that describes the emergent young generation as less capable and intelligent than the preceding one, and it is for this reason that I believe her work speaks to a disability studies critique of traditional attitudes

toward learning that view engagement with technology or the use of accommodations as a movement away from true learning. And while the idea of humans serving as batteries may be implausible, I would argue that it serves as a useful symbol, not only of how young people are made to feel as though their lives are worthless, but of the reality that a globalized world *is* powered off of the labour of people whose bodies are viewed as disposable.

Throughout this dissertation, I explore the idea that the metaphor of parasitism, which also appears in Ms. Marvel: Generation Why, is pervasively applied to people with disabilities. While disabilities are sometimes understood as parasitic in the sense that disability is understood to harm an individual, media channels, governments, other parties also routinely characterize disabled people as parasites in the sense that they are understood to take from the social environment. Disabled people have been presented as financial burdens on the rest of society, as individuals who benefit without contributing if they are unable to complete paid work. The idea that an emerging generation is not chronically disabled in their thinking and action or unnecessarily dependent on new comforts, but is merely assuming an alternative course, is one that Wilson promotes as she champions the efforts of movements led by young people like Black Lives Matter and Occupy, and offers an implicit defense of the use of media from smartphones to comic books (TEDxRainier). In pointing toward Ms. Marvel as example of the movement toward new metaphors, I am not suggesting that we view the Millennials as more able than the generation preceding them, but that we should be alert to how the means by which individuals communicate and their resulting signifying practices are often targeted as invalid and impure.

Many young people within disability communities are spearheading movements that will allow for greater recognition of the diversity of language and speech, and particularly a celebration of diverse forms of communication often discounted as noise. One of the points that I

made with respect to autistic symptoms is that they are interpreted as pollution in the sense that autistic bodies are often said to be more susceptible to toxicities, but also in the sense that their ways of communicating are referred to as noise; echolalia and other forms of repetitive speech are understood as noise pollution within a world that places significant value on fluid speech. In the Canadian Journal of Disability Studies, Joshua St. Pierre takes up the concern that dysfluent speakers, such as stutterers, are stigmatized as communicators because of how neoliberal capitalism instructs us to value efficient speech. He explains that, "In failing to conform to the expectations of expediency, the stutterer herself is constructed as a faulty instrument that is inefficient and less useful. From this angle, the stutterer feels the pressure of pace from within, the pressure to be the sort of efficient subject valued and required for participation" (12). Speaking to a dearth of scholarship on disability studies and stuttering, St. Pierre explains how the idea that stuttering is an impairment is produced by social expectations. The belief that the speech of stutterers needs to be purified, normalized, and rendered more efficient is disabling for stutterers. However, while St. Pierre recounts how economic logics contribute to our understanding of impairment, he also points toward other possibilities for understanding speech.

Along with fellow disability studies scholars Zach Richter and Erin Schick, St. Pierre created and developed the Did I Stutter? project, which is a multi-platform online space for contributing to a positive conception of stuttering and other forms of dysfluent speech. On the Did I Stutter webpage, the project is defined as "a space for community, art, and discussion where stutterers and other speech dysfluencies can be rethought in affirming ways" (Richter, Schick, and St. Pierre). In contrast to many other stuttering organizations that focus on the individual's speech as in need of rehabilitation, contributors to Did I Stutter? emphasize that people should be exposed to positive dysfluent-identity discourses and communities before

deciding whether to undergo speech therapies. Challenging pervasive social beliefs that view dysfluent speech as polluted with unnecessary noise, Did I Stutter? aims, "to empower stuttering voices everywhere, and to hear the diversity of sound present in human speech" (Richter, Schick, and St. Pierre). As I noted in Chapter Four, contributor Zach Richter makes a crucial argument linking appreciation for dysfluent speech with appreciation for wild environments, as he explains that "embodiment" conservation, like environmental conservation, looks at the value of difference in non-monetary terms (Richter). The concept of disability culture as a form of conservation forms the subject of my next section. While disability has often been associated with alienation from nature and community, disability culture might be conversely understood as a conservation, the conservation of difference for its own value.

## Disabled Life as Alienation/Disability Culture as Conservation

One of the major difficulties of living with disability, as many disability studies scholars and activists have shown, is confronting barriers to participation in social life due to communicative or physical differences that the built environment does not accommodate. Ray discusses how disability has also been figured as a barrier to participation and interaction with the natural world, and how disabled literary characters are interpreted as representing humanity's alienation from nature (61). I would argue that one example of disability conservation ideologically aligned with the values of environmental conservation is The Loud Hands Project, which was spearheaded by Julia Bascom and the Autistic Self Advocacy Network. The project is a transmedia collection of essays, videos, and poetry written by autistic adults, which was anthologized in a print collection as well in 2012. Loud Hands presents an alternative formulation of autistic difference and its potential to disrupt ideas of what the body should be

and do. In Bascom's poem "Quiet Hands," she tells the story of her experience with Applied Behaviour Analysis (ABA) and its role in disciplining and normalizing the body. She recounts how as a child, she was asked to refrain from waving her hands or feeling textures with the expression, 'Quiet Hands'. She explains that her hands form part of a signifying economy that is not recognized by ABA. She writes of her hands, "They tell me what I think, what I know, what I remember. They don't always need a keyboard for that" (Bascom 121). Speaking out against the efforts to silence ways of communicating understood to be non-productive, Bascom's poet speaker cautions that seemingly well-intentioned efforts to restrain certain forms of movement serve to silence autistic people. The Loud Hands Project, embracing signifying practices that have been called behaviours and symptoms, is a crip practice that conserves disability, and intentionally makes it more visible. Projects like this one prompt an important rethinking of both the deficit and surplus models of autism, their associated hierarchies, and the futures they call up.

The Loud Hands Project, and its means of preserving autistic signifying practices, can also be aligned with the concept of Deaf Gain. H-Dirksen L. Bauman and Joseph J. Murray define Deaf Gain as, "the unique cognitive, creative, and cultural gains manifested through deaf ways of being in the world" (xv). Deaf Gain is an alternative to the term, "hearing loss," which emphasizes that the experience of being part of Deaf culture is not only defined through absence. As Derrick Behm from the Office of Campus Design and Planning at Gallaudet explains, "very often, people refer to hearing loss, as an example, which negatively frames the whole approach from the outside. But let's imagine the Deaf baby who has never heard, and yet is still described as experiencing hearing loss, and instead, we propose a different framing – that of Deaf Gain" (Vox). The belief that Deaf culture is worth fostering in this way is similar to Rosemarie

Garland-Thomson's concept of conserving disability, in which she too proposes that disability should be understood through a different paradigm than that of loss.<sup>151</sup>

The linkages between disability conservation and environmental conservation that Garland-Thomson proposes are also useful for thinking through my next example. Another parallel example of disability conservation and environmental conservation pertains to my introduction, in which I addressed how on July 31, 2014, members of the Grassy Narrow First Nation and their allies marched to Queen's Park in Toronto to call for Ontario Premier Kathleen Wynne to address mercury contamination in the Wabigoon River in Kenora, Ontario. As I explained previously, many people from Grassy Narrows have been adversely affected by methyl mercury released into the river by a paper mill in the 1970s, which continues to affect the water that they drink and the fish that they consume (Willow 73-74). Many of the residents of Grassy Narrows are now disabled as a result of the health consequences of Minamata disease, or mercury poisoning. The march itself was designed to capture the appearance of a river moving through the downtown core of Toronto, with individuals collectively holding a blue fabric banner and cardboard cut-outs of fish. One of the aspects of this event that was crucial to the organizers was that the people from Grassy Narrows First Nation, who had travelled from Kenora to Toronto to send their message to Kathleen Wynne, would be at the front of the march. Accessibility in this march was not an afterthought, but was entirely built in to the event, as many of the individuals who had made this trek were wheelchair users. The experience of disability in Grassy Narrows calls for recognition that the belief that disability is an abnormal state may be a culturally contingent one (Barker and Murray; Carrigan); the community of

<sup>&</sup>lt;sup>151</sup> In 2014, Rosemarie Garland Thomson gave a presentation at York University in Toronto in which she made connections between fostering American Sign Language and fostering disability clear through the introduction of the concept of Disability Gain.

Grassy Narrows advocates for accountability for the disabling conditions that the Ontario Government allowed to take place because disability is so pervasive.

While the people of Grassy Narrows clearly draw attention to how they have suffered, they also have criticized the belief that they are only defined by their suffering, preferring to be defined by the force of their advocacy and their resilience. The strength of the community's efforts to combat clear cutting and draw attention to environmental pollution is a clear focus of Anna J. Willow's *Strong Hearts*, *Native Lands: Anti-Clearcutting Activism at Grassy Narrows First Nation*. Peggy Smith opens her review of Willow's book in *AlterNative* by contrasting the story that she did tell about people affected by disability with the story that she could have told:

Rather than treat the members of the Indigenous Community of Grassy Narrows First Nation as victims of the industrial exploitation of forests in their territory, Anna Willow has written a book that attempts to understand their motivation and the role of the people who were instrumental in establishing Canada's longest-lasting blockade, as well as those affected by it. In taking such a perspective, Willow vows to not repeat the hopelessness expressed in a book about the impacts of mercury poisoning written on the community in 1985 - Anastasia Shkilynk's *A Poison Stronger Than Love*. (535)

Since the publication of Willow's book and the march in July 2014, Grassy Narrows First Nation has applied to the United Nations for recognition of Canada's culpability. In February 2016, Grassy Narrows met with a United Nations committee reviewing Canada and Ontario's records on human rights, in hopes of holding Canada accountable for its inaction regarding mercury poisoning in its rivers (Free Grassy Narrows). The people of Grassy Narrows are campaigning for literal conservation of the environments they inhabit, and yet at the same time, we might see them campaigning for disability conservation. It is not the painful results of disability, of course,

that the community wants to conserve, but the lives of people with disabilities who are denied access to appropriate health care. Steve Fobister Sr. of Grassy Narrows, who receives \$250.00 a month as a result of being unable to work due to mercury poisoning told Barb Nahwegahbow, *Windspeaker* contributor, that, "by poisoning our river, and then clearcut logging our forests, Ontario has ruined our health and now threatens to destroy who we are" (qtd. in Nahwegahbow). While the public efforts of Grassy Narrows clearly indicate that painful disabilities in the community can be traced to environmental pollution, as demonstrated through the March on Queen's Park, their political actions position disabled people in the community as experts with insight to conserve. As they advocate for both their rights to accessible health care and their rights to a clean environment, the people of Grassy Narrows also take a nuanced approach to the concept of cure, which I will discuss in my next section.

## Cure as Rebirth/Cure as Technological Fix

Throughout this dissertation, by putting into dialogue writers who are critical of the lack of attention toward the relationship between nature and embodiment with those who are critical of correlations between disability and degradation, I consider how similarities between eco-critical critiques of techno-fix solutions and disability studies critiques of 'cureist' thinking can be cultivated to resist a return to the medical model for explanatory authority. Skepticism, not of technology in itself, but of the presentation of technology as a master solution to social problems, unites both disability studies thinkers and thinkers in the environmental humanities. Disability studies thinkers are critical of the concept of cure because in many cases to cure means to normalize as opposed to relieve one of suffering. However, others provide a caveat that even individuals aligned with the political project of disability studies may advocate for medical

advances that could lead to cures. As discussed previously, thinkers such as Erevelles, Kafer, Siebers, and Wendell have all provided cautions to the celebratory imperative of disability studies, as they point out that embracing one disability identity does not necessarily mean that a person will embrace another, and that some disabilities will not be improved by changes to the built environment. Some individuals may support scientific research into cures and treatments for their disabilities, while advocating for greater rights, since the research in question often consists of long-term projects that do not address present experiences.

The relationship between scientific knowledge and knowledge from the humanities has been a source of contention in both environmental criticism and disability studies. While disability studies thinkers may often critique the ethical import of scientific research, at the same time, they acknowledge that disabled people benefit from many advances in medical technology that alleviate pain, as well as from the construction of prosthetics. Similarly, ecocriticism values scientific research that emphasizes the material realities of climate change, species extinction, and other environmental problems that can be traced to human behaviour. And yet, while scientific research on such topics as clean and renewable energy, or the creation of more sustainable homes, is clearly important, environmental critics also emphasize the significance of changing attitudes toward the environment, as well as the importance of economic change. Ursula Heise discusses how environmental criticism in North America emerged later than other academic branches of civil rights movements such as feminism and critical race theory, coming to fruition during the science wars of the 1990s, in which clashes were taking place between scientific thinkers and postmodern theorists. She explains that the discipline's relationship to scientific knowledge and practice continues to be a vexed one:

On the one hand, science is viewed as the root cause of environmental deterioration, both in that it has cast nature as an object to be analyzed and manipulated, and in that it has provided the means of exploiting nature more radically than was possible by premodern means. On the other hand, environmentalists are aware that social legitimation of environmental politics and their own insights into the state of nature centrally depend on science. (509)

As Heise captures here, science has been aligned with environmental destruction because it has provided the means to manipulate nature. However, another clear target of critique is the economic system that requires such manipulation, and requires it to the point of resource exhaustion. Just as disability studies scholars challenge a system of capitalist production that devalues certain bodies, scholars in the environmental humanities are critical of corporate-led initiatives to be more sustainable that do not address the problem of overproduction. For example, Simon Enoch, writing from an eco-socialist standpoint, critiques the argument that corporate social responsibility (CSR), or "the adoption of socially responsible business practices in areas such as human rights, labour standards, and the environment" will lead to meaningful change (79). Enoch argues that capitalism is inherently ecologically destructive, explaining, "even with CSR-inspired countermeasures in place to ameliorate the worst ecological excesses of capitalist production, the incessant need for expansion must eventually collide with the natural 'limits to growth' imposed on us by both the finite number of resources (taps) and the ability of ecosystems to absorb the resulting waste (sinks)" (83). While the creation of more sustainable technologies is important, a techno-fix solution will not address the issue that global economic systems are inherently damaging to the environment, in the same way that research into cures for

disability will not improve the position of people with disabilities in the present, and will also not address how new scientific advances often lead to new forms of bodily difference.

Cure is the subject of a recurrent cultural trope analyzed by disability studies scholars, which is the restoration of mobility to fictional characters. Mitchell and Snyder refer to this as the 'cure or kill' trope, which means that narrative resolution in literary and cinematic works often involves fixing the problem of disability, either by providing a cure that normalizes the disabled character, or by eliminating the character entirely (165). A variant of this recurring cultural trope is the restoration of mobility to fictional characters as a reward for their outlook toward the environment. For example, in the popular science fiction film Avatar (2009), wheelchair user Jake Sully, who aids an extraterrestrial species in their efforts to preserve their planet, escapes his body by transporting his consciousness into an alien avatar using future technologies. <sup>152</sup> Some might argue that fictional narratives about the restoration of mobility are positive stories, and that some individuals who are wheelchair users would like to be free of their assistive devices. Characters on television and film are certainly presented in this way. However, such pervasive narratives have the potential to influence the self-perception of disabled people in damaging ways. In the documentary Code of the Freaks, which investigates the representation of disability in Hollywood film, performer Tekki Lomnicki notes that watching movies as a child contributed to her perception that she would be cured. 153 In addition to perpetuating disempowering narratives, curing disabled characters can decrease the identification that individual audience members may feel, as cure can be seen as an erasure of disability identity.

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<sup>&</sup>lt;sup>152</sup> Sara Palmer provides a thorough examination of the intersection of race and disability in the film in her article, "Old, New, Borrowed and Blue: Compulsory Able-bodiedness and Whiteness in *Avatar*."

<sup>&</sup>lt;sup>153</sup> Lomnicki explains: "I had this like crazy notion that I would someday be cured. Now I don't know if that meant that I was going to grow tall, or did that mean I would walk without crutches. I wasn't quite sure. But I used to have a dream where I was tall and I did walk without crutches, and I think Heidi is the movie that made me think of that" (*Code of the Freaks*)

As the concept of cure is aligned with biomedical and spiritual miracles alike, the metaphor often associated with a cure to an illness or disability is that of rebirth. However, etymologically, the word cure comes from the Latin *curare*, which means "to take care of" (OED). While techno-fix is one way in which we can read curative approaches, nuanced approaches to cure that involve recognition of the work needed to improve the quality of life of people experiencing illness or disability might be aligned with understandings of cure as a practice of taking care. For example, alternative forms of education, counselling services, and clean environments can improve an individual's quality of life; they may not cure disability, but they are forms of care that can decrease disabling experiences. And yet, some individuals may still prefer that medical advances eliminate certain disabilities. Cure can be a form of technological erasure of disability, but there are also nuanced approaches to cure that depend upon the visibility of disability, and that position disabled people as agents. For example, Peter Wayne Moe describes how Michael J. Fox's advocacy for increased research into treatment for Parkinson's disease depends upon using his disabled body to generate meaning. As a disabled person, Fox assumed control of his own representation in advocating for research, but, by not taking his medication, he also performed a loss of the kind of self-mastery over the body that rhetorical training promotes (Moe 445). However, while advocacy efforts that focus on medical research are not automatically incompatible with a disability studies lens, working toward the elimination of disability as a category has dangerous implications that I want to close on.

I would like to end on a personal note, and briefly mention a project that I contributed to in April, 2015, which was the I Don't Need a Cure Autism flash blog. April is widely regarded as Autism Awareness Month, but as I explained in Chapter Three, many autism activists and groups have renamed April as Autism Acceptance month. Project creator Lori Pollard created the

flash blog as a means of drawing attention to the dangers of cureist thinking with respect to autism. Both members of the traditional biomedical field and practitioners of alternative medicine often work within a disease model of autism and promote the discovery of cures. The intention of this project was to assemble reflections, articles, poems, and other writing that focus on the dangers surrounding many purported cures, and that reiterate the message that many individuals with autism do not wish to be cured, and have friends, family members, and other allies who support their beliefs in this regard (Pollard). This project was strongly affiliated with efforts to ban the use of Chlorine Dioxide/Miracle Mineral Solution, and in that respect, the project communicated that presenting cure as the only solution to disability is not only ableist, but can also be actively dangerous; in other words, it warned against the untested and unregulated technological fix for disability as having disastrous consequences.

Aligning the deployment of discourse surrounding cure with the concept of the technological fix has been the trajectory of this dissertation, and so of the four metaphors I discuss here, it is the one for which I have provided the most textual examples of how we can see this idea played out. Before closing, I will introduce one final example of a work that presents cure as a techno-fix, and that introduces possibilities for welcoming disability. This example is the film *Guest Room*, by writer and director Joshua Tate, which stars Lauren Potter and Michael Iovine. The opening scene is a love scene between the two protagonists, who both have Down syndrome. This scene alone is in some ways a radical representation of disability, given that people with disabilities, and specifically individuals with Down syndrome, are often represented as childlike and non-sexual. Potter's character Amber is visiting Daniel, played by Iovine, and staying in his family's guest room. The film follows Amber, from a conversation with Daniel's

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<sup>&</sup>lt;sup>154</sup> Robert McRuer and Anna Mollow's edited anthology, *Sex and Disability*, addresses a lack of attention to sex and disability studies, and disability in gender and sexuality studies.

mother who encourages her to stay the night once more, to her uncomfortable visit to a pharmacy, to her job at a hairdresser's, where well-intentioned staff and customers patronize her by referring to her in childish epithets and speaking about her in the third-person when she is clearly within earshot. Her day culminates in a birthday celebration for Daniel, but the celebration is short-lived – after the guests have left, Amber overhears an argument between Daniel and his parents, who chastise him for not having used protection. When Amber overhears and is encouraged to join them, Daniel's mother tells them both, "You know, your children have a fifty percent chance of..." (*Guest Room*). While the character perhaps realizes the cruelty of her words before finishing the sentence, the implication is clear – Amber and Daniel, as individuals with Down syndrome, have a much greater chance of having a child who shares this disability.

And yet, while the film includes this statistic, *Guest Room* ultimately questions the perception that disability be perceived as pure risk. Initially, Amber blames herself for not having been careful. Meriah Nichols, exploring this point, suggests that the film illustrates not only the persistence of ableism amongst a well-intentioned public, but the disturbing realities of internalized ableism. As Amber sits before her niece's crib, she repeats Daniel's mother's words, "Fifty percent chance," as her sister approaches (*Guest Room*). Without understanding the context, her sister asks, "Of what?" When Amber explains, "Down syndrome," her sister replies, "So? So what? You turned out alright" (*Guest Room*). After hearing her sister's words, Amber becomes more comfortable with the future, returning to Daniel, whose earlier proposal she had left unanswered. The film ends happily, presenting hope that Amber and Daniel, with the support and acceptance of their families, will be good parents. Although the film itself is not explicitly about curing Down syndrome, it is clearly informed by, and contributes to, debates surrounding genetic screening, selective abortion, and the presence or absence of Down syndrome in

humanity's future. By presenting the possibility of Down syndrome as simply a possibility and not a risk, the film overturns the assumption that "to want a disabled child, to desire or even to accept disability in this way, is to be disordered, unbalanced, sick," (Kafer 3). Insisting upon Amber and Daniel's right to a future, and to a family, Tate's film moves away from cureist logic by presenting one vision of what it means to welcome the possible disability to come. In the next section, I will reiterate four main components of reading for critical ecologies that welcome disability, based on the chapters from this dissertation.

# **Component One: Acknowledging the Presence of Disabling Environments**

Embracing a critical ecology of embodiment involves expanding our understandings of how the decisions that we make about the spaces that we inhabit shape disability. The social model of disability has long held that we need to look outward from the body in order to better understand how the built environment of buildings, campuses, and cities exclude people with disabilities. An ecological approach to embodiment involves both a turn inward and a turn outward; it involves a turn inward to acknowledge the presence of unwanted substances in the body, but it involves a turn outward to think about the social and economic structures that allow for such substances to permeate bodies in the first place. It also involves a temporal shift, from thinking about the immediate needs of the individual to thinking about the accessibility needs of communities.

Literary works can experiment with temporality to prompt audiences to consider the implications

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<sup>&</sup>lt;sup>155</sup> In *Feminist*, *Queer*, *Crip*, Kafer uses Human Genome Project Co-founder James Watson's statement that any parent who wanted a child with Down syndrome would be crazy to explore the assumption that it is abnormal and crazy to desire a child with a disability (3).

<sup>&</sup>lt;sup>156</sup> A recent case in Toronto has drawn attention to discriminatory immigration policies in Canada. York University Professor Felipe Montoya's family was denied permanent residency status in Canada because his son has Down syndrome and might, according to Citizenship and Immigration place undue stress upon the healthcare system (YFile). Canadian entertainer Rick Mercer recently brought public attention to the issue in a video released that was entitled, "My Canada includes an Extra Chromosome" (Mercer Report).

of such turns. *Burning Vision*, by Marie Clements, suggests the necessity of these turns by looking at both the site of the body and the health of a community over an extended period.

Component Two: Examining Narrative Strategies for Representing Slow Violence

Moving toward critical ecologies of embodiment involves planning on a larger scale,
acknowledging the reality of environmental racism and addressing structural inequity. It also
involves cultivating memory, moving from a consideration of the moment of disablement and the
acquisition of pain to a recognition of disablement as an extended process, a process which has
the potential to affect future generations. However, it requires balancing the material realities of
individuals living in pain with the social realities of stigma. Literary works can experiment with
narrative voice to consider the interplay between the desire for recognition and accountability
with respect to disabling environments, and the critique of the ideological nature of definitions of
such terms as 'health,' 'disability,' and even 'human'. As I argue in Chapter Two, Indra Sinha's
novel *Animal's People*, which presents the voice of a disabled protagonist while drawing
attention to how assuming this voice is itself a complicated move, presents a nuanced and
irreverent take on disability that takes structural inequality seriously.

Component Three: Attending to the Rhetorical Aspects of Risk in Scientific Discourse

An accessible approach to ecological study involves thinking critically about our relationship
with science. It means that, in the spirit of interdisciplinary cooperation, we devote attention to
the insights produced by scientific and medical bodies and researchers. However, it also means
that we need to commit ourselves to a critical interrogation of the questions that guide such
research inquiries, the methodologies undertaken to produce them, and the rhetorical
presentation of the results. If we recognize that scientific discovery is a narrative, and that

science, like other disciplines, is rhetorical, than we can read literary works and see how they provide insight into gaps in scientific understandings. This is the approach that I take in my discussion of Tito Mukhopadhyay's memoirs and poetry in the *The Mind Tree*, which demonstrated clearly, at the time of its publication, that scientific understandings of autism and intelligence needed to be rethought, and that the risks surrounding autism needed to be reframed.

### **Component Four: Recognizing Voices of Embodied Subjects**

A disability studies approach to ecological questions also involves considering the voices of embodied subjects. Ultimately, it argues that individuals should have a larger role in determining what should constitute a risk. In recognition of this principle, my chapters all engage with both fictional representations of disability and writing from disability. The relationship between disability fiction and disability non-fiction has sometimes been contentious. Literary works are often criticized for their distance from real world events, as some argue that the use of fictional people and places to discuss real events depoliticizes conflict. However, another clear issue is that works of fiction about disability often gain more cultural capital than non-fiction by people with disabilities. Throughout this dissertation, I argue that fictional and non-fictional works by disabled and non-disabled writers that nonetheless position disabled people as experts on their own lives, and that enact both internal and external strategies for encouraging greater knowledge, allow for this recognition of the voices of embodied subjects. In this dissertation, I used Gerardine Wurzburg's documentary Wretches & Jabberers, starring Larry Bissonnette and Tracy Thresher, to argue for a celebration of both the political and aesthetic possibilities of resituating disabled people themselves as the experts on their own lives. In my next section, I consider how work in other disciplines might continue the work of shaping accessible ecologies.

#### **Future Possibilities for this Work**

While my work argues for recognition of the voices of embodied subjects, it also has a very clear textual focus, and engagement in my case largely means engagement through citational practice, and through the conversations that guided me through this research. In this work, I celebrate literary production and its possibilities, even as I caution against the fetishization of literature as an end point. When I first began this project, I conceptualized it as a project that focused specifically on fiction. I soon realized that I wanted to expand outward and look at historical context, disability memoir, and media discourse in order to gain a fuller picture of the issues that I wanted to explore. In looking forward to future possibilities, I would like to suggest that while the analysis of literature was my starting point, this work can be continued in other ways. In particular, the questions that I explore here could also be the subject of ethnographic research involving interviews, which would be a fruitful second stage. Disability studies is an interdisciplinary field of study, and it is my hope that some of the knowledge that I have produced here might be used to generate further knowledge in other disciplines.

I have concluded with metaphors because I think that while activism needs to focus on bettering the everyday experiences of people with disabilities through policy creation, governmental changes, and resource allocation, I also think that challenging ourselves to interrogate our assumptions about disability is central to enacting these changes, and the literature classroom is one place in which we can undertake these challenges. In February of 2016, I had the opportunity to attend a conference called "Crip Futurities: The There and Then of Disability Studies" at the University of Michigan. Canadian disability studies scholar Eliza Chandler, who presented on disability aesthetics, made a central point to our American colleagues that in Canada, we will soon have the right to die through legislation that will legalize

assisted suicide, but we do not have national disability act, like the Americans with Disabilities Act (ADA) in the United States. As a Canadian, her reminder brought to mind for me how our national mythologies that elevate nature, as something to be both revered and feared, have influenced our perceptions of disability. Catherine Frazee, who is now on the review committee for this new legislation on assisted suicide, discusses these mythologies. Frazee's review of Global's short documentary, "Taking Mercy," which I discussed in Chapter One, shows how cultural understandings of what is natural influence our perceptions of whose bodies matter and whose bodies deserve a place in our national body. Frazee's review describes how the film portrays Robert Latimer, the Saskatchewan canola farmer who took the life of his disabled daughter Tracy. Naming her quarrel as one with "the clichés and platitudes that foster and condone a very particular homicidal impulse," she states, "it is a preposterous notion that Tracy's life did not conform to the law of nature that Robert somehow epitomizes" (Frazee). Canadian literature scholar Maria Truchan-Tataryn also suggests that support for Latimer is bound up in our cultural myths. She asks to what extent Canadian support for Robert Latimer that exists despite Canadian pride in the Charter of Rights and Freedoms stems from our textual encounters with disability and its erasure (191). Disability has been labeled as a fate worse than death, as death is often presented as a more palatable or more noble alternative to living with disability. However, stories have the potential to present alternatives to the mythologies that continue to define certain bodies as other. They can help us craft new disability metaphors. They can work to contest an 'ideology of ability' that holds that disability is a test of will, and to subvert the idea that aspiration toward a fit body is a sign of moral worth. They can work to reject the idea that healthy bodies are closer to nature. And finally, they can allow us to imagine inclusive futures.

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