

# Touching Theory: AIDS Activism and Disability Justice

by

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A thesis submitted to the Faculty of Graduate and Postdoctoral  
Affairs in partial fulfillment of the requirements for the degree of

Master of Arts

in

Sociology

Carleton University  
Ottawa, Ontario

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## **Abstract**

This thesis is grounded in critical disability studies and queer phenomenology to identify and analyze the social relations of touch surrounding 1980s and 1990s AIDS activism. I analyze a collection of interviews with AIDS activists across Canada, acquired through the AIDS Activist History Project. Using these interviews, I identify and analyze the various modalities of touch deployed in state, medical, and activist responses to HIV and AIDS. This analysis reveals that state and medical acts of oppressive touch were ultimately driven by the impetus to quarantine people living with HIV and AIDS away from society, and ultimately, away from their communities. These acts of oppressive touch were challenged and resisted by liberatory touch, which manifested through informal care networks that were organized around people living with HIV and AIDS. The thesis concludes by emphasizing the radical potential of care, interdependence, and ultimately, disability justice, amidst broader attempts to eradicate difference.

## **Preface**

This project was partially funded by the Social Sciences and Humanities Research Council of Canada.



## Acknowledgements

I would like to start by extending my deepest gratitude to my supervisor and mentor, Dr. Alexis Shotwell, whose unwavering support and encouragement instilled in me the confidence needed to complete this project. In addition to her thoughtful engagement with my work, Alexis's commitment to community organizing and social transformation motivated me to think through what a politics of interdependence and disability justice might look like.

Thank you to my committee member, Dr. Zoe Todd, for emphasizing the importance of care-ful practices in the academy and beyond, and to my internal examiner, Dr. Susan Braedley, for her generous feedback and enthusiasm. I would also like to thank the Department of Sociology and Anthropology's administrative team—Darlene Moss, Paula Whissell, Kimberley Séguin, Kim Mitchell, and Stephanie LeBlanc—for their support and dedication to their students.

I am grateful to have worked on the AIDS Activist History Project, which brought me into closer contact with the moments of care recounted in this thesis. Thank you to its research team, and in particular to Alexis Shotwell, Gary Kinsman, Sarah Rodimon, Ryan Conrad, and Ryan Coulling, for working so hard to archive this vital history, and for inviting me along on interviews, workshops, and presentations.

A special thank you is owed to Dr. Susanne Luhmann and Dr. Melissa Jacques for sparking and encouraging my interests in critical theory, trauma studies, and memory studies as an undergraduate student. Your pedagogy is truly inspiring.

This thesis would not have been possible without the love and support of my family and friends. Thank you to my parents and sisters, for teaching me the importance of hard work and perseverance. To my chosen family and friends—Alex Wilson, Alysha Anderson, Daisy Raphael, Monty Bal, Lena Saleh, Keegan Gibson, Samantha West, Leigh Spanner, Dougal MacDonald, Drew Brown, Sarah Murphy Brown, Randi Nixon, and Kit Carole, thank you for your sense of community and endless humour.

Lastly, I extend my love and gratitude to my partner, Janet Phillips, for enacting access intimacy and disability justice in everyday life, and to our canine companion, Iris, for always keeping me present in the moment.

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## **Chapter 1: Introduction**

### **Introduction and Statement of Research Problem**

This is not the thesis that I intended to write. My intention was to build off of my undergraduate research in postmemory and trauma studies to explore the ways through which the 1980s and 1990s HIV and AIDS crisis was remembered in Canadian queer and trans communities. Situated as a white settler who is not themself positive, I was interested in the ways that HIV/AIDS figured largely in queer and trans cultural production, specifically referencing past and ongoing legacies of HIV/AIDS-related losses. These memories were—and are—foundational to my understanding of queerness, transness, and disability justice as someone situated at these intersections. Entering into graduate studies with an interest in memory studies, I was curious about the hierarchization of collective loss, and in particular, the remembering of some lives amidst the forgetting of others. The effects of this forgetting exceed the boundaries of academic work, yet are evident in infuriating experiences of medical and psychiatric abuse directed against people living with HIV and AIDS in the present moment, particularly those further marginalized along the lines of Indigeneity, race, class, disability, age, and gender.

I am privileged to work on the AIDS Activist History Project (AAHP) at Carleton University, on unceded Algonquin territory. My research assistantship provided me with the opportunity to conduct, transcribe, and review interviews with Canadian AIDS activists. My interest in touch—the focus of this thesis—was sparked by these interviews, where touch was referenced in testimonials of medical abuse and neglect, but also in accounts of informal care networks formed across identifications around people living

with—and dying from—HIV and AIDS. The multiple modalities of touch captured by AAHP interviews range from touch as a form of state sanctioned violence, to touch as a powerful form of resistance and collective action. This is not to say that my interest in memory studies dissipated, but as will be discussed later in this chapter with reference to the work of Sue Campbell and Alexis Shotwell (2016), that memory is one component in a broader network of relationality, which as this thesis suggests, informs how we think about and enact touch.

Touch is central to the ways we organize ourselves socially. This thesis explores the radical potential of touch as an act of resistance. As a case study, it examines the AIDS crisis during the period before effective medications became available to many people in North America, while recognizing that for many, AIDS remains an ongoing crisis. This project deploys a theoretical framework grounded in queer phenomenology and critical disability studies to examine what touch is and what it means, politically. This thesis also demonstrates, however, that the concept and act of “touch” is not static. Rather, it performs multiple functions. I will argue that touch can function as both oppressive and liberatory, depending upon the context and the people involved. 1980s-90s AIDS activists deployed touch to resist the oppression experienced by people living with HIV and AIDS. Touch took many forms, but especially notable was providing care and affection to people living with HIV and AIDS that the state otherwise deemed untouchable. This thesis identifies these moments as instances of “access intimacy,” which Mia Mingus, an organizer for disability justice, writer, and educator, defines as solidarity and collectivity among those with shared experiences and understandings of ableism (Mingus 2011, website). However, touch has also been used to perpetuate



disability oppression. Mingus defines the oppressive use of touch as “forced intimacy”—that is, everyday moments of touch that are involuntary, but necessary to survive in an ableist world (2017, website). This thesis explores AIDS activism, forced intimacy, and access intimacy to reveal the multiple and shifting meanings of touch, and to demonstrate the role of touch in disability justice and queer and trans liberation. Touch functions in various ways across AIDS activism. In some instances, it functions as a collective way of thinking about care, and ultimately, as an act of resistance to the refusal of touch by medical service providers. In contrast, touch also functions as an undesired prerequisite to care (Mingus 2017). Importantly, these various forms and functions of touch are not mutually exclusive and cannot be easily isolated.

Touch is not limited to human relations, and extends to non-human life and the physical environment. It builds worlds, and shapes our contact with others. Donna Haraway, a feminist, science, and technology theorist who examines the relationship between human life and the environment, and in particular, between humans and animals, explains in *When Species Meet* (2008) that

touch ramifies and shapes accountability. Accountability, caring for, being affected, and entering into responsibility are ethical abstractions; these mundane, prosaic things are the result of having truck with each other. Touch does not make one small; it peppers its partners with attachment sites for world making. Touch, regard, looking back, becoming with—all these make us responsible in unpredictable ways for which worlds take shape. In touch and regard, partners willy nilly are in the miscegenous mud that infuses our bodies with all that brought that contact into being. Touch and regard have consequences (36).

Here, Haraway takes up touch to account for the myriad of “knots of entanglements” humans have with companion species such as dogs and wolves, as well as the physical environments where these entanglements take place (36). She argues that the act of touch has the messy capacity to create worlds at the same time as it has the capacity to transfer

the histories we inherit through the forms of contact we experience being in our social worlds. She argues that “multispecies knots” are so vital because of their “reciprocal action,” an action where co-constitution between attachments take place (35). Touch, in other words, embodies interdependence. The expression “stay in touch” refers to human connection through regular communication. A “touching” moment moves bodies towards a particular feeling of connection. Indeed, touch functions in multiple ways. And, as introduced above, it can be used to both liberate and oppress. Despite its forms and functions, touch is managed, policed, and regulated. Moreover, touch is embedded across multiple social institutions. The state continues to put barriers in place that limit some forms of touch while letting other forms continue, and in some cases, forcing touch. Touch is policed through the prison industrial complex (Abu-Jamal, 1998; Davis 1998), it is sanitized through the medical-industrial complex (Ehrenreich 1970), and its reach is regulated through the non-profit industrial complex (INCITE! Women of Color Against Violence, 2007). Barriers to touch are both external and internal. Physical barriers limit touch through prisons, housing, universities, and hospitals. These infrastructures are also internalized, however, wherein some self-regulate who, and what, they care to be in touch with, while others lack this choice (Wilson 2016).

Touch is not static, but shifts alongside the meaning and function of care. Here, touch is informed by the ways we think about and enact care. For example, the quarantining of people living with HIV and AIDS by the medical-industrial complex was informed by a concern for the health of hegemonic groups, and was directed towards the separation of people living with HIV and AIDS away from the rest of society as a contaminant. The care received within the medical-industrial complex was directed

towards this end, wherein some medical practitioners refused to touch people living HIV and AIDS in the first place. When touch was enacted in these settings it was highly mediated through the use of gloves and masks. Conversely, the informal care networks that emerged around people living with HIV and AIDS within and across queer communities was informed by a concern for them, as well as for the sustenance of their communities. This thesis is particularly concerned with the shifting role of touch amidst neoliberalism and individualization. Individualization here names “a compulsion, albeit a paradoxical one, to create, to stage manage, not only one’s own biography but the bonds and networks surrounding it and to do this amid changing preferences and at successive stages of life, while constantly adapting to the conditions of the labour market, the education system, the welfare state and so on” (Beck and Beck-Gernsheim 2002, 4). Neoliberal individualization reframes what were once social problems as individual responsibilities (Brodie 2007, 103-104). Individualization has exacerbated the framing of care as an individual, rather than as a collective responsibility. This thesis engages with touch as a moment of collective resistance against the individualization of care. Regardless of state intervention into who and what can and should be cared for, movements have mobilized to resist these narratives of isolation and disposability.

## **Methodology**

My thesis is grounded in queer phenomenology and critical disability studies, with a focus on intersections of touch, gender, sexuality, illness, disability, queerness, and transness. In doing so, it borrows from Sara Ahmed, a feminist, queer, and race theorist who examines the shaping of bodies and worlds, to both queer phenomenology, and to

isolate acts of queer touch using a queer phenomenological lens (2006, 5). Ahmed defines phenomenology as that which “attends to the tactile, vestibular, kinesthetic, and visual character of embodied reality ...” (2006, 110). In her text, Ahmed unpacks heterosexism by attending to desire lines and orientations. Ami Harbin, a feminist philosopher in bioethics and moral psychology, explains that for Ahmed, orientations refer to “how we are most at ease when our body habits align with those shared by others, and with those others expect of us” (2016, 9). These orientations make “some embodiments so intuitive we do not (because we need not) notice ourselves enacting them” (Harbin 2016, 9). Ahmed explores queer phenomenology as a series of disorientations that resist heterosexist desire lines (5). This thesis extends Ahmed’s conceptualization of queer phenomenology to include illness, disability, and transness. Ultimately, the ways in which people living with HIV and AIDS experience touch are shaped by a series of dominant desire lines, which are defined not only by heterosexism, racism, and colonialism, but also by cis-genderness, able-bodiedness, and able-mindedness. These desire lines converge into networks, or infrastructures, such as the medical-industrial complex, which informs what touch should look like. To transgress these desire lines, Harbin argues, is disruptive beyond the bodily, and opens up “new possibilities for action” (9). As this thesis argues, to carve out new desire lines of transness, illness, and disability, is to map out new infrastructures and ultimately, to engage in queer and trans world building, which are integral—and certainly not new areas of connection—to disability justice.

Critical disability studies informs us that bodies and minds matter, while centring the experiences of ill and disabled bodies/minds to identify and critique exclusions

produced by ableist social norms (Kafer 2013, 41; Titchkosky 2009, 54). Tanya Titchkosky, a disability studies scholar situated within cultural studies and phenomenology, argues that sociology has historically treated ill and disabled experiences as symptoms of, rather than as contributions to, how we understand ourselves socially (2009, 54). This approach perpetuates a conception in which disabled people are seen only as objects of care and, structurally, not as relational, caring subjects. Using a critical disability studies lens, I centre the experiences of ill and disabled people to consider the impacts of dominant notions of touch on their survival within, and erasure from, ableist society. Specifically, I borrow from writers such as Eli Clare, a disability justice activist, writer, and speaker, who in *Brilliant Imperfection: Grappling with Cure* (2017), considers intersections of disability and illness with race, settler colonialism, and gender.

This thesis seeks out and engages with the work of queer phenomenologists and critical disability scholars and activists to explore the relationship between touch, intimacy, gender, sexuality, illness, disability, queerness, and transness. Mingus considers the relationship specifically between touch, ableism, and intimacy, introducing the concept of “forced intimacy” as “the common, daily experiences of disabled people being expected to share personal parts of ourselves to survive in an ableist world” (2017, *website*). Mingus explains that forced intimacy

often takes the form of being expected to share (very) personal information with able bodied people to get *basic* access, but it also includes forced physical intimacy, especially for those of us who need physical help that often requires touching of our bodies. Forced intimacy can also include the ways that disabled people have to build and sustain emotional intimacy and relationships with someone in order to get access – to get safe, appropriate and good access (Mingus 2017, italics in original, *website*).

Here, Mingus demonstrates that touch is not necessarily desirable, but is nevertheless a prerequisite for survival in an ableist society. Moreover, forced intimacy is located within and informed by the medical-industrial complex, which frames people living with HIV and AIDS as a threat or contaminant to the rest of society (Mingus 2017, website). This way of thinking about people living with HIV and AIDS went on to inform the types of forced intimacy HIV positive people received, and in some cases, underscored the absence of skin on skin touch within a system of quarantine in the first place. Here, forced intimacy simultaneously functioned as both the experience of undesirable touch (or its absence altogether), as well as the separation of people living with HIV and AIDS from their informal networks of care. Hence, at the same time that the medical-industrial complex informed dominant approaches to touch, it comprised a form of infrastructure made up of heterosexist desire lines that made it difficult for queer and trans people to be “in touch,” or to exchange physical touch between themselves and their chosen relations and communities.

In contrast, Mingus defines “access intimacy” as a sense of care and solidarity across those who understand access. She defines it as “that elusive, hard to describe feeling when someone else ‘gets’ your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level” (Mingus 2011, website). She explains it further as

the intimacy I feel with many other disabled and sick people who have an automatic understanding of access needs out of our shared similar lived experience of the many different ways ableism manifests in our lives. Together, we share a kind of access intimacy that is ground-level, with no need for explanations. Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don’t have to justify and we are able to start from a place of steel vulnerability. It doesn’t mean that our access looks the same, or that we even know what each other’s access needs are. It has taken the

form of long talks into the night upon our first meeting; knowing glances shared across a room or in a group of able bodied people; or the feeling of instant familiarity to be able to ask for help or support (Mingus 2011, website).

In this passage, Mingus reframes intimacy, not as the act of physical touch experienced via medical services, but rather, as a feeling of connectedness and interdependency. This thesis locates access intimacy in the informal care networks that emerged within and across communities around people living with HIV and AIDS. Eve Sedgwick, a poet, literary critic, artist, AIDS activist, and formative queer theorist, argues that touch not only consists of skin on skin contact, but also of being “beside” (2003, 8). “Beside” refers to the physical putting within reach of people living with HIV and AIDS, and more broadly refers to a sense of solidarity and social relations between people living with HIV and AIDS, their communities, and those who are in solidarity with them—what Harbin refers to as “in-this-togetherness” (112). Harbin explains further that “queers have experienced in-this-togetherness as facing near certain death, and fighting against it, together. The disorientation involved in being queer in a heteronormative world in some cases has made individuals feel only able to go on together” (114). The coming together into informal care networks around people living with HIV and AIDS was grounded in a sense of in-this-togetherness, which went on to inform the AIDS activism that has resisted—and continues to resist—their treatment within cis-heterosexist and ableist infrastructures.

I collected my data from interviews with Canadian AIDS activists from the 1980s-90s, who witnessed the AIDS crisis first hand. I obtained these interviews from the AIDS Activist History Project (AAHP). The AAHP offers an online archive that contains over 70 interview transcripts. These interviews are significant because there has not been

an AIDS activist oral history project in the Canadian context. These transcriptions are current and centre Canadian experiences of AIDS activism. I worked with several interviews so as to help ensure greater consistency in my analysis, while casting a wider net around the range of experiences that my project examines. In total, I reviewed 40 interviews, 11 of which are cited in this thesis. In my analysis of these interviews, I deployed an iterative approach that brings together queer phenomenology and critical disability studies in a methodological commitment to the complexities of embodiment. In my analysis, I do not claim that interviewees were shaped by the same experiences. Rather, the interviews this thesis engages with reference a range of different geographic and political contexts. The perspectives and accounts offered by individual interviewees were shaped by these different contexts and experiences. This thesis does not discount these differences, but rather, identifies and analyzes shared ways of thinking about touch across the interviews, in both its liberatory and oppressive forms. Given the devastating loss of people living with HIV and AIDS, particularly throughout the 1980s and 1990s, the majority of those interviewed are not themselves HIV+, but were entwined in interdependent care networks that were vital to AIDS activist organizing, and witnessed the medical treatment, or lack thereof, of people living with HIV and AIDS firsthand.

In addition to AAHP interviews, this thesis engages with legislation, specifically, 1980s quarantine legislation. During this period, quarantine legislation was largely informed by the medical-industrial complex and emerged as a state response to the AIDS crisis. Establishing state authority over those with a contagious illness, quarantine legislation ultimately framed HIV and AIDS as a threat to society—that is, to a cis-heterosexist and ableist society. It is important to examine such legislation because it



represents dominant ways of thinking about HIV and AIDS. In addition to academic literature, this thesis also engages with blogs, particularly where gaps exist in the academic literature. This thesis takes blogs seriously as sources that are as vital as academic literature. However, blogs are also significant in that they exist outside of the academy, and are not bound by its racist, colonial, ableist, and saneist confines. In other words, universities are fundamentally racist, colonial, ableist, and saneist spaces, and as such, blogs provide greater access to information on critical disability studies as well as to other marginalized fields of inquiry. In this sense, blogs make influential thinking about illness and disability accessible to a greater mass of people and are less mediated by repressive institutions.

### **Chapter Breakdown**

This thesis is divided into five chapters. The current chapter introduces the project and outlines the methodology that guides my analysis. Chapter 2 explores the theoretical framework guiding this project. It begins by exploring the relationship between touch and desire using Ahmed's *Queer Phenomenology* (2006). For Ahmed, sexuality is influenced by spatiality, or what she identifies as an interactive "field of action" (66). It is within this field that bodies orient themselves in directions that are already carved out and made habitual to them, such as heterosexuality (68)—and I would add, cis-heterosexuality, as gender also functions as an orientation device that sustains cisnormativity. In this sense, heterosexuality is a particular orientation, or desire, in cis-heterosexist space (70). In the face of cis-heterosexuality, Ahmed suggests that acts of queerness function fundamentally as moments of disorientation, which transgress normative, heterosexist

desire lines and carve out new ones (70). Here, heterosexuality functions as what Ahmed terms a “straightening device,” which directs bodies in cis-heterosexist directions (102). In this context, Ahmed explores touch as a form of contact, where she argues that one must first be located in relation to others in order for contact to first occur (103). The chapter integrates the work of Harbin, and especially her assertion that disorientation is vital to political reorientation (2016, 78). Absent from Ahmed’s text is an analysis of illness, disability, and transness. To address this gap, I integrate the work of Tanya Titchkosky, Robert McRuer, and Alison Kafer into Ahmed’s analysis. For Titchkosky, moments of disorientation are vital, but also, distressing, highlighting interdependence (2011, 67), or what Harbin calls, “in-this-togetherness” (2016, 112). McRuer, a critical theorist who works at the intersection of queer and crip theory, importantly unpacks the relationship between compulsory heterosexuality and compulsory able-bodiedness (2002, 89). Kafer, whose work focuses on disability, queer, and feminist theory, adds that compulsory heterosexuality and compulsory able-bodiedness are further entwined with compulsory able-mindedness (2013, 17). I would add that compulsory heterosexuality, able-bodiedness, and able-mindedness are also bound up with compulsory cis-genderness. Here, it is important to take seriously the differences between sexuality and gender, and also pay attention to the role of compulsory able-bodiedness and able-mindedness in the normalization of cisgender bodies, with violent consequences. Compulsory cis-genderness also perpetuates transnormativity, wherein trans people are expected to adhere to strict gender binaries and conform to compulsory cis-genderness in order to get basic access to vital health care.

Chapter 2 also engages with Sedgwick's theorizations of "beside" and "texture." For Sedgwick, "beside" is a highly interactive space, and emblematic of social relations (2003, 9). In the context of this project, beside exists in two forms: first, in the physical besidedness that puts people living with HIV and AIDS within reach of others; and, second, in the solidarity that exists amongst people living with HIV and AIDS, and across multiple relations and communities. In this context, touch is an important point of contact that takes place between dualisms. This contact challenges binaristic thought as it shows that relations between dualisms are complex and interconnected, rather than separate and distinct (2003, 8). Texture is next explored, which as Sedgwick explains, accounts for the interactive perceptions of touch, and the coming together of multiple senses around it (13). At this point, the chapter examines Titchkosky's analysis of texture, who importantly incorporates a disability studies lens into her analysis of contact (11). Ultimately, Chapter 2 locates touch within a network of desire lines that together comprises what Jeannine Tang (2016), art historian and critic, and Ara Wilson (2016), a scholar in feminist, gender, and sexuality studies, refer to as infrastructure. Here, infrastructure also includes memory, which is embodied in the spaces between people. Feminist philosophers Alexis Shotwell and Sue Campbell demonstrate that memory is fundamentally relational, shaping us as people (Shotwell 2016, 56).

Chapter 3 centres on touch as forced intimacy, and explores moments of forced intimacy in dominant medical-industrial complex approaches to HIV and AIDS. It suggests that amidst the AIDS crisis of the 1980s-90s, forced intimacy functioned in at least three, interrelated ways: first, by quarantining people living with HIV and AIDS away from the rest of society as a risk that might contaminate it; second, by isolating

people living with HIV and AIDS from their community networks; and, third, by preventing skin on skin contact. The chapter begins by asserting that intimacy even more generally is located within a broader network of desire lines—that is, infrastructure, which establishes normative forms of touch. Infrastructure ultimately guides intimacy, informing what it should and should not look like and do. Mingus’s theory of “forced intimacy” is next explored, which refers to undesired forms of physical touch that are nevertheless necessary in order to meet one’s basic access needs. This thesis extends an understanding of forced intimacy beyond physical contact, however, suggesting that forced intimacy not only exists in physical touch, but also in the absence of touch, as well as the isolation of people living with HIV and AIDS away from potential moments of access intimacy. The chapter goes on to explore the medical-industrial complex, which it identifies as a form of infrastructure. As Clare (2017) explains, the medical-industrial complex functions as a “thicket” that defines what health looks like, establishes gender, informs diagnosis, and ultimately sets normative standards by which bodies are evaluated and managed throughout the course of their lives (69). This thicket is primarily organized around cure, which in itself is comprised of multiple functions, namely “diagnosis, treatment, management, rehabilitation, and prevention” (70). The chapter next explores 1980s quarantine legislation, and specifically, British Columbia’s 1987 *Health Statutes Amendment Act*, which established public health officer authority over those deemed to have a contagious illness. This legislation is more broadly reflective of dominant ways of thinking about HIV and AIDS at the time, as informed by the medical-industrial complex, and especially, its preventative and eradivative functions. Chapter 3 goes on to engage AAHP interviews with Gary Kinsman, Paul Craik, Anita Martinez, Cynthia

Brooke, Bet Cecill, and Jamie Lee Hamilton to explore the relationship between touch, forced intimacy, and quarantine, as well as the impact it had on the lives of people living with HIV and AIDS and their activist networks.

Chapter 4 further engages with AAHP interviews to chart moments of access intimacy as sites of resistance against state attempts to keep people living with HIV and AIDS away from the rest of society, and especially, from their informal care networks. In a context of contamination discourses and quarantine measures, “bearing witness” and “being beside” were radical acts that carved out new desire lines towards disability justice. The chapter begins by exploring Mingus’s definition of access intimacy, and its importance to what Mingus terms “liberatory access” (2017, website). It suggests that liberatory access provides a framework through which to challenge interlocking systems of oppression. The chapter proceeds to analyze moments of access intimacy revealed in interviews with Renee du Plessis, Douglas Stewart, Cynthia Brooke, Anthony Mohamed, and Eric Smith, and John Greyson. In doing so, it first explores the radical potential of being beside amidst contamination discourses, the isolation of people living with HIV and AIDS, and the refusal of healthcare practitioners to touch. The chapter then identifies care as a driving force behind the informal care networks that emerged around people living with HIV and AIDS, and which went on to inform AIDS activism. These care networks existed across difference, revealing that liberatory access is so radical because it can be carried out across identifications and movements. The chapter concludes by stressing the importance of liberatory access and uncontrollable flourishing to challenging state attempts at what Clare terms “monocultures”—that is, attempts at eradication and containment, with what Leah Lakshmi Piepzna-Samarasinha terms “permacultures”

(2017). Chapter 5 offers concluding thoughts and discusses the radical potential of access intimacy. It further suggests future areas of potential study, and highlights the project's key contributions to both critical disability studies and trans studies.

## Chapter 2: Theoretical Framework

This chapter engages with touch by examining what it means for laws to exist in the spaces between people. That is to say, laws regulate touch. For example, British Columbia's *1987 Health Statutes Amendment Act* states:

- (1) Where a medical health officer has reasonable grounds to believe that
  - (a) a person has a reportable communicable disease or is infected with an agent that is capable of causing a reportable communicable disease, and
  - (b) the person is likely to, wilfully, carelessly or because of mental incompetence, expose others to the disease or the agent,he may order the person to do one or more of the following:
  - (c) to comply with reasonable conditions the medical health officer considers desirable for preventing the exposure of other persons to the disease or the agent;
  - (d) to take or continue medical tests or treatment for the purpose of identifying or controlling the disease or agent;
  - (e) to place himself in isolation, modified isolation or quarantine as set out in the order (Chap. 55, No. 8, 397).

As demonstrated in this passage, quarantine legislation frames people living with HIV and AIDS as health hazards to be contained away from the rest of society. By placing people in isolation, the statute frames particular bodies as hazardous, and dangerous to public health. Gender theorist and political philosopher Judith Butler argues that the state regulates the ways in which the body is at once public and vulnerable to others. As she writes, “the skin and the flesh expose us to the gaze of others, but also to touch, and to violence, and bodies put us at risk of becoming the agency and instrument of these as well” (2004, 26). Through quarantining people living with HIV and AIDS away from others, these laws function to prevent marginalized forms of touch and to uphold what Ahmed calls “straight orientation” (2006, 68). Furthermore, these laws do not just exist in the past. Rather, their effects reverberate into the present through embodied memory, as what Reina Gossett, a filmmaker, activist, and writer, describes as the “forcefields” that

continue to persist “all around and between us” (2015). These embodied effects are present in the ways that people interact—or come into contact—socially.

While these laws are important, they also exist within a wider political context that informs quarantine legislation, particularly the ways in which touch is enacted in hospital settings. These discourses shape the ways that health professionals engage with patients behind hospital walls. In many AAHP interviews, people describe their relationships to these spaces as very fraught, as HIV+ patients were neglected by the medical system. One of the forms of medical neglect that is most central to this thesis is the refusal of health professionals to touch patients living with HIV and AIDS. Often this refusal to touch manifests in forms of touch that are mediated by gloves, masks, and other reactionary barriers that physically prevent skin on skin contact between healthcare professionals and patients. While these barriers importantly allowed some forms of touch to take place by both medical practitioners and informal care networks, much like condoms, they were also part of a broader way of thinking about people living with HIV and AIDS as contaminants to the rest of society. This way of thinking informed quarantine practices. It is also important to acknowledge that much like condoms, gloves allowed some forms of touch and access intimacy to take place. A September 16, 2016 interview with Cynthia Brooke in Vancouver illustrates that touch functions as a form of resistance against quarantine practices and laws:

And for people to get really that mobilized and, like I said, it was quarantine that did it. But the beautiful thing—the really beautiful thing—is that we committed to doing very specific acts of resistance. And you could use a lot of your own imagination around what you would do for acts of resistance. But there was a group of us that our specific act of resistance was around contact. It was around going and being with our brothers that were in hospital, many of whom were incarcerated in the hospital because of the quarantine. Because, like I said it was truncated, but you couldn’t go out and were incredibly limited about who could



come and see you. And when you went, you weren't actually supposed to touch. You weren't supposed to actually have skin on skin contact. So, my personal act of resistance was to insist on having skin on skin contact and to be able to touch and hold and hug. If that's what he wanted (9).

Brooke's reflection demonstrates the power of touch as an act of resistance, particularly amidst the refusal to touch what were deemed "contaminated" bodies, such as through the use of gloves, or the refusal to bring food trays into hospital rooms. Contamination discourses seek to spatially and physically isolate contaminated bodies. The simple act of touch, as contact between people, resists its effects.

This chapter outlines the theoretical framework guiding this project. It begins by taking up Ahmed's theorization of desire and spatiality to locate the various modalities of touch deployed in AIDS activism within a broader system of interwoven desire lines. Ultimately, Ahmed suggests that queerness, and queer forms of touch, go against dominant desire lines to carve out new—and queer—spaces. I link Ahmed's examination of disorientation with that of Titchkosky to contribute a critical disability studies lens to Ahmed's analysis. The touching of queer ill and disabled people simultaneously resists dominant contamination and cis-heteronormative discourses, while also carving out new spaces of collective resistance. The next section takes up Sedgwick's theorization of touch and texture to further explore the impact of spatial politics on how we perform our identifications, as well as how we relate to each other. Butler's theorization of relationality is next explored as a way of understanding our vulnerability to others. The chapter concludes with a discussion of memory, suggesting that the spatial and discursive systems within which acts of touch in the present are located are also shaped by memories.

## **Queerness, Desire, and Touch**

In *Queer Phenomenology* (2006), Ahmed offers a theoretical framework that locates touch and desire in relation to queerness, phenomenology, orientation, and contact. This section begins by exploring the relationship between spatiality and sexuality. Ahmed introduces the concept of desire lines, suggesting that we are hailed towards heteronormativity, where queer forms of desire take others in new, unmapped directions. She then takes up lesbian desire as a means of thinking through contact and touch. This section next explores Ahmed's work on the politics of disorientation. Here, "contact zones" refer to the coming together of queer bodies in heteronormative spaces. Next, I tie together Ahmed's examination of disorientation with that of Titchkosky's to link a critical disability studies lens with Ahmed's analysis. Ahmed's theorization of touch is next discussed, as a means for queer bodies to relate to each other within the confines of heterosexual spaces.

Ahmed explores the ways in which sexuality has been understood in relation to spatiality. By drawing on Maurice Merleau-Ponty's work that asks "how the subject's relation to space is reoriented," Ahmed locates sexual orientation in relation to the "queer" moments in this work (65). Importantly, she theorizes the relationship between queerness and phenomenology. Space, here, is a highly interactive "field of action" (66). That is, Ahmed asks us to reconsider how queer is "a spatial term," as its etymological roots are from the word "twist" (67). In this way, queer is a spatial term, a term in which we can examine queer bodies' relationships to space that are not so simply straight, or in line (67). Rather, Ahmed explains that "The body orientates itself in space, for instance, by differentiating between 'left' and 'right,' 'up' and 'down,' and 'near' and 'far,' and

*this orientation is crucial to the sexualization of bodies*” (67, italics in original). She notes that “Phenomenology helps us to consider how sexuality involves ways of inhabiting and being inhabited by space” (67). This is particularly useful in theorizing touch because it shows how bodies are oriented in ways that make manifest forms of touch that are based on physical proximity, a manifestation of bodily proximity that is inherently political and contingent on norms of social worlds.

Ahmed explains that sexuality can be understood as the way in which sexual orientation itself *faces* subjects in particular directions (68). Notably, she also recognizes that not only is heterosexuality an orientation in a particular space, but is also the ways in which bodies internalize and are shaped by heterosexual ideology. Importantly, she states that

Merleau-Ponty’s model of sexuality as a form of bodily projection might help show how orientations “exceed” the objects they are directed toward, becoming ways of inhabiting and coexisting in the world. If we presume that sexuality is crucial to bodily orientation, to how we inhabit spaces, then the differences between how we are orientated sexually are not only a matter of “which” objects we are oriented toward, but also how we extend through our bodies into the world. Sexuality would not be seen as determined only by choice, but as involving differences in one’s very relation to the world—that is, in how one “faces” the world or is directed toward it. Or rather, we could say that orientations toward sexual objects affect other things that we do, such that different orientations, different ways of directing one’s desires, means inhabiting different worlds (68).

Here, she problematizes the common-sense notion that heterosexuality is a default position by looking at how sexual orientation often overlaps with the belief that to be queer is to be someone “who ‘deviates’” from that default position (69). Borrowing from Louis Althusser, and building off of Butler’s interpretation of him, Ahmed suggests that heterosexuality pre-exists the individual, who through “hailing,” is interpellated as a heterosexual subject (15). Ahmed argues that it matters which way the subject turns and

faces towards this hailing. She suggests that bodies not turn in the direction of heterosexuality, but rather, turn towards each other, the queer subject being the sum of these directions (15). The queer subject, in this sense, is the direction one faces when one rejects the hailing of heterosexuality.

Ahmed demands the reconsideration of what it means to be orientated in relation to sexual orientation. Indeed, she argues “the term ‘orientation’ is itself a spatial term: it points to how one is placed in relation to objects in the sense of ‘the direction’ one has taken toward objects” (69). However, she discusses how spatiality is often missed in reference to orientation itself. When Ahmed discusses orientation as the direction of desire, she focuses on the ways in which the direction of one’s desire relates and pulls people towards others by following lines of desire (70). To desire otherwise—other than heteronormativity—is to go off the grid of intelligibility and into unmapped directions (70). A queer phenomenology pushes us to reconsider this hailing. By moving in different directions towards other forms of hailing, we can create new spaces, and come into contact in different ways to create new worlds, potentially queer worlds. Ahmed encourages us to resist the hailing of heterosexuality and to move in non-linear directions. In doing so, it is possible to shape spaces, bodies, and their desires in new ways, which in turn, shape each other.

Heterosexuality is reproduced through the acts that heterosexual bodies do. Queer bodies fail at reproducing this compulsory heterosexuality. Ahmed writes, “Queer desire ‘acts’ by bringing other objects closer, those that would not be allowed ‘near’ straight ways of orienting the body” (92). In other words, desire functions as an action that resists repeating heterosexual acts. In this sense, heterosexuality shapes what bodies do through

action, but also, shapes the ways in which public space allows for bodies to more easily enact things like touch and intimacy. This in turn affects the ways in which bodies inhabit public space. To Ahmed, compulsory heterosexuality produces a space that allows some to “kiss and hold hands with a lover without thinking, without hesitation” (102). At the same time, however, heterosexual spaces make it dangerous for queer bodies to engage in these forms of intimacy in public. Ahmed refers to compulsory heterosexuality as a “straightening device,” which constructs “space as well as bodies,” and the ways that bodies come into contact in particular social spaces (102). As previously discussed, state laws function as straightening devices that isolate, prevent, and make dangerous public forms of queer touch.

For Ahmed, lesbian desire resists the straightening device of “compulsory heterosexuality” (Rich 1993). She argues that “lesbian desire can be rethought as a space for action, a way of extending differently into space through tending toward ‘other women’” (102). This is what constitutes “becoming lesbian” as a social experience (102). Importantly, Ahmed defines desire as “what moves us closer to bodies” (103). She states, “lesbian desire puts women into closer ‘contact’ with women” (103). Highlighting intimacy as an integral component of the shaping of bodies, Ahmed relates this to the ways in which bodies “orientate toward each other” (103). She states that “in being oriented toward other women, lesbian desires also bring certain objects near, including sexual objects as well as other kinds of objects, that might not have otherwise been reachable within the horizon of the social” (103). Here, Ahmed shows that desire at once pulls us toward particular paths, but also shows us which paths are more easily inhabited by particular hegemonic identities. If desire is how we move closer to other bodies, this

shows us how, ultimately, the spaces in which people are social are constructed to allow particular bodies to flow more easily through them.

Ahmed puts lesbian desire forth as a way of thinking through contact. She writes, “I am arguing that lesbian desire is contingent as a way of reflecting on the relations between sexual and social contact” (103). It is here that she introduces touch as a form of contact, explaining

It is useful to recall that the word “contingent” has the same root in Latin as the word “contact” (*contingere*: *com-*, with, *tangere*, to touch. Contingency is linked in this way to the sociality of being “with” others, to getting close enough to touch. To begin to think of lesbianism as contingent is to suggest not only that we become lesbians but also that such becoming is not lonely; it is always directed toward others, however imagined (103).

Here, Ahmed points out that to be hailed, or recognized, one must first inhabit the world towards others. For contact to occur, one must first be located in relationship to others. Loneliness, however, is not apolitical because it compels “the body to extend differently into the world, a body that is alone in this cramped space of the family, which puts some objects and not others in reach, is also a body that reaches out towards others that can be glimpsed as just about on the horizon” (104). Loneliness allows the lesbian body to extend into and create new social spaces, “where there are others who return one’s desire” (105). Loneliness compels the body to re-orientate itself in such a way that puts it into contact with other bodies, a way in which the body might reach out to touch.

Ahmed calls for a politics of disorientation, which is intimately connected with her discussion of loneliness. She defines disorientation as “bodily experiences that throw the world up, or throw the body from its ground. Disorientation as a bodily feeling can be unsettling, it can shatter one’s sense of confidence in the ground, or one’s belief that the ground on which we reside can support the actions that make life feel liveable” (157).

Disorientation is to break away from conventional understandings of how to relate oneself to the world in which one resides. In this sense, disorientation is an affect that occurs when things fail to cohere along normative lines. Ahmed writes, “then queer moments happen when things fail to cohere. In such moments of failure, when things do not stay in place or cohere as place, disorientation happens” (170). Queer moments are so unsettling because they do not fit into heteronormative spaces. Although these moments may be unsettling, Ahmed argues, they sometimes carry radical potential. For, it is by breaking with heteronormative space and desire that makes possible queer spaces and ways of being in relation to others. Loneliness exists at the cusp of disorientation, propelling people in new directions along new desire lines towards contact and proximity with others who may, in turn, return their desire.

Ahmed identifies the radical possibilities of disorientation. At the same time, however, Ahmed situates the individual at the centre of disorientation, overlooking the question of access. Here, we can look to Titchkosky, who builds off of Ahmed’s work on disorientation to incorporate access. In *The Question of Access: Disability, Space, Meaning* (2011), Titchkosky takes up disorientation in relation to disability access and the ways in which signs orient people through social spaces. Titchkosky’s work centres on the ways in which access and inclusion in university spaces frame disability in a very particular way, specifically, as a problem needing fixing. In this setting, access signs signal points of purported accessibility, including bathrooms and ramps. Titchkosky questions whether markers of access in university spaces truly accomplish what they claim to do (65). She suggests that these signs can in themselves be “disorienting” (65):

Sara Ahmed (2006:8) says that orientations are “about how we begin; how we proceed from ‘here’ which affects how what is ‘there’ appears.” The “here” is clearly not accessible to us if we notice signs of access “there.” Signs gesture and promise a way to go through a network of taken-for-granted background expectations. Like all other images of disability, signs recommend ways to live in the movement that is social space. It is, then, disorienting to find signs that do not fulfil their promise of direction. It is also disorienting to experience access signs doing the opposite of what they promise; and it is disorienting, finally, to experience signs as bringing the background order of inaccessibility to awareness. We can imagine that every image of disability – good, bad, or merely practical – can end up pointing to the unexamined background order of normalcy as well as the socio-political order that sustains it (65).

For Titchkosky, accessibility signs are designed to point us in very specific directions, suggesting that these signs “are a form of orientation” (65). Here, disorientation occurs when signs “do not fulfill their promise of direction” (65). Like Ahmed, Titchkosky identifies the radical potential of disorientation, arguing that “disorientations are vital in the sense that they testify to the possibility of something new arising in the face of the same” (67). She adds, however, that “‘vital’ does not preclude distress” (67).

Inaccessibility is disorienting. While Titchkosky contributes a disability lens to Ahmed’s take on disorientation, she also acknowledges that disorientation can in itself be distressing, and not necessarily a moment in time that can be overcome or fixed. As will be discussed later in this thesis, ill and disabled people rely on access intimacy to navigate and move through such disorienting experiences, as these experiences of disorientation are symptomatic of living in an abled world (Mingus 2011).

Like Ahmed and Titchkosky, Harbin shows the radical potential of disorientations through stressing the importance of relationality to such moments. Notably, in *Disorientation and Moral Life*, Harbin takes up disorientation as a vital form of political re-orientation, where one can become “oriented toward action” with others (78). In this work, Harbin defines disorientation as experiencing moments in life that “*make it difficult*



*to know how to go on*” (13, italics in original). Here, she importantly describes such scenarios as moments that disrupt everyday habits of life, such as the death of loved ones, newly emerging queer desires and identifications, or living with chronic illness. These disruptions to habits are linked to corporeal experiences of relating to others, as disorientations challenge the unconscious acts between people and the ways in which these acts are normalized through repeated action (8). Rather than experiencing these moments in isolation, however, Harbin pushes for disorientation to be taken up in such a way that recognizes its political complexities and capacities for collective responses. Specifically, in relation to queerness, Harbin describes disorientations as prompting “capacities for in-this-togetherness” (112). She states that,

Capacities for in-this-togetherness mean simply increased capacities for acting as though one’s well-being is partly conditioned by or tied up with the well-being of others. [...] In other words, in some cases, the disorientations of being queer have politicized individuals in the particular sense of becoming collectively minded” (112).

The “in-this-togetherness” that Harbin describes refers to the capacity for collectivity. The experience of disorientation might bring about feelings that make it difficult to know how to go on. As discussed above in relation to Titchkosky, these distressing feelings necessitate interdependence. What Harbin identifies here is the potential of this interdependence, not only for surviving these distressing moments, but also for bringing about politicized change, a change that propels collectivity.

In Ahmed’s work, “contact zones” are a tool to think through how bodies relate to space, specifically, how lesbian bodies come together in heteronormative spaces (Pratt 1992). The emphasis, here, is on how heterosexuality constructs the way certain bodies

flow more easily through spaces, as these spaces are formed through heteronormative ideology. She writes,

The sociality of lesbian desire is shaped by contact with the heteronormative, even if this contact does not “explain” such desire. We could think of this “contact zone” of lesbian desire not as a fantasy of likeness (of finding others who are “like me”), but as opening up lines of connection between bodies that are drawn to each other in the repetition of this tendency to deviate from the straight line. Lesbian desires enact the “coming out” story as a story of “coming to,” of arriving near other bodies, as a contact that makes a story and opens up other ways of facing the world. Lesbian desires move us sideways: one object might put another in reach, as we come into contact with different bodies and worlds. This contact involves following rather different lines of connection, association, and even exchange, as lines that are often invisible to others” (105-106).

Here, the contact zone is all about lesbian desires, as the place at which lesbian desires are enacted between people. Ahmed importantly moves from the rhetoric of isolation and loneliness towards sociality and one’s proximity to others. Notably, the contact zone that Ahmed describes is a site that is still very much in contact with heteronormative ideology. However, lesbian desire persists in spite of it, moving those who identify with this desire sideways instead of forward. Straight lines and straightening devices may be linked with the notion of progress, but moving sideways, in this sense, puts bodies into contact in ways that propel collectivity and mutual support. Despite the impetus towards heteronormativity, propelling people in very rigid directions, Ahmed conceives of a “contact zone” where desires that deviate from heterosexuality come together to create new worlds.

As I have discussed, it is useful to extend Ahmed’s conception of “lesbian desire.” This is because it fails to account for the complexities of desires and identifications that reside outside of lesbian identifications, such as other queer and trans identities, illnesses and disabilities. As previously explored, there are many different

straightening devices that function to uphold heterosexuality—or what Adrienne Rich terms, “compulsory heterosexuality” (1993). In the same way, there are many different devices that uphold what McRuer terms compulsory able-bodiedness, which are intertwined with compulsory heterosexuality:

Through a reading of compulsory heterosexuality, I want to put forward a theory of what I call compulsory able-bodiedness. The Latin root for *contextualize* denotes the act of weaving together, interweaving, joining together, or composing. This essay thus contextualizes disability in the root sense of the word, because I argue that the system of compulsory able-bodiedness that produces disability is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness; that—in fact—compulsory heterosexuality is contingent on compulsory able-bodiedness and vice versa (McRuer 2002, 89).

Here, McRuer suggests that it is only possible to understand able-bodiedness in its relation to heterosexuality. Notably, Kafer (2013) extends McRuer’s analysis of compulsory able-bodiedness to include compulsory able-mindedness (17). Here, Kafer explains that compulsory able-mindedness is one way in which critical disability studies can “take seriously the criticism that we have focused on physical disabilities to the exclusion of all else” (16). I would also add that these straightening lines are intertwined with compulsory cis-genderness, which orients people in particular ways along gender lines—often perpetuating a binary: man and woman. These gender lines are upheld by mechanisms such as the *Diagnosis and Statistical Manual of Mental Disorders* (2013), which has historically pathologized trans bodies and minds. Sexuality and gender are often analyzed together without distinction, which overlooks their nuances. It is important to attend to the ways that compulsory able-bodiedness and able-mindedness perpetuate and are intertwined with compulsory cis-genderness, which has manifested in the medicalization of trans bodies and minds, and attempts to categorize trans people into rigid gender binaries. Even binary trans people are part of a wider struggle against gender

binaries, a struggle that pushes back against the constraints of compulsory cis-genderness. That is to say, transness challenges the ways that binaries contain gender to very specific Western attributes, identifications, and medical regimes.

Compulsory heterosexuality, able-bodiedness, able-mindedness, and cis-genderness point bodies in straight lines. Contact zones not only embody points of contact between Ahmed's focus on lesbian bodies, but between other bodies—in all their complexities—resisting these straightening devices. McRuer writes, “critical queerness and severe disability are about collectively transforming (in ways that can not necessarily be predicted in advance) the substantive uses to which queer/disabled existence has been put by a system of compulsory able-bodiedness, about insisting that such a system is never as good as it gets, and about imagining bodies and desires otherwise” (97). This thesis looks at how AIDS activism conceives of a contact zone between bodies that blur Ahmed's conception of lesbian desire in such a way that cuts across multiple identity categories. While identification in Ahmed's work is primarily about lesbian desire, later on, this thesis examines how Sedgwick extends contact to include those outside of particular lesbian identifications, while also taking into account the ways these identifications intersect with illness and disability.

Ahmed conceives of queer touch as a way for queer bodies to relate to each other within the confines of heterosexuality. Touch in this way functions as a way for the queer body to connect with others, who return that connection. In this sense, queerness is about the potentiality of contact. Touch, here, is between bodies that support each other through their deviation. Ahmed motions back to Merleau-Ponty, writing

he offers us a reflection on touch and on forms of contact between bodies as well as between bodies and the world. As he states: “My hand, while it is felt from

within, is also accessible from without, itself tangible, for my other hand, for example, if it takes its place among the things it touches” (1968:133). What touches is touched, and yet “the toucher” and “the touched” do not ever reach each other; they do not merge to become one (106).

As illustrated in this passage, desire does not eradicate difference. The impetus to become one with what we desire is never truly obtained when the act of touch does not result in the merging of bodies. Rather, desire, here, is about one’s interaction with various relations. Hence, desire is always something that *moves* one towards particular paths and relationships. Rather, the toucher is always left in desire for another—reaching. Yet, Ahmed suggests, “not all bodies are within reach” (107). It is here that Ahmed introduces an economy of touch, what she refers to as “a differentiation between those who can and cannot be reached” (107). If touch is an economy, then certain bodies are more desirable to hegemonic forms of touch than others. Ahmed states that “touch then opens bodies to some bodies and not others” (107). Queer orientations are crucial because they “put within reach bodies that have been made unreachable by the lines of conventional genealogy” (107).

Ahmed’s analysis of touch is significant to this thesis because she provides a framework for thinking through touch in the context of 1980s-90s AIDS activism. Here, in the context of what the medical-industrial complex identified as contaminated and untouchable bodies, the act of touch opened people living with HIV and AIDS to the radical potential of touch and desire. It put bodies that were categorized by society as untouchable within reach, while at the same time, these bodies contributed towards queer spatiality amongst dominant heterosexual spaces. This is not to say that people living with HIV and AIDS were solely recipients of touch, but rather, that the act of touch was given and received across illness and disability. Ahmed explains, “A queer

phenomenology would involve an orientation toward queer, a way of inhabiting the world by giving ‘support’ to those whose lives and loves make them appear oblique, strange, and out of place” (179). Here, touch extends beyond the act of physically coming into contact to bring together the “untouchable,” who collectively embody a form of radical queer world-building and experience—that is, a queer phenomenology.

### **Touch and Texture**

This section examines Sedgwick’s “White Glasses” (1994) and *Touching Feeling* (2003) to explore three concepts central to my theoretical framework: *beside*, *touch*, and *texture*. To exist “beside” is to be situated next to another, however, it is also a way to analyze what happens in the “in between,” a highly interactive space. As Sedgwick describes, touch is much more than a physical point of contact, but is where dualisms collide to create new meanings. Texture refers to the materiality underlying touch, and to its interactive and affective properties.

At a talk on July 9, 1991, two months prior to the death of AIDS activist, poet, and scholar Michael Lynch, Sedgwick gave a talk entitled “White Glasses” at a conference in New York at the CUNY Centre for Lesbian and Gay Studies. The talk itself is presented in the form of an obituary for Lynch, though at the time Sedgwick offered it he was still living. It begins with an epigraph from a poem in one of Lynch’s poetry books, *These Waves of Dying Friends*. The prose is from the poem “Tobaco”:

*Today as you passed a dark-skinned man younger than you his eyes plucked yours (Indian? West Indian?), set you to wondering what he saw: a close-cropped man with briefcase, white rolled shorts, white glasses, a lope on tiptoes, a scowl, blue eyes behind frames, licking a cone of ice-cream... (252).*

As the title of the talk insinuates, Sedgwick observes the first time she meets Lynch, noting her intense fascination with his white glasses. Not only does Sedgwick take up the

form of an obituary, but she does so in a way that bridges into an interactive conversation between herself and Lynch, as he is actively involved in her preparation of this talk through phone calls and in-person conversations. At one point, she even mentions that she is recording the talk so that he can listen to it, ending with: “Hi Michael! I know I probably got almost everything wrong but I hope you didn’t hate this. See you in a couple of weeks” (259). This form merges the past, present, and future of Sedgwick’s ongoing relations with her friend.

It is important to emphasize the ways in which Sedgwick takes up the rhetorical force of obituaries. Doing so, Sedgwick articulates the various complex relations formed through the “graphic proximity of intimate loss” (252). Here, as she does in *Touching Feeling*, Sedgwick shows how spatial politics manifest complex relations between people. Interestingly, Sedgwick explores the ways in which social relations between people can even be framed as identification between and across identities. For the purposes of this thesis, I will focus on what identification means and how it constellates the roles of relationality, identity, and desire in disability justice. I argue that if one has the capacity to identify with those outside of oneself, then one is not so simply an individual. Rather, one is, as so many people suggest already, a relational subject. Sedgwick pointedly explicates a politics of interdependence, which is fundamental to studying illness, disability, and AIDS activist organizing.

Touch functions variously throughout Sedgwick’s piece. More broadly, Sedgwick demonstrates the collective efforts of Lynch’s community of caregivers. She uses touch to situate herself in relation to broader community organizing around AIDS in the early 1990s. However, touch also functions as a means through which Sedgwick individually

cope with Lynch's illness and loss. Sedgwick identifies touch as a grounding force amidst the overwhelming feelings she experiences from witnessing the progression of Lynch's illness. During a visit with Lynch and his son, she observes that "When they finally left, it felt utterly bitter to let them out of sight or to stop hugging him, maybe because it was only physical touch that ever seemed, all weekend, to burn (Michael feels very hot) through the static of concern, distraction, (his) unpredictable fragility, (my) misplaced bustling, distance (whose?) ..." (260). The act of touch in this passage embodies relationality. Sedgwick's worries throughout Lynch's visit concern his eventual absence. Touch, and the hot texture of Lynch's skin, interrupt Sedgwick's worries to remind her of his presence. It is through the physical sense of touch that Sedgwick feels connected to Lynch.

In another reference, Sedgwick points to Lynch's craving for physical touch, and her relationality to him across her own illness:

I think Michael is very, very tired of being sick, and I think I can feel that with him—though I also feel that every day that Michael is there and recognizably himself, gossipy, courageous, universally inquisitive, perhaps crabby, communicative, and craving physical touch, is a day that I have an important reason to be happy. My own illness hasn't really even begun to come home to roost—it probably won't for some years, *maybe* never—but I also see, or imagine, some of the people who love me beginning to deal with the possibility that someday the same calculus may operate around my own fatigue, discouragement, pain, flares of zest and creativity, the recognizable, recognizing, and hurting shards of relation and identity. I still want to know more and more about how Michael and other people deal with this long moment, and about how I will. As whom, as what I may deal with it; out of what spaces I may speak of it, or be spoken for in these identities and struggles—I know these are not simply for me or even for my immediate communities to decide; yet I relish knowing that enough of us will be here to demonstrate that the answer can hardly be what anyone will have expected (266).

Here, Sedgwick takes up touch, not as an action or point of contact, but as constitutive of Lynch. To crave physical touch, in this sense, is to crave a broader net of social relations,



which as discussed below, is conveyed through texture. This passage also situates Lynch and Sedgwick “beside” each other. It is by being “beside” Lynch that Sedgwick anticipates and identifies with her own illness. Sedgwick identifies Lynch’s tiredness of being sick with her own. It is through her proximity to Lynch that Sedgwick can imagine the course of her own illness.

In “White Glasses,” Sedgwick demonstrates that touch, texture, and being situated “beside” are important to the social relations surrounding illness and disability. Sedgwick argues that spatial politics inform the ways in which we perform our identifications. As such, it is important to tend to touch and the texture of affiliated affects. Sedgwick further demonstrates that studying “beside”—the spaces between people—is as important to studying affect and social relations as the physical act of touch itself.

In *Touching Feeling*, Sedgwick points to the significance of attending to what the preposition “beside” might mean to the study of social relations. She notes,

*Beside* is an interesting preposition also because there’s nothing very dualistic about it; a number of elements may lie alongside one another, though not an infinity of them. *Beside* permits a spacious agnosticism about several of the linear logics that enforce dualistic thinking: noncontradiction or the law of the excluded middle, cause vs effect, subject vs object. Its interest does not, however, depend on a fantasy of metonymically egalitarian or even pacific relations, as any child knows who’s shared a bed with siblings. *Beside* comprises a wide range of desiring, identifying, representing, repelling, paralleling, differentiating, rivaling, leaning, twisting, mimicking, withdrawing, attracting, aggressing, warping, and other relations (8).

The preposition “beside” is the exact position at which non-dualistic relations take place. Semantically, prepositions are used to emphasize relations between words—they link words together to reveal their interactive qualities. Sedgwick extends the use of “beside”

beyond words to expose the ways in which we relate to others. In doing so, she demonstrates that relations are formed between various dualisms.

Sedgwick examines “beside” as a form of spatial politics. “Beside” refers, then, to the spatial politics taking place when people are simply “‘beside’ each other in a room” (9). In terms of space itself, Sedgwick looks at how geographers and anthropologists often tend to the ways that “ecological or systems approaches” interact with “identity and performance” (8). Sedgwick elucidates her argument through a critique of Butler’s analysis of drag as performative. Sedgwick argues that Butler overlooks an analysis of “the ecological attention to space” (9). In *Mother Camp*, anthropologist Esther Newton examines the ways that spatial politics—such as the floor plans of drag clubs—inform drag performances. In turn, Sedgwick observes that this attention to space in Newton’s work necessarily shows how complex interactions between people are part of the space in which performances are situated. She then states that interactions in these spaces highlight “Newton’s continuous assumption that drag is less a single kind of act than a heterogeneous system, an ecological field whose intensive and defining relationality is internal as much as it is directed towards norms it may challenge” (9). Sedgwick takes up temporal and spatial politics in such a way that pushes back against simplistic interpretations of the performative aspects of drag, which do not attend to “the rich dimension of space” (9). Here, Sedgwick points out that Butler’s analysis of drag loses spatial politics and internal complexity. Building off of this, Sedgwick argues that “temporal and spatial thinking are never really alternative to each other” (9). The spaces between people—the ways that people can be “beside” one another—is a highly interactive sphere that cuts across materiality and emotions.

In *Touching Feeling*, Sedgwick defines touch as a point of contact that exists at intersections between dualisms. She states,

Even more immediately than other perceptual systems, it seems, the sense of touch makes nonsense out of any dualistic understanding of agency and passivity; to touch is always already to reach out, to fondle, to haft, to tap, or to enfold, and always also to understand other people or natural forces as having effectually done so before oneself, if only in the making of the textured object (14).

Here, touch is shown to be a fundamentally interactive sense, as it has social aspects. In this work, Sedgwick discusses touch as a physical sense—the way in which sensory information is engaged through multiple acts, such as reaching out to touch something or someone. Much of Sedgwick’s discussion of touch is located in her analysis of queer performativity in Henry James’s novels. Interestingly, she identifies touch as an enactment of impurity when characters in James’s work meet “the ‘touch’ of another” (47). Here, touch is taken up in relation to skin and contact and the different affects this contact evokes. Touch always exposes us to others, and is therefore never pure (Shotwell 2016). Sedgwick states that, “All the blushing/flushing that marks the skin as a primary organ for both the generation and contagion of affect seems linked to a fantasy of the skin’s being entered—entered specifically by hand, a hand that touches” (59). The image of touch that Sedgwick explores here is more broadly associated with penetration—the way a hand touches and physically fishes out something from the cavity of a body. She further links this particular touch with James’s favoured word choices for this relation: “glove or gage” (59). She explains, “glove or gage is, for James, a prime image of *engagement*, of interest, motivation, and cathexis *tout simple*—of the writerly ‘charm that grows in proposition as the appeal to it tests and stretches and strains it, puts it powerfully to the touch’ (111)” (59). Here, touch infiltrates skin through basic contact and

engagement. It is valuable to look at how her focus on touch points to the ways that bodies are intimately connected to each other through physical acts of touch. Sedgwick specifically uses the language of impurity in relation to James's fixation with anal eroticism, what she terms "fisting-as-écriture" (48). Here, the touch of someone becomes an instance of contamination and interaction between bodies. It is in this analysis that I find Sedgwick to be an important source in exploring how touch and texture are important to understanding how one might perceive "how physical properties act and are acted upon over time" (13).

Texture takes into account the interactive perceptions of touch. Through it, affect is linked with phenomenology. Sedgwick thinks through texture by asking: First, "What is it like?" And, second, "How does it impinge on *me*?" (13). That is, she states, "textural perception always explores two other questions as well: How did it get that way? and What could I do with it?" (13). Indeed, she points out that these questions are "intrinsically interactive properties" (13). Further, Sedgwick explains that, "to perceive texture is to know or hypothesize whether things will be easy or hard, safe or dangerous to grasp, to stack, to fold, to shred, to climb on, to stretch, to slide, to soak" (44). Whereas touch is a single sense in itself, related to haptic perception, texture embodies the coming together of multiple senses—such as vision, scent, taste, sound. In other words, to perceive texture is to perceive the multiple possibilities of interactions between various senses. Texture exists in relation to feeling. Sedgwick explains,

The title I've chosen for these essays, *Touching Feeling*, records the intuition that a particular intimacy seems to subsist between textures and emotions. But the double meaning, tactile plus emotional, is already there in the single word "touching"; equally it's internal to the word "feeling." I am also encouraged in this association by the dubious epithet "touchy-feely," with its implication that even to talk about affect virtually amounts to cutaneous contact (17).

As this passage demonstrates, touch is always relational and entwined with meaning. Here, the significance of touch is not limited to the act itself. Although important, touch is instilled with meaning beyond contact. Touch evokes an emotional response, and is not simply tactile. Hence, to exist “beside” is not merely to be located alongside another, but is one means through which we internalize our social relations and feel their effects.

I turn now to Titchkosky’s analysis of the concept of texture, linking it with Sedgwick’s examination of spatial politics. Here, Titchkosky contributes a disability studies lens to texture. Specifically, in *Reading and Writing Disability Differently: The Textured Life of Embodiment* (2008), she examines the framing of disability in everyday print-media and considers how discourse shapes mainstream attitudes towards disability. She suggests that media often frames disability as a problem that needs to be overcome, prevented, managed, and contained (17). Titchkosky ponders the ways in which we might imagine disability beyond being “a clear-cut problem in need of solution” (9). This reframing consists of noticing, reading, and writing disability differently than what appears in everyday discourses (9). Notably, she states:

texturing the life of disability as a problem leads me to wonder just what sort of problem disability has been imagined to be for and by the contemporary minority world. As, for example, a blanketed dead body in a wheelchair and as a derogatory metaphor to express inadequate responses to a storm, disability is made present as a space of provocation where we might begin to reread how culture puts our embodiment to text and textures all of our lives. Attending to our taken-for-granted lives as embodied beings by analyzing how disability is put into text in ordinary ways can begin to disrupt the seemingly natural conflation of disability with undesired vulnerability and ineptitude. In this way, perhaps embodied existence can be lived and imagined a little differently (9-10).

Titchkosky identifies a wide range of possibilities where disability is not “an empirical problem,” but instead “an interpretive issue” (9). In this sense, she moves disability away

from the realm of the experiential—where often the individual is at the centre of experience—towards what can be interpreted through text by and through multiple perspectives. Interpretation, here, is fundamentally relational, as it is interdependent with others to read, write, and notice the meanings that a text can produce. Texture, then, as Sedgwick notes, is importantly relational and embodied, which relates to the idea that discourse shapes bodies and interactions *between* bodies.

Titchkosky links text with the life of disability, but also applies it to phenomenology. In this sense, she locates the various meanings of text and how they are enacted in terms of disability (11). It is here that she examines “textual constructions of disability” (11). Importantly, she defines “disability” as a

process of meaning-making that takes place somewhere and is done by somebody. Whenever disability is perceived, spoken, or even thought about, people mean it in some way. The ways that disability comes to have meaning have something to teach us about our life worlds. Understanding disability as a site where meaning is enacted not only requires conceptualizing disability as a social accomplishment, it also means developing an animated sense of that which enacts these meanings. Again, disability, made by culture, is a prime location to reread and rewrite culture’s makings (12).

Notably, Titchkosky’s aim is “to open an inquiry that develops a desire to uncover the meanings of disability within contemporary Western culture, while resisting the temptation to simplify by rendering disability into a definable objectified *thing*” (11, italics in original). Indeed, this definition orients disability in the realm of “already existing talk and conduct” (12). This is important because this orientation puts forward disability as an embodied—relational—existence.

Unlike Sedgwick, Titchkosky does not look at how touch functions. However, her approach to texture incorporates an important disability studies lens into thinking through how we make sense of contact. Titchkosky demonstrates that disability is made

meaningful through discourses that shape our embodiment in everyday life. These discourses, in Ahmed's terms, shape how we are oriented towards particular embodied relations. Touch, in this sense, always involves texture. For Titchkosky, the ways in which we perceive and think about touch are influenced by discourse:

To know that the body is made manifest through our word-filled relations to embodiment actualized through our reading and writing of the body, is to know that any manifestation of language is an embodied activity that might open us to something other than what appears on the page. Reading and writing are socially oriented activities of embodied actors situated in the same world they are busy making. Attending not only to the sense in which texts give us versions of embodiment, but also to the ways in which we apperceive these versions, can teach us much about the ordering of relations to the bodies of ourselves and others through the medium of everyday texts (210-211).

Titchkosky suggests that our perception of disability is shaped by discourse. Taking Ahmed, Sedgwick, and Titchkosky together, this thesis suggests that touch exists within a broader system of meaning, both discursively and spatially, that shapes it. Instances of touch throughout AIDS activism were subversive given the AIDS discourses shaped by the medical-industrial complex of the times. Within this system of meaning, the act of touch was tied to contamination discourses. Activists reframed touch as a moment of care rather than an act of contamination.

### **Infrastructure, Relationality, and Vulnerability**

It may seem odd to link infrastructure with touch. However, as Sedgwick and Ahmed reveal, spatial geography is important to the study of touch. In the essay, "Contemporary Art and Critical Transgender Infrastructures" (2016) Jeannine Tang turns to Angela Mitropoulos's conceptualization of infrastructure as "a form of social relation":

For Mitropoulos, infrastructure comprises not only forms of transportation, communication, and logistics, but also everyday forms and patterns of contact and

access. Infrastructures are, in her words, ‘how worlds are made, how forms of life are sustained and made available.’ Mitropoulos’s turn toward infrastructure offers a different model of relation from liberal-democratic regimes (that prioritize ‘identity, demands, promises, rights and contracts’); instead, infrastructure points to how ‘knots of attachment, adherence, care or fondness’ are tied, but never incontestably, by kinship, race, money, sexuality, nationality, and other assemblages. Infrastructures are pliable and not static; they scaffold how we attach or adhere to, or care or experience fondness for, one another. We flex, reinterpret, and scale these infrastructures to the needs of those we encounter and, in doing so, change the very weave of infrastructures themselves (379).

As demonstrated in this passage, infrastructure is a form of social relation that guides us towards what we attach and adhere to. Wilson (2016) similarly conceives of infrastructure as being “involved in social relations” (247). She argues that “infrastructures shape the conditions for relational life” (247). Likewise, Ahmed argues that “the world is shaped by the directions taken by some bodies more than others” (2006, 159). The arrangements of infrastructure as relationality makes possible certain laws, for example, the emergence of quarantine laws in the 1980s. Quarantine laws physically separate out bodies from normative society, while putting many bodies out of reach. Through quarantine legislation, the state seeks to separate ill and disabled people from collective forms of touch and care, while exposing them to what is often involuntary medical touch. In turn, ill and disabled people are supported by particular arrangements of infrastructure that work to exclude particular types of touch and create particular types of orientations towards state supported care models. Whether or not quarantine laws were actually passed, people living with HIV and AIDS were still in many ways quarantined. Brooke’s interview reveals that at the same time that quarantine laws are practiced within Canadian hospital themselves, skin on skin contact, and the touch of somebody else—a queer body—on someone who has HIV or AIDS is already prohibited, socially and physically.



Butler's theory of vulnerability is critical to understanding relationality, and provides a lens through which to understand touch as it relates to our exposure to others. In "Violence, Mourning, Politics" (2004), Butler considers "a dimension of political life that has to do with our exposure to violence and our complicity in it, with our vulnerability to loss and the task of mourning that follows" (19). More precisely, Butler theorizes corporeal vulnerability by reimagining "the possibility of community on the basis of vulnerability and loss" (20). That is to say, Butler starts and ends with the question of the human life—as vulnerable, and as grievable, but also as inherently bodily and public (20). Butler defines corporeal vulnerability as the way in which we are all "constituted politically in part by virtue of the social vulnerability of our bodies – as a site of desire and physical vulnerability, as a site of a publicity at once assertive and exposed" (20). Butler goes on to state that "loss and vulnerability seem to follow from our being socially constituted bodies, attached to others, at risk of losing those attachments, exposed to others, at risk of violence by virtue of that exposure" (20). In this sense, Butler uses corporeal vulnerability to reformulate the term relationality by transforming the notion that we are all "constituted by our relations" to argue that we are all "dispossessed" by these relations as well (24). As Butler suggests here, we are not individuals, rather, other bodies act on us. Butler relates violence to the act of touch, arguing that violence "is surely a touch of the worst order, a way a primary human vulnerability to other humans is exposed in its most terrifying way, a way in which we are given over, without control, to the will of another, a way in which life itself can be expunged to the action of another" (29). This human vulnerability is inherently "a part of bodily life" and is "highly exacerbated under certain social and political conditions" (29).

In *Frames of War* (2010), Butler responds to the individualizing demands of contemporary political contexts by further expanding on her ethics and politics of corporeal vulnerability. Butler uses affect to argue that “the body invariably comes up against the outside world” and this “‘coming up against’ is one modality that defines the body” (34). Through Butler’s description, then, we are shown the ways in which bodies are bound up and impacted by other bodies. These bodies, and their affective responses, are accordingly impacted by certain “fields of intelligibility” that “frame our responsiveness to the impinging world” (34). Thus, the affective responses our bodies make towards one another are inherently preconditioned and mediated by our social environments.

Butler argues that our survival is dependent upon the recognition that we are all bounded to each other, stating that

if we accept the insight that our very survival depends not on the policing of a boundary [...] but on recognizing how we are bound up with others, then this leads us to reconsider the way in which we conceptualize the body in the field of politics. We have to consider whether the body is rightfully defined as a bounded kind of entity [...] We can think about demarcating the human body through identifying its boundary, or in what form it is bound, but that is to miss the crucial fact that the body is, in certain ways and even inevitably, unbound – in its acting, receptivity, in its speech, desire, and mobility (52).

In other words, Butler is arguing that the body is constituted by certain frames that are culturally prescribed. The body, in this sense, “does not belong to itself” (53). Rather the body is open to a shared corporeal vulnerability where we can encounter a wide range of “perspectives that may or may not be our own” (53). The way that bodies are encountered and sustained are dependent upon that particular body’s “social and political networks” (53). That is to say, bodies are made particularly vulnerable when they exist outside of normative cultural frames. Being outside of culturally intelligible frames renders bodies

abnormal, and therefore, not worth “protecting, sheltering, living, mourning” (53). These frames of intelligibility, in turn, justify violence towards bodies that exist outside the boundaries of the normative, a violence where war can “be righteously waged on behalf of some lives, while the destruction of other lives can be righteously defended” (53). The lives that reside outside of normative frames are rendered unlivable, ungrievable, and unworthy of humanization. Butler’s intervention shows that certain bodies experience the world from highly mediated perspectives stemming from various social and political networks. These normative frameworks frame the world in such a way that fails to recognize the violence being done to bodies that exist beyond these boundaries. Notably, these frameworks perpetuate violent forms of touch onto bodies that reside outside of these frameworks.

### **Touch and Memory**

Touch is intimately bound up with memory. In an interview with Grace Dunham, Gossett discusses how the state and various social institutions move through us to create force fields that isolate us from desirable touch. As Butler describes, bodies that reside outside of normative frameworks are often isolated from non-violent forms of touch in public spaces. In this interview, Gossett states that while she was giving a talk at the ONE Archives in Los Angeles she noticed a sign which asserted: “Touch One Another.” She goes on to explain that she didn’t understand the meaning of this flier until she was told about no-touch laws. She explains,

Then, we understood that the state had existed in the space between two people. I thought about how law creates forcefields between us, isolating us from the touch we need and want. I thought about the after-life of these laws, the way that forcefields still exist all around us and between us.

It was profound, and scary, to think about the way those anti-touch laws still affect my experience of myself (Gossett 2015, web).

While the original sign constituted an activist response to anti-touch laws, Gossett importantly points out that these laws are equally effective in the present. These textual references to a past Gay Liberation Front flier, which demonstrate the ways in which the state policed, managed, and produced discourses that legally prevented gay men from “touching,” do not simply disappear with the passage of time. Rather—as Gossett tells us—they reverberate into the present, indeed existing in the “space between” people. Hence, studying the multiple modalities of touch surrounding HIV/AIDS, particularly how it can both exclude and resist, is important to further understanding the effects of touch as an act of exclusion in the present moment.

Memories are embodied in the relations between people. In *Against Purity* (2016), Shotwell engages with Campbell’s work on memory as relational. Shotwell explains that “Sue Campbell’s work on the importance of understanding memory and feeling as relational helps understand the histories of death and loss, resistance and fierce joy, crystallized in activist responses to HIV and AIDS” (56). She further writes that “the work of memory is part of the network of interaction that shapes us as persons. Memory is held not only, or perhaps even not primarily, in our skull. Rather, it might be best understood as ‘held’ within precisely the complex network of relationships that shapes affect and personhood” (60). Shotwell demonstrates that embodied memories evoke particular affects through their relation to histories of marginalization. She further suggests that “Feeling and expressive uptake require one another, which is to say that we require certain kinds of worlds in order to have certain kinds of feelings” (59). The

feelings and memories we experience are spatially and discursively shaped by the worlds within which we exist. As Shotwell further shows, “one piece of oppression, then, is the constraint and torquing it wreaks on affective and expressive possibility” (59). Shotwell offers a framework through which to understand queer touch in the present moment. For example, quarantine laws functioned to prevent queer acts of touch, thereby functioning as a straightening device. These laws reverberate into the present as the discomfort one feels with something as simple as holding a lover’s hand in public. As Gossett discusses, the feelings evoked by queer and trans acts of touch in the present are directly connected to the past treatment of queer and trans acts of touch in public.

## **Conclusion**

This chapter argued that touch is intertwined with spatiality, relationality, and memory. Ahmed’s analysis of desire lines and disorientation offered a framework within which to spatially locate touch within heteronormative spaces. In this context, queer acts of touch resist the straightening device of quarantine legislation, and practices to carve out new spaces. Desire and contact, as Sedgwick shows, is not predicated upon lesbian identification, but rather, predicated upon the relationships we form across multiple identity categories. Here, collectivity is located in the space of being beside, and with, others. Touch exists within a broader system of relationality. Butler shows that bodies are inherently vulnerable to others, but that this relationality is shaped by a broader political imagination that privileges some lives over others. In addition to spatiality and relationality, Campbell and Shotwell illustrate that our actions and affects are shaped by embedded memories.

The next two chapters build off of this theoretical framework to examine touch in relation to what Mingus coins “forced” and “access intimacy.” I argue that intimacy is part of a broader infrastructure that points communities and individuals in particular directions. Touch is always political. It can be both violent, and in other cases, a form of resistance. Touch exists within, and is shaped, by the spatiality, relationality, and memory around it. However, this is not to say that touch is passive, and something solely to be shaped. In the same sense that touch is shaped by these factors, it in turn shapes them. In other words, the act of touch does something—including resistance. For example, the act of touching people living with HIV and AIDS by their activist caregivers, lovers, and friends amidst quarantine practices functioned to resist dominant medical-industrial framings of contamination. This resistance continues into the present moment in the community building that happens through the consensual acts of touch between queer, trans, ill and disabled people in compulsory cisgender, heterosexual, and abled, spaces.



### Chapter 3: Forced Intimacy and Oppressive Touch

The shadows, legacies, and ongoing realities of environmental destruction and genocide, incarceration and involuntary sterilization rise up. They haunt me. The desire for eradication runs so deep. It is revealed in specific moments, places, and histories—in a fleeting experience of sameness at the San Francisco airport, in an agribusiness cornfield before it's mowed for the winter, in a hundred-and-forty-year-old photo of a mountain of bison skulls. But the desire for eradication is also a pattern reaching across time and space. The un-choosing of disability, one force among many, threatening to create a human monoculture.

—Clare (2017,135)

This chapter analyzes 1980s quarantine legislation and AAHP interviews to identify and explore moments of “forced intimacy” in dominant medical-industrial approaches to HIV/AIDS. I argue that “forced intimacy” functions in two ways: first, as a prerequisite for medical care; and, second, as a means to prevent marginalized forms of touch and ultimately, moments of “access intimacy.” “Forced intimacy” primarily manifests in the medical-industrial complex as the dominant approach to HIV and AIDS. The medical-industrial complex comprises what in the previous chapter I identify as an infrastructure that guides various modalities of touch. This chapter begins by locating intimacy in infrastructure, and then moves on to define forced intimacy. It then argues that forced intimacy creates and sustains the conditions for what I call “oppressive touch.” Next, it locates forced intimacy within a broader medical-industrial complex that informs what touch does in this context. This medical-industrial complex is next explored, which as Clare explains, is oriented around cure and the eradication of illness and disability. Cure, in turn, is comprised of five overlapping processes, including diagnosis, treatment, management, rehabilitation, and prevention.

After locating “forced intimacy” within a broader medical-industrial framework, this chapter analyzes 1980s quarantine legislation and AAHP interviews to highlight and



examine three key modalities through which “forced intimacy” worked towards the eradication of HIV and AIDS: first, through the quarantine of people living with HIV and AIDS away from the rest of society, treating them as a risk that might contaminate it; second, through the isolation of people living with HIV and AIDS from their community networks; and third, through the prevention of skin on skin contact between people living with HIV and AIDS and their loved ones and communities. Through quarantine, isolation, and the prevention of skin on skin contact, medical-industrial framings of HIV and AIDS limited moments of “access intimacy.” This is not to say that “forced intimacy” prevented “access intimacy” altogether, but rather, points to the radical potential of the moments of “access intimacy” explored in the next chapter.

### **Intimacy and Infrastructure**

As introduced in the previous chapter, intimacy is located within a broader framework of desire lines. This framework—referred to here as infrastructure—delineates acceptable and unacceptable forms of touch, and stipulates a set of norms that govern these forms of touch. It is within this framework that touch is deployed as a manifestation of a dominant medical-industrial complex. In “The Infrastructure of Intimacy” (2016), Wilson defines infrastructure as

a system or assemblage that includes physical and immaterial elements, usually intended to operate in the background, and is intended to facilitate living and activity [...] What this framing makes clear is that the interest in infrastructure applies not only to technology or to literal immaterialized objects; it also includes a sense of systems, management, and energy, as well as planning and design—hence, discourse, symbols, and, arguably even affect (273-274).

Touch, in the sense I am taking it from Sedgwick and Ahmed, is thus an infrastructure.

As explored in the previous chapter, the spaces that we inhabit are designed in ways that

unconsciously facilitate our social arrangements. These arrangements inform the ways in which bodies move through space and interact with others and their environment in ways that become so normalized that they often go unnoticed. Here, infrastructure can be interpreted to extend beyond material structures to encapsulate, for instance, what Ahmed identifies as “desire lines,” explored in the previous chapter, or what Titchkosky identifies as the discourses that shape our embodiment in everyday life (2008, 210). The ways in which we think about illness and disability are embedded in these seemingly everyday infrastructures. In this sense, infrastructure captures the material and immaterial impetuses guiding our conduct, and ultimately, the ends and goals of touch.

Infrastructure guides intimacy, which is why it is important to identify and critically examine it. In her definition of infrastructure, Wilson makes a case for exploring the relationship between the two, suggesting that,

relationships take place in environments comprised of these material and immaterial, functional or failing networks. Understanding how infrastructures enable or hinder intimacy is a conduit to understanding the concrete force of abstract fields of power by allowing us to identify actually existing systems rather than a priori structures (248).

In this passage, Wilson illustrates that acts of intimacy, such as touch, occur within a framework of material and immaterial networks. Wilson gives the example of infrastructure as relating to systems of flow, such as “transportation (roads, ports), energy (hydroelectric dams, power plants, pipelines), communications (telephone lines, cell phone towers), and water and waste (aqueducts, sewers, treatment plants) (Warf 2006)” (248). As Ahmed puts it, our environments are structured to put within reach hegemonic social relations, and to put distance between undesired forms of interaction between marginalized bodies. Some move through their worlds more easily than others, and the

ways in which infrastructure is designed makes things more easily accessible for hegemonic identities. Mitropoulos similarly defines infrastructure as “how worlds are made, how forms of life are sustained and made available” (379, in Tang (2016)). Tang builds off of Mitropoulos’ definition to argue that “Infrastructures are pliable and not static; they scaffold how we attach or adhere to, or care or experience fondness for, one another” (Tang (2016), 379). That is to say, certain bodies flow through spaces with ease and without stress, as they do not have to experience everyday barriers that inhibit their very livelihoods and existence. Conversely, infrastructures put in place barriers that inhibit moments of intimacy between marginalized bodies, for instance as will be seen later in this chapter, in the separation of trans people living with HIV and AIDS from their communities and care networks. Infrastructure is an overt concretization of power. As such, it is by studying acts of intimacy that we can uncover the very power structures shaping it. In this context, touch not only does something, but it says something about the broader infrastructure within which it occurs.

### **Forced Intimacy and the Medical-Industrial Complex**

This section defines forced intimacy and locates it within the medical-industrial complex. The medical-industrial complex is a set of infrastructures that put forth particular forms of intimacy as a violent technology. At the same time, however, ill and disabled people come to rely upon these technologies in everyday experiences as prerequisites to basic access needs. Here, Mingus defines forced intimacy as:

the common, daily experience of disabled people being expected to share personal parts of ourselves to survive in an ableist world. This often takes the form of being expected to share (very) personal information with able bodied people to get *basic* access, but it also includes forced physical intimacy, especially for those

of us who need physical help that often requires touching of our bodies. Forced intimacy can also include the ways that disabled people have to build and sustain emotional intimacy and relationships with someone in order to get access—to get safe, appropriate and good access (2017, blog).

In this context, touch refers to forced physical intimacy in the pursuit of basic access to medical care. In instances of forced intimacy, touch is undesired but necessary to obtain basic healthcare and access needs. In the case of HIV and AIDS, forced intimacy included the diagnosis and quarantine of people living with HIV and AIDS away from the rest of society, the isolation of people living with HIV and AIDS from their community care networks, and the prevention of skin on skin contact, and therefore, of queer and trans forms of touch.

One of the tenets of forced intimacy that Mingus draws attention to in an attempt to dismantle it is that “disabled people should be grateful for whatever we can get” in terms of access. Here she pushes “back against the forced intimacy and emotional labour” ill and disabled people engage in on a daily basis so that people can feel good about having to provide basic access. She states that “disabled people know all too well, able bodied people will not help you with your access unless they ‘like’ you” (2017, website). What this shows then is that often, simple access relies on one’s social capital. Mingus importantly points out that “This is a very real and important caged reality that I and many other disabled people live in and it is one of the main reasons why forced intimacy exists” (2017, website). It is of note that Mingus deploys the term “caged” to refer to this reality, as trans HIV and AIDS patients were quite literally isolated from their community networks. Mingus explains further that

Another example of forced intimacy is when I am somewhere and need an arm to lean on while walking, as I often do, and I have to be physically close to and touch someone I do not want to. This happened much more when I was growing

up as a disabled child and youth, before I had more say over my life and the people in it. Forced intimacy is also my entire experience in the medical industrial complex with doctors, nurses, brace makers, physical therapists and practitioners, none of which I ever consented to. It is also the many moments in my daily adult life when I have to share more information than needed to get access for events I would like to attend from folks, including “comrades,” who do not post any accessibility information on their event pages or flyers ... (2017, blog).

Mingus’s passage illustrates that abled people often do the bare minimum to include or provide basic access for ill and disabled people. Even in activist communities, ill and disabled people often fall through the cracks if there is no concerted effort to include them. People determine others’ social value in terms of whether or not they benefit from their relationship with them, and whether or not they contribute something to them, which cuts across other marginalized identity categories, creating the material and immaterial realities that sustain racism, colonialism, ableism, and transphobia. Mingus adds that “Sadly, in an ableist world, access and disability get stripped of their transformative powers and instead get distorted into ‘dependent,’ ‘burden’ and ‘tragic.’ Forced intimacy is a byproduct of this and functions as a constant oppressive reminder of domination and control” (2017, website). What “‘dependent,’ ‘burden’ and tragic” mean in this context is a disruption to the normalized flow that cis-hetero-abled white people experience, one that is located within a system of compulsory able-bodiedness, able-mindedness, and cis-genderness. This system is located in the medical-industrial complex, but also informs everyday relations between people seeking access in the communities of which they are a part.

The medical-industrial complex is central to forced intimacy. Here, the medical-industrial complex is one form of infrastructure, a broader network of material and immaterial structures that shape different modalities of touch. In this context, touch is

intended to accomplish medical goals—primarily, cure (Clare 2017, 70). However, as will be shown, touch is not only comprised of a form of contact between bodies, but rather, can be interpreted as broader systems that function to divide, contain, and separate out abled people from ill and disabled people in the pursuit of cure. Touch, in this context, operates as what I call “oppressive touch.” As will be further discussed below, and as Clare explains, cure comprises several overlapping processes ranging from diagnosis to eradication.

Ultimately, the medical-industrial complex functions as a set of ableist structures. In her blog, “Leaving Evidence,” Mingus provides an illustration of the complexities inherent to the medical-industrial complex (MIC). Her post, “Medical Industrial Complex Visual” (2015) outlines the various ways through which the “MIC cuts across all of our work and continues to be a major site where ableism is manufactured, perpetuated and fed” (2015 Mingus, blog). She stresses that all work that seeks to “challenge and transform the MIC and its influences *must* have a sharp analysis of and understand the history of ableism” (2015 Mingus, blog). Importantly, she also adds that “when fighting for healthcare, let us remember that we cannot simply fight for the right to care, but also the right to *refuse care*” (2015 Mingus, website, italics in original). In other words, touch—as a manifestation of care—can both liberate and oppress. For instance, as Christina Sharpe points out, care can function as a violent state technology, producing and contributing to an environment of anti-Blackness. To this end, she points to the powerful example of the slave ship with a name that translates from the Dutch word *Zorg* into English as *Care*, where she defines care “as ‘the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something,’ as support

and protection but also as grief”) (45). Here, care signifies a violent relationship with the Middle Passage and the dehumanization of Black lives. In this instance, care is located as a violent technology of the state, linked to public “health, welfare, and protection” (45). Clare locates care along a similar trajectory in his discussion of Fairview Hospital, stating, “The impact of diagnosis at Fairview didn’t stop with removal. It also justified why people needed long-term care and authorized many kinds of abuse. Using head cages and straightjackets, drugging with psychotropic meds, locking people into isolation cages became means of keeping residents ‘safe,’ practices of ‘care’ rather than forms of violence” (2017, 47). As these examples illustrate, care is undertaken to prolong, provide ‘comfort’ and ‘wellness’ to, and protect certain lives, at the expense of others. In the case of HIV and AIDS patients, patients were isolated away from the general population out of care and safety for the latter. Here, public health becomes synonymous with genocide and eradication.

The medical-industrial complex ultimately functions as a complex system comprised of multiple points that at one and the same time can be sought after in the pursuit of a cure, while also upholding multiple forms of oppression. More specifically, Mingus defines it as

an enormous system with tentacles that reach beyond simply doctors, nurses, clinics, and hospitals. It is a system about profit, first and foremost, rather than “health,” wellbeing and care. Its roots run deep and its history and present are connected to everything including eugenics, capitalism, colonization, slavery, immigration, war, prisons, and reproductive oppression. It is not just a major piece of the history of ableism, but *all* systems of oppression [...] (Mingus, blog).

Clare notes the various mechanisms deployed by the medical-industrial complex, and the ways in which it sets normative standards throughout our everyday lives as a “thicket”:

The medical-industrial complex is an overwhelming thicket. It has become the reigning authority over our body-minds from before birth with prenatal testing to after death with organ donation. It shapes our understandings of health and well-being, disability and disease. It establishes sex and gender. It sets standards for normal weight and height. It diagnoses, treats, and manages the human life cycle as a series of medical events: birth, puberty, pregnancy, menopause, aging, and death, each with its own medicine.

All of our body-minds are judged in one way or another, found to be normal or abnormal, valuable or disposable, healthy or unhealthy. Our body-minds bring us pleasure and distress, sometimes needing medical care and technology to stay alive and other times needing just a little bit of improving—or so we're led to believe. In the process, most of us become reliant on the medical-industrial complex, snagged by its authority (69).

This passage is significant to this thesis because it demonstrates that bodies and minds are pathologized and medicalized at every stage of life. In cases where bodies and minds diverge from the standards set by the medical-industrial complex, medical touch is employed as a violent device to normalize them. Mingus explains further that “In flushing out what the MIC is, we are naming a system. We are calling attention to the systematic targeting of oppressed communities under the guise of care, health and safety” (2015, website). Mingus and Clare point to the complexity inherent to the medical-industrial complex, wherein ill and disabled people depend upon it for their survival at the same time that it is structured towards their classification and containment, and ultimately, towards their prevention in the first place. Hence, as Mingus explains, ill and disabled people must depend upon a broken system at the same time that they fight to change it, and even seek out alternatives to it (Mingus 2015). Indeed, the medical-industrial complex functions to oppress the very ill and disabled people that are reliant upon it for care.

One of the reasons that the medical-industrial complex is so complicated is that it embodies a number of oppressive systems. In “Care as Colonialism: Immigrant Health



Workers at Canada’s Frontiers” (2017), for instance, Baijayanta Mukhopadhyay explores Canada’s healthcare system as an extension of colonialism. He explains that this system functions forcefully, stating that “A history of missionaries, the military, and miners, medicine in Canada cannot be understood without understanding colonization: serving those who claimed people, those who claimed resources, and those who claimed land” (2017, website). This history preexisted hospitals themselves, which were themselves a result of colonizing practices:

But this history began even prior to the establishment of hospitals. When pre-contact economies were disrupted by colonial shifts in ecology and in social power, access to land for traditional means was compromised and living conditions deteriorated rapidly (Mukhopadhyay, website).

Ultimately, as Mukhopadhyay points out, Canadian hospitals were—and are into the present moment—a racist colonial response to the effects of colonial practices. Along these lines, hospitals, and Canadian medicine more broadly, function as a colonial tool. Importantly, Mukhopadhyay draws attention to a critical component of the medical-industrial complex—to separate out ill and disabled people, as well as people marginalized along other identity categories from the rest of society.

The medical-industrial complex is made up of multiple functions and processes.

Ultimately, however, these functions and processes are directed towards “cure.” Clare elaborates,

Cure saves lives and ends lives, propels eradication and promises us that our body-minds can change. It is a tool in the drive to normalize humans, to shrink the diversity of shape, form, size, and function among us. Through cure, we believe we can control our fragile, changeable, adaptable selves. It takes the shape of medical research, medical abuse, medical healing. It plays a role in making billions of dollars of profits and in providing the most basic of health care. Amidst this cacophony, cure always revolves around the perception of a disease, infection, virus, chronic illness, dysfunction, disorder, defect, abnormality, or body-mind difference. For now, let me name this pivot “the trouble” (2017, 70).

Here, Clare identifies cure as an element of normalization, setting out the standards that our bodies and minds must achieve. As described above by Mukhopadhyay, these standards are intimately entwined with other systems of oppression, such as racism, colonialism, and as Ahmed points out, gender and heterosexism. Furthermore, cure is predicated upon what the medical-industrial complex initially identifies as difference—that is, on a system of classification and diagnosis. It is here that Clare identifies within cure a network of “five overlapping and interlocking medical processes” (70), which he in turn identifies as “a far-reaching network”: “diagnosis, treatment, management, rehabilitation, and prevention” (2017, 70). Clare expands upon each of these processes in more detail, indicating that diagnosis is employed “to locate and name the trouble within a system of categorization developed and authorized by the medical-industrial complex,” and where treatment is next undertaken “to diminish the trouble, moderating its symptoms to the greatest degree possible” (70). Management is next defined as the strategies pursued “to make the trouble as unobtrusive as possible,” and rehabilitation “to restore as much body-mind function as possible after the trouble has run its course” (70). Lastly, prevention strategies are designed “to stop the trouble from occurring at all” (70). It is within this framework of processes that forced intimacy exists. Although ill and disabled people must rely upon the medical-industrial complex for their treatment and access needs, as a system, it is ultimately directed towards their prevention and eradication in the first place.

## Quarantine

The next three sections analyze AAHP interviews to identify and analyze three modalities of “forced intimacy” as it relates to HIV and AIDS patients: quarantine, isolation, and the limitation of skin on skin contact. Through this analysis it will be made clear that HIV and AIDS patients had to rely upon a medical-industrial complex that was ultimately organized around their eradication. Through quarantine, patients were discursively and physically separated out from the general population to prevent the spread of HIV and AIDS. Quarantine functioned as an example of forced intimacy and “oppressive touch” because it limited touch to mediated, medical forms, such as masks, gloves, or the refusal to touch at all. Isolation functioned to keep patients away from their community care networks, thereby preventing instances of “access intimacy” through the limiting of being “in touch with others.” Lastly, “forced intimacy” functioned to prevent skin on skin contact, and therefore moments of physical touch.

During the HIV and AIDS crisis, forced intimacy was informed by a quarantine mentality, which suggested that the spread of HIV and AIDS could be prevented through the separation of people living with HIV and AIDS away from society. The intention of quarantine was to physically prevent the spread of HIV and AIDS throughout the rest of the population. One manifestation of quarantine as a broader way of thinking about HIV and AIDS was British Columbia’s 1987 *Health Statutes Amendment Act*. As Cecill explains in her interview with the AAHP, “They wanted legislation—I can’t remember what the bill number was—but they wanted legislation that would allow them to quarantine people with AIDS. They wanted to be able to put them in quarantine” (2). The *Health Statutes Amendment Act*, 1987, stipulated the following:

- (2) Where a medical health officer has reasonable grounds to believe that
  - (f) a person has a reportable communicable disease or is infected with an agent that is capable of causing a reportable communicable disease, and
  - (g) the person is likely to, wilfully, carelessly or because of mental incompetence, expose others to the disease or the agent,he may order the person to do one or more of the following:
  - (h) to comply with reasonable conditions the medical health officer considers desirable for preventing the exposure of other persons to the disease or the agent;
  - (i) to take or continue medical tests or treatment for the purpose of identifying or controlling the disease or agent;
  - (j) to place himself in isolation, modified isolation or quarantine as set out in the order (Chap. 55, No. 8, 397).

This passage illustrates public health responses to the HIV and AIDS crisis, which authorized public health officers to test and quarantine people living with HIV and AIDS on the grounds that they threatened the health of the broader population. Ultimately, the Act grants medical health officers the power to impose conditions upon those with a communicable disease that would remove them as a threat away from the rest of society. Such conditions might include medical testing, physical isolation, or more generally, whatever the medical health officer deems necessary to further prevent the spread of the illness. The overarching goal of these measures was the prevention of the further spread of the disease to the remainder of the general population. The Act frames HIV and AIDS patients as health hazards that pose a threat to public health. In fact, the Amendment adds an additional definition to the original Act, defining “health hazard” as “a condition or thing that does or is likely to (a) endanger the public health, or (b) prevent or hinder the prevention or suppression of disease” (395). The wording of this definition is particularly notable, dehumanizing those diagnosed with HIV and AIDS as “a condition or thing,” instead of people living with HIV and AIDS. This Amendment was made just fifteen

years after the repeal of British Columbia's sterilization laws, which were designed to eradicate and prevent the spread of those categorized as social and medical problems.

The theme of quarantine runs throughout the AAHP interviews, particularly as it relates to public health and the several measures mobilized by it. In a February 8, 2014 interview with Gary Kinsman in Toronto, Ontario, he explains that

Public health—is the major orientation—which is, you know, I always say that, what you always have to ask about public health is, which public and whose health? Because it really was about defending the so-called 'general population' from infection, right? In that sense, people living with AIDS and HIV and the communities of people associated with them were the problem for public health. I mean all of the stuff around contact tracing, mandatory reporting, possible quarantine measures, all of that was mobilized by what public health is actually about, right (9-10).

As discussed further above, public health is a manifestation of the medical-industrial complex, which functions as an infrastructure upon which intimacy and oppressive touch exist. As Kinsman points out, public health only functions in the interests of a particular public, problematizing the illnesses, disabilities, and sexual pleasure that presumably pose a threat to that public. Here, public health measures are not undertaken with the goal of comforting or caring for those already diagnosed, but for preventing and eradicating their further spread throughout populations deemed desirable. As Kinsman points out, one way through which this prevention was carried out was contact tracing, which criminalized and put anonymous sex as an act of access intimacy out of reach for many. Contact tracing, in this sense, regulates how many sexual partners people have, privileging the couple and monogamous sexual relations, while also legislating what forms of sex and pleasure are culturally acceptable. In "I'm Not the Man I Used to Be: Sex, HIV, and Cultural Responsibility," Chris Bell describes this cultural acceptability as a way in which people who are HIV positive are legally required to disclose their

seropositive status to potential and past sexual partners, which, in turn, often means having to know all sexual partners, thereby criminalizing anonymous sex as a potential site of pleasure (2012, 213). Bell argues that the policing of anonymous sex responsabilizes behaviour in such a way that “sanitizes” public environments and restricts sexual relations to specific “possibilities of pleasure,” the effects of which do not take into account the complexities of sexual pleasure that may take place between HIV-negative and HIV-positive people (218). Notably, Kinsman frames public health as an “orientation.” As Ahmed explains, orientations are directed towards certain bodies, while putting others out of reach (2006, 107). In this sense, public health measures truly functioned as orientations, pursued for the health of those deemed desirable, while subjecting others to violence, or what Butler designates “a touch of the worst order” (2004, 29). In this context, such violence took the form of medical neglect and criminalization, allowing people living with HIV and AIDS to die whilst efforts were underway to protect those who qualified as members of the “public.”

1980s quarantine legislation did not exist in isolation. Rather, it was one manifestation of broader quarantine discourses that were further bound up with a hostility towards gay rights. In an October 30, 2014 interview with Paul Craik in Vancouver, British Columbia, he recalls that in 1987

there was the provincial government under Bill Vander Zalm, the Social Credit government. They were consistently hostile to gay rights. They consistently refused to deal with the AIDS crisis. One of the cabinet ministers would say, “what we said in the army was if you shot yourself, it was a self-inflicted wound” and that’s what their attitude was with AIDS, and then there was talk of quarantining, I think Bill Vander Zalm himself actually came out in favour of quarantining. And they brought in a law, and we discussed this in the Front for Active Gay Socialism in one of our meetings, it was the Health Statutes Amendment Act – Bill 34. And basically what it did was it dusted off provisions for quarantining people with any kind of infectious, communicable disease. But

there were already provisions in the law for that. They didn't really need to bring that up legally, because that was already in place. So, the real reason I think they brought that up was as a propaganda ploy to stir up homophobia and get support from their social conservative base. But I also think that there was a real danger of quarantine, because I think there was enough homophobia. Gay bashings were on the rise (4).

Craik importantly locates quarantine legislation alongside public hostility towards gay rights, and the government's refusal to respond constructively to the HIV and AIDS crisis. Importantly, Craik points out that whether or not quarantine was formalized in legislation, it still existed in practice as part of a broader way of thinking about and responding to HIV and AIDS, as well as the people living with it. That is to say, that quarantine legislation was passed in the 1980s within an infrastructure that already separated out people living with HIV and AIDS, and responsabilized them for their illness on the basis of their sexuality. It was within this context that people living with HIV and AIDS were forced to depend upon a medical system that was oriented towards not only the eradication of their illnesses, but also of their sexualities.

Throughout the interviews, quarantine was not just identified as a practice, but was often referred to as a feeling and social relation. For instance, Brooke remembered the urgency of the feeling that "They're going to fucking start shipping us off to islands" (8). In a September 17, 2016 interview in Vancouver, British Columbia, Bet Cecill describes this feeling as the threat of being "seen as a chronic disease" (20). Similarly, in another Vancouver interview on September 13, 2016, Jamie Lee Hamilton describes the popular belief that

And so, based out of ignorance, or hatred they [the Social Credit Party], you know, "These people are immoral. They're spreading this disease around," instead of treating the issue as a health issue. And so, that's when the talk of quarantine—of quarantining the gay men—came into play in the 80s there. It was

frightening because, you know, we knew the government can just create policies (10).

In these instances, quarantine was internalized into an affect that impacted the daily lives of people living with HIV and AIDS and their communities, and shaped how many interacted with their environments. Ultimately, these feelings reflect the internalization of the infrastructure that made quarantine legislation possible in the 1980s. Quarantine existed in both legal discourse and medical practice, but was also something that happened socially, shaping how people living with HIV and AIDS move through the world and come into contact with others.

### **Isolation**

Isolation exists in relation to quarantine. Whereas quarantine refers to the separation of people living with HIV and AIDS away from the rest of the population, and the restriction of touch to mediated, medical moments of forced intimacy, isolation refers to the byproduct of the isolation of people living with HIV and AIDS away from their community networks, often behind hospital walls. In the absence of community caregivers, people living with HIV and AIDS had no other option but to rely upon forced intimacy within the medical-industrial complex, in order to meet their basic medical needs.

It is important to note, however, that isolation affected some people living with HIV and AIDS in different, and often particularly isolating, ways than others. For some it was a feeling and a threat, but for others, it was a material reality, as seen for instance in the isolation and violent treatment of trans people living with HIV and AIDS away from



their communities. When discussing trans organizing around HIV and AIDS, Jamie Lee Hamilton explains that

Then at one point our trans community were—and I don't know why this happened—they were being placed at, you know if they had AIDS, they were being placed at this private hospital way out in the West side on Arbutus Street called the Normandy Hospital. And it was awful ... you know, I'd visit a friend or two in there, and it was just very alien for them, you know.

**AS [Alexis Shotwell]: And probably hard for people to get to visit them.**

JLH: Hard to get to. Bus service was not good. They weren't treated that well. So, I started doing some awareness around trans issues and AIDS, as well.

**AS: Do you know why would they have been sending trans AIDS patients to that place?**

JLH: It makes you wonder, right? Still to this day I don't understand why. I realize there wasn't much, but we could have worked together, put our heads together. And why Normandy Private Hospital was chosen as a rest home? It didn't make sense. It was *way* out of the downtown core where our community is (9).

This passage reflects one instance of the ways in which people living with HIV and AIDS, and especially those marginalized upon further identity categories, experienced isolation from their community networks. Central to isolation was the feeling of abandonment. Jamie Lee Hamilton explains further that trans people living with HIV and AIDS “were abandoned in a foreign—it might as well have been in a foreign country, it was just sick” (17-18). As discussed previously in Mingus’s definition of “forced intimacy,” activist communities themselves are guilty of the exclusion of members marginalized along the lines of illness and disability. In Mingus’s example, this marginalization took the form of the exclusion of disability access information from event organizing. In regard to the example provided by Jamie Lee Hamilton, however, missing from the wider protests on quarantine was a focus on trans issues pertaining to

healthcare and basic access to community supports. This passage demonstrates that there was little community input and discussion surrounding the healthcare options for trans people living with HIV and AIDS, which contributes to the fact that trans-led resistances have been historically excluded from dominant histories of AIDS activism. It also reveals that trans people living with HIV and AIDS were kept away from opportunities to mobilize, thereby preventing the opportunity to organize against their isolation. In isolation, there also lacked accountability on the part of healthcare practitioners for the medical and psychiatric abuse of trans people living with HIV and AIDS. This violence persists today.

Isolation relates directly to Ahmed's theory of orientation, wherein as Ahmed suggests, bodies are faced in particular directions. Together, these directions comprise a form of infrastructure upon which some bodies move through the world more easily than others. In Jamie Lee Hamilton's example, the Normandy Hospital functioned as a straightening device that separated out trans people living with HIV and AIDS, serving as a hurdle for accessing the community support they needed. Here, the straightening device extends beyond compulsory heterosexuality, but also includes compulsory cis-genderness. The isolation of trans people living with HIV and AIDS from their broader communities literally put them out of reach, reflecting Ahmed's claim that some bodies are put more in reach than others. This example further demonstrates that through being put out of reach, trans people living with HIV and AIDS were, as Jamie Lee Hamilton phrases it, abandoned. This abandonment often led to increased exposure to medical violence and deaths that were particularly isolating and lonely.

This example also illustrates Sedgwick's theory of "beside," which Sedgwick identifies as a form of spatial politics and as important to touch as touch itself (9). The isolation of trans people living with HIV and AIDS removed them from "beside" their care networks. Some did not have anyone "beside" them, except for medical practitioners, many of whom refused to treat trans people living with HIV and AIDS. Hence, some activists identified simply being beside people when they died as an act of resistance. For instance, Brooke remembers "being with lots of people who died, as they died" (14). However, it was easier for some people living with HIV and AIDS to be beside their communities than others. This example demonstrates that the "beside" is, as Sedgwick points out, political. Furthermore, the "beside" can be located spatially as part of a medical-industrial infrastructure, which places great distances between trans people living with HIV and AIDS and their communities. It is also important to consider the ways in which being "beside" medical practitioners rather than community networks in moments of forced intimacy further contributed to the ongoing medicalization of trans people.

### **Skin on Skin Contact**

A key theme running throughout the interviews was resisting the prevention of skin on skin contact between people living with HIV and AIDS and their loved ones. Even when physically located "beside" one another, the medical-industrial complex stigmatized skin on skin touch. Recall Brooke's statement that

And for people to get really that mobilized and, like I said, it was quarantine that did it. But the beautiful thing—the really beautiful thing—is that we committed to doing very specific acts of resistance. And you could use a lot of your own imagination around what you would do for acts of resistance. But there was a

group of us that our specific act of resistance was around contact. It was around going and being with our brothers that were in hospital, many of whom were incarcerated in the hospital because of the quarantine. Because, like I said it was truncated, but you couldn't go out and were incredibly limited about who could come and see you. And when you went, you weren't actually supposed to touch. You weren't supposed to actually have skin on skin contact. So, my personal act of resistance was to insist on having skin on skin contact and to be able to touch and hold and hug. If that's what he wanted. So it was really, yeah (8).

In this passage, Brooke points out that in addition to the quarantine of people living with HIV and AIDS, the few visitors that they did have were advised against skin on skin contact out of fear of contamination, limiting the touch they did receive to medical forms. As Sedgwick points out, touch is an important component of social relations. In this example, no-touch discourses and regulations functioned as a straightening device that sought the prevention of skin on skin contact between queer and trans people. In this sense, to reach out and touch, as Brooke describes it, is truly political because it marks a reaching out that goes against what Ahmed identifies as straightening devices. This passage will be examined further in the next chapter as a key moment of access intimacy.

This passage also offers an important moment to think through Sedgwick's theory of texture. As discussed in the previous chapter, texture refers to the interactive properties of touch, its meaning beyond mere contact (13). In this case, acts of touch took place within a backdrop of quarantine discourses, and conjured up feelings of risk or threat—hence, the radical potential of going against no-touch measures and reaching out to touch people who were positive. At the same time, however, quarantine discourses also comprised part of the infrastructure upon which instances of forced intimacy occurred with medical practitioners. This is not to say that all medical contact was forced, but rather, is to point to the multiple meanings of texture that extend beyond the act of touch itself.

The interviews also revealed moments wherein the refusal to touch on the part of healthcare practitioners had devastating outcomes for people living with HIV and AIDS. In a July 10, 2014 interview with Anita Martinez and Eric Smith in Halifax, Nova Scotia, Martinez describes the medical neglect of Dinetia Johnson:

On her record, in the hospital in the Valley, she had AIDS written across it. So, every time she had a headache or anything like that, they said, “Oh, here. Take two aspirins.” They wouldn’t touch her. This one time she had passed out. She had a temperature and she had a bad headache. Again, they gave her aspirin and she ended up back in the hospital again. She couldn’t take it anymore. They put her in an ambulance and sent her down to the hospital. By the time she got there she was gone (24).

In this passage, Martinez importantly draws attention to the very real outcomes of quarantine discourses and practices. Even within a dominant medical-industrial setting, HIV and AIDS patients were often denied basic access to healthcare. At first glance, it would appear that this was not a moment of forced intimacy, given that no touch actually took place. However, this moment occurred within a broader infrastructural framework defined by the medical discourses that shaped moments of actual forced intimacy.

## **Conclusion**

This chapter examined AAHP interviews to locate and analyze three modalities of touch as “forced intimacy”: quarantine, isolation, and the prevention of skin on skin contact. It began by exploring the relationship between intimacy and infrastructure. It argued that intimacy occurs within a broader infrastructure that defines and guides its various forms and functions. Here, infrastructure is comprised of the material and immaterial elements that guide and shape us. The medical-industrial complex was next explored, using Mingus and Clare, as a type of infrastructure that during the height of the HIV/AIDS

crisis defined acceptable and unacceptable forms of touch, in addition to prescribing quarantine measures, and ultimately, the isolation of HIV and AIDS patients away from their communities. As Clare explains, the ultimate goal of the medical-industrial complex is cure—that is, the eradication of illness and disability. Using Mingus, this chapter next examined “forced intimacy” as moments of unwanted intimacy that people living with illness and disability must rely upon in order to access their most basic needs.

The second half of this chapter examined three modalities of touch as “forced intimacy” in AAHP interviews: quarantine, isolation, and the prevention of skin on skin contact. Quarantine refers to the separation of people living with HIV and AIDS away from the rest of the population, as seen for instance, in the 1987 *Health Statutes Amendment Act*. Quarantine measures were undertaken out of concern for “public health.” However, as made clear through Kinsman’s interview, “public” refers to members of hegemonic identities only, putting marginalized bodies and sexual pleasure out of reach. Quarantine measures led to the isolation of people living with HIV and AIDS away from their communities, as seen in the poignant example of the isolation of trans people living with HIV and AIDS in Normandy Hospital. Not only did quarantine and isolation prevent moments of access intimacy, but they prescribed medical forms of “oppressive touch,” or forced intimacy. Quarantine and isolation also prevented the feeling of what Sedgwick coins the “beside,” a highly political space. In addition to quarantine and isolation, the medical-industrial complex prescribed the prevention of skin on skin contact. In this context, instances of skin on skin contact functioned as important moments of “access intimacy” and resistance, to be explored in the next chapter.



## Chapter 4: Access Intimacy and Liberatory Touch

Just over the rise, we need to choose between monocultures and biodiversities,  
eradication and uncontainable flourishing.

—Clare (2017, 187)

The more systems are not a monoculture, the more sustainable they will be. The more there are a lot of different kinds of folks giving and receiving different kinds of care, the more there's room for boundaries, ebbs and flows, people tapping out and people moving up. Care doesn't have to be one way. It can become an ongoing responsive ecosystem.

—Piepzna-Samarasinha (2017, website)

This chapter engages with access intimacy as a form of resistance to state attempts to keep people living with AIDS apart from the rest of society, and especially from their chosen communities of care. It explores the radical potential of “bearing witness” and “being beside” in the face of contamination discourses and quarantine measures. In this sense, access intimacy resists quarantine measures as “straightening devices,” and carves out new desire lines, contributing to disability justice. This chapter identifies and analyzes moments of access intimacy in AAHP interviews, especially instances of liberatory touch, and considers their impact on a politics of relationality that formed around people living with HIV and AIDS. It suggests that “bearing witness” and “being beside” functions as care “across” illnesses and disabilities, contributing to what Piepzna-Samarasinha identifies as systems of permacultures. In the face of state attempts towards monocultures, which were directed towards the containment and eradication of illness, disability, transness, and queerness, these permacultures ultimately serve— in Clare’s terms—as moments of uncontainable flourishing (187).



## **Access Intimacy and Liberatory Access**

Access intimacy was central to the communities of care that organized around people living with AIDS. Here, I borrow from Mingus to define access intimacy in two ways: first, as a feeling of comradery or understanding between ill and disabled people that foregoes the need to explain one's experiences, desires, and needs—that is,

the intimacy I feel with many other disabled and sick people who have an automatic understanding of access needs out of our shared similar lived experience of the many different ways ableism manifests in our lives. Together, we share a kind of access intimacy that is ground-level, with no need for explanations. Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don't have to justify and we are able to start from a place of steel vulnerability. It doesn't mean that our access looks the same, or that we even know what each other's access needs are. It has taken the form of long talks into the night upon our first meeting; knowing glances shared across a room or in a group of able bodied people; or the feeling of instant familiarity to be able to ask for help or support (2011, website).

In this sense, Mingus identifies access intimacy as a mutual understanding between people with access needs, one that foregoes explanation and isolation. Through it, ill and disabled people share the experiences of one another, even in cases where exact access needs are unknown. It is also a moment of vulnerability that ill and disabled people potentially recognize in each other, one that can be instantly captured with a look of acknowledgement.

The feeling of access intimacy is not limited to instances of ableism, however, but can be experienced between ill and disabled people, and abled people as well as people experiencing other forms of oppression. That is, access intimacy may also refer to the feeling experienced when ill and disabled people have their needs understood by abled people, as a form of solidarity:

Access intimacy is that elusive, hard to describe feeling when someone else “gets” your access needs. The kind of eerie comfort that your disabled self feels

with someone on a purely access level. Sometimes it can happen with complete strangers, disabled or not, or sometimes it can be built over years. It could also be the way your body relaxes and opens up with someone when all your access needs are being met (2011, website).

What is particularly notable in Mingus's definition is that access intimacy can be shared across identities. That is to say, that not all engagements with abled people are of forced intimacy. Rather, a politics of relationality between abled people and ill and disabled people is a vital form of solidarity that can be expanded to include various other forms of mutuality and support across differences.

Access intimacy is critical to disability justice as a liberatory tool. Mingus identifies it as a form of reorientation. Its power lies not in the simple inclusion of ill and disabled people into an abled people's world, but rather, it "calls upon able bodied people to inhabit our world" (2017, website). That is to say, that access intimacy challenges an "add and stir" approach to illness and disability, and calls for the reorganization of social structures along disability justice lines. It challenges what Ahmed identifies as normative desire lines to build new worlds that centre ill and disabled people. This type of reorientation is made possible by interdependence, a type of moving away that requires a recognition of social relationality between people, rather than individualized oppressive labels of ill and disabled people as being "dependent" on others. Indeed, Mingus refers to access intimacy as "interdependence in action" (2017, website). In terms of being beside, Mingus writes that "the most powerful part is having someone to navigate access and ableism with" (2017, website). In other words, she explains, access intimacy "is knowing that someone else is with me in this mess. It is knowing that someone else is willing to be with me in the never-ending and ever-changing daily obstacle course that is navigating an inaccessible world" (2017, website). Here, Mingus challenges normative discourses, such

as those embedded in quarantine legislation in the 1980s, that isolate ill and disabled people away from society. Moments of proximity—that is, moments of access intimacy—challenge state attempts to eradicate and contain illness and disability, and put ill and disabled people “in touch with” others. That is to say, that access intimacy puts people in proximity to each other in ways that challenge ableism, rather than perpetuate it. Equally important, access intimacy embodies the right to self-determination, including the right to refuse care, the right to get appropriate care, and the right to be imagined and viewed as more than a recipient of care, but also, as a caregiver, organizer, lover, friend, kin, and person.

Key to challenging ableism and its “add and stir” politics of inclusion is the restructuring of society using a “liberatory access” framework:

Liberatory access calls upon us to create different values for accessibility than we have historically had. It demands that the responsibility for access shifts from being an individual responsibility to a collective responsibility. That access shifts from being silencing to freeing; from being isolating to connecting; from hidden and invisible to visible; from burdensome to valuable; from a resentful obligation to an opportunity; from shameful to powerful; from ridged to creative. It’s the “good” kind of access, the moments when we are pleasantly surprised and feel seen. It is a way of doing access that transforms both our “today” and our “tomorrow.” In this way, Liberatory access both resists against the world we don’t want and actively builds the world we *do want* (2017, website, italics in original).

Liberatory access demands the revaluation of accessibility, not as something in the mix of a politics of inclusion, but rather, as a defining element of the structuring of society. It resists the responsabilization of ill and disabled people for their own access needs, and calls for a politics of proximity, or being “beside.” However, Mingus shows that liberatory access must not be solely focused on future outcomes. It is radical because it resists, what Clare calls, “future-focused commitment” and places an emphasis on learning from movements in the past to enact and practice these politics in the present,

thereby insisting that movements value liberatory access *now* (86). Like Clare, Mingus emphasizes the need to change present conditions in everyday life through action, in whatever way this action can be expressed. Rather than focusing solely on a commitment to change for the future, it is the enactment of these liberatory practices *now*, the effects of which will transform our tomorrow. Liberatory access resists the impulse of forced intimacy to isolate and contain illness and disability away from the rest of society, and offers a framework through which we can move “closer to the world we want and ache for, rather than simply reinforcing the status quo” (2017, website). Central to Mingus’s liberatory access framework is access intimacy. Indeed, she affirms that “there is no liberatory access without access intimacy, and in fact, access intimacy is one of the main criteria for liberatory access” (2017, website).

Mingus’s framework of liberatory access is a useful tool through which to understand disorientation and queer liberation. In the context of AIDS activism, illness, disability, transness, and queerness do not exist in silos, but rather, as McRuer suggests, are intertwined oppressions. In other words, oppressive systems of able-bodiedness, able-mindedness, cis-genderness, and heterosexism cannot be understood as separate systems. For example, and as noted in the previous chapter, quarantine legislation, specifically the legislation surrounding HIV and AIDS in the 1980s, was entwined with heterosexism, neither of which can be understood apart from the other. Mingus’s call for liberatory access is not only a call to redefine the world we live in along lines of access, but also, to enact liberatory practices that seek to dismantle *all* forms of oppression.

In what follows, I identify and analyze moments of access intimacy within AAHP interviews with an attention to the various modalities of touch. It is important to note that

these moments are not isolated instances to be considered apart from the broader context of the AAHP. The AAHP is in itself an archive of access intimacy, as it captures a wide range of activisms driven by care for people living with HIV and AIDS, ultimately, in pursuit of their access needs. Rather, this chapter explores key moments of access intimacy within this series of interviews to emphasize and dissect the nuanced ways through which access intimacy functions, turning to such instances as exemplary of disability justice. What I call “liberatory touch,” in its various modalities, factors in largely in these interviews as a means of working towards liberatory access. In one form, liberatory touch refers to the physical act of skin on skin contact, as will be seen for instance in Brooke’s reference to touch as an act of resistance. Equally important, however, liberatory touch extends beyond skin on skin contact to incorporate Sedgwick’s theorization of being ‘beside’—that is, to the putting within reach of bodies that were framed by contamination and quarantine discourses as untouchable. In the face of an infrastructure comprised of heterosexist desire lines, contamination discourses, and quarantine practices, being beside people living with HIV and AIDS was in itself radical and indicative of disability justice.

### **Care, Being Beside, and Bearing Witness**

The previous chapter identified the medical-industrial complex as the dominant framework through which HIV and AIDS were understood. Indeed, it largely informed contamination discourses, and in their most concrete form, quarantine measures, designed to separate people living with HIV and AIDS away from the rest of society. In the face of the isolation of people living with HIV and AIDS, being “beside” stood as an act of

resistance. In an October 31, 2014 interview in Toronto, Ontario, Renee du Plessis describes how during her time working as a freelance contract worker in a Toronto hospital, she attended to patients' needs amidst quarantine practices as a way to combat the isolation of people living with HIV and AIDS within the medical-industrial complex:

I never forgot this moment – this young man of about 30 was coming for chemo and he was just furious and angry, he was dying and nobody would help in any way... and he was angry with the way they treated him. He would be screaming in the hallways, and staff just would not respond to him and find out what he needed. And I remember having to go up and say, you know, “Can I get you a glass of water or whatever?” I was totally stunned that health care workers were so over- the-top reactionary. Of all people, they were the ones who should've known what AIDS was and how you could get AIDS, and that they were creating this bizarre, very unwelcoming situation when they were supposed to be the healers. He had been complaining about the way everyone was dressing up in their masks and responding to him not as a person but as a contamination, just what we see with Ebola right now. You know, like, “You won't even touch me,” and I found myself being really challenged by him emotionally that I needed to do something so others in his situation wouldn't have the same experience at the end of their young lives (3).

In this example, du Plessis was propelled into action after witnessing the dehumanization of people living with HIV and AIDS by healthcare practitioners, who as du Plessis points out, treated patients as a contaminant rather than as people in need of vital healthcare. This dehumanization was embodied in the use of masks and the refusal to touch the medical charts of HIV and AIDS patients, and especially in the refusal to attend to the needs of a patient urgently screaming for basic care in the hospital hallways. Here, heterosexist desire lines and contamination discourses contributed to an infrastructure designed to erase people living with HIV and AIDS. In this context, the act of resistance pursued by du Plessis was to resist this infrastructure by attending to a patient's needs, which, in this instance, was the act of bringing him a glass of water. In doing so, du Plessis put herself in proximity and in reach, situating herself in relation to him, bringing

him water, and refusing to let him go unnoticed. More broadly, du Plessis worked towards liberatory access by countering contamination discourses, and mobilizing efforts to resist its effects.

The moment shared by du Plessis embodies what it meant to be “beside” in an infrastructure of contamination discourses. In a similar instance, in an April 2, 2016 interview with Douglas Stewart in Toronto, Ontario, Stewart recounts the story of a young man hospitalized while on vacation in Canada:

But, already when they explored the possibility of him going home there were all these barriers that were put up around him. He was kind of in limbo. Where would he go? And his family here was not being very supportive. It makes you realize what services were not available, so there weren't any shelters or places that he could go as somebody with HIV at that time. His brother had a painting business and his brother had a little, like, an office way out there where it's all just industrial buildings, and he ended up in his brother's office; I think there was a washroom, but no kitchen. And I remember we had to take him a space heater because it was in the winter, and that was where he was recovering. And we got a buddy for him, and then we'd go visit him. But there were no shelters, there was nowhere for him to go. That's the best he could do. He was on this little sofa in his brother's office in an isolated area with nothing around him except for being able to call us. There was a phone, so he could call or reach out if he needed to and that was where he was with nowhere to go. I think occasionally people visited him, but people would go with a gown and mask and not touch him, sit far away, and all of this, so I was one of the few people who would sit with him (26).

What is especially poignant about this story is the number of barriers preventing this young man from accessing his care needs, including an unsupportive family, a lack of social and medical services, immigration status, physical isolation in an isolated area, and gowns and masks. Contamination discourses and quarantine practices manifested in the refusal by visitors to touch him. Together, these factors coalesced into an infrastructure designed to isolate people living with HIV and AIDS away from the rest of society, framing them as a threat to public health. In the face of these barriers, Stewart's act of resistance was to sit “with” him, thereby serving as a moment of access intimacy. By

locating himself beside this young man, and putting himself within reach, Stewart countered those who would visit the person but wear gowns and masks, or sit far away from him. Putting himself in proximity to this young man served as a means of support amidst the multiple barriers set up against him.

Locating oneself “beside” people living with HIV and AIDS was driven by care, which was ultimately the organizing principle at the heart of AIDS activism. Stewart recalls that, “But in terms of what we were doing on the ground in the early days of organizing most of what we did was care” (16). The significance of care as a driving factor was that it put people living with HIV and AIDS within reach, at a time when disorientation in relation to heteronormative and abled desire lines put them out of reach. Putting people living with HIV and AIDS within reach was a radical act of resistance against these normative desire lines. The reorientation of these desire lines contributed to the architecture of a new infrastructure organized around care, being beside, and being witness to ongoing AIDS-related deaths and medical neglect.

### **Touch as an Act of Resistance**

One of the most moving acts of resistance against contamination and quarantine measures was the act of skin on skin touch. To recall, Brooke’s “personal act of resistance was to insist on having skin on skin contact and to be able to touch and hold and hug” (8). Here, Brooke pinpoints quarantine measures as a key driver of AIDS activist organizing. As Brooke describes, people living with HIV and AIDS were physically quarantined, and ultimately, incarcerated. In response to quarantine measures, Brooke’s example illustrates the putting in reach of bodies deemed untouchable, as well as the act of touch itself.



Liberatory access existed in the insistence of being present. Here, the radical potential of touch extended beyond skin on skin contact, into what Ahmed describes as contingency: the “sociality of being ‘with’ others, to getting close enough to touch” (2006, 103). As Ahmed describes, and as seen in Brooke’s example, touch is fundamentally relational. Hence, access intimacy and liberatory access depend upon being in proximity to others. Importantly, Brooke’s recollection also illustrates the importance of consent to access intimacy, stressing that touch was only enacted if that is what was wanted.

As demonstrated by Brooke’s example, skin on skin contact served as an important act of resistance against dominant medical-industrial complex approaches to HIV and AIDS. Another instance of contact within AAHP interviews was offered by Anthony Mohamed on April 3, 2016, in Toronto, Ontario:

And, of course, there was an incredible amount of uncertainty among public services – police, nursing, etc. What do we do? How transmissible is this? We don’t know. You know, should we wear gloves? Should we not wear gloves? All of those kinds of questions came up. And those are reasonable questions. However, at the same time people within the community, we were hugging and kissing people living with AIDS and nothing was being transferred, so it was very anger provoking that people wouldn’t touch people living with AIDS, or this idea of using separate dishes, all of those kinds of things. I understand the uncertainty and I understand why that happened. But, in terms of your question about when was it more than a medical issue and when did it become a social and political issue, were those types of things that had occurred (2-3).

In this example, Mohamed identifies queer acts of intimacy within a culture of uncertainty surrounding HIV and AIDS, perpetuated by the medical-industrial complex. Here, queer acts of intimacy offered a counter-narrative to dominant framings of HIV and AIDS—that is, these acts demonstrated that HIV and AIDS could not be transferred through touch. As Mohamed explains further, the refusal to touch—and the labeling of

people living with HIV and AIDS as untouchable—was a source of anger, and therefore, of AIDS activist organizing.

Brooke's and Mohamed's recollections importantly illustrate touch as an act of resistance, in two senses: first, as skin on skin contact; and, second, as being "beside" someone despite the dominant discourses surrounding HIV and AIDS disseminating the myth that isolation and quarantine practices were an appropriate response. An important component of being beside also included bearing witness to AIDS-related deaths. Brooke states that:

That's the other part of the conversation that we don't often talk about, when we talk how our community changed. Our community fucking died. I can't even fill up a whole hand with the men who are actually left from that time in my life. All three of them that are from that time—those gay men that are actually from that time—are an absolute gift. But when they walk around, they're as wounded as the rest of us. It was devastating. So, I do remember lots of people who died. I remember being with lots of people who died, as they died. Like I said, that was part of my act of resistance (14).

In this example, Brooke recounts the tragic loss of friends, and ultimately, members of Brooke's communities. At the same time, Brooke identifies another important act of resistance—being beside people as they died, and bearing witness to those deaths. Here, Brooke points to the importance of remembering in the face of an infrastructure designed for many to forget and not notice.

### **Caring Across Movements and Identifications**

A key component of AIDS activist organizing that featured largely in AAHP interviews was the creation of informal care networks for people living with HIV and AIDS. These networks functioned as important acts of resistance against medical-industrial complex

care models. The power of informal care networks was captured in an interview with Eric Smith, in Halifax, Nova Scotia, on July 10, 2014, who states that

I mean it sounds strange when you say, late '80s early '90s, working in an AIDS organization was probably the best time of my life. I mean that sounds odd, because those were crisis days and people were sick and dying all the time. I mean as far as positive, rewarding feelings you were accomplishing a lot of stuff that in a regular job you weren't doing. You know, sitting up all night with someone who wanted to die at home. You know, you only met the person three times, but in that space of three nights you become best of friends and here you are wiping their backside. And a lot of people think, "Okay, how is that exciting or rewarding?" It is. You're accomplishing something. And it is... It was wonderful (16).

In this passage, Smith identifies important moments of touch and more generally, being beside, including sitting with someone who had chosen to die at home, or the more everyday elements of care work. These intimate moments contrast sharply with the quarantine measures enacted within hospitals and even, as seen in the previous chapter, through 1980s state legislation. Together, these intimate moments comprised an important component of AIDS activist organizing, that is, caring for someone that the medical-industrial complex had deemed untouchable. As Mingus explains, access intimacy exists not only between people with shared access needs, but can also exist through solidarity across differences. One example of care across identity categories included the provision of care by women to gay men when the AIDS pandemic was predominantly framed as a gay men's disease. For example, Mohamed stated that "You couldn't walk down the street without seeing someone. And there were whispers within the community, 'Oh, he has it. Oh, he has it.' Women, especially the lesbian community, they really took up the torch in terms of forming care teams and around the clock care for people who were dying" (2). As expressed by Mohamed, women in queer communities were a critical component of the informal care networks put in place to care for people

living with HIV and AIDS. This is of course not to say that HIV and AIDS only affected gay men, nor that there were no women living with HIV and AIDS at the time. Rather, this example is meant to illustrate the vital forms of queer infrastructure that took place through informal care networks, new forms of care networks that spanned across marginalized identity categories in the face of heteronormative desire lines.

Skin on skin touch, being beside, and bearing witness served as important acts of resistance in the face of an infrastructure comprised of contamination discourses and quarantine measures. Embedded in this infrastructure were heteronormative desire lines, which ultimately, created barriers for queer acts of resistance. In the face of this, acts of touch were significant for many reasons, one of which was the formation of queer desire lines and the construction of an alternative queer infrastructures. Here, touch not only refers to skin on skin contact, but also to broader efforts towards liberatory access.

Together, these efforts comprised an activist network that Shotwell and Brooke discuss as capillaries: “But, like you said, the capillaries actually are a really beautiful way of stating it, because that’s what happened. There were all these little ripples here and there” (11). As Brooke describes, acts of resistance functioned as ripples that disrupted dominant approaches to HIV and AIDS, which as discussed previously, were largely informed by the medical-industrial complex. Collectively, these “ripples” worked to construct an alternative infrastructure grounded in liberatory access. This infrastructure came together in the formation of a collective body of activism. As Brooke explains,

what ACT UP and Queer Nation did was said we could actually take those and put those into action. It forced the body politic into its body. Right? It was like, “Oh, wake up. You actually do have a body. You have something to do here. You have a responsibility. That body’s under attack. We can actually breathe. We can actually respond. We can actually do things and work with one another together (11).

Brooke's example importantly illustrates the impact of the collective acts of being "beside." This sentiment is echoed by Cecill, who stated that "The good stuff was about the connections. It was about the activism. It was about people giving a shit and doing something about it" (20). These acts of resistance merged into an entire activist body. AIDS care-teams and AIDS activism became intimately entwined. As Mohamed expressed, "It was strange because there were kind of two paths. Like, people who were looking at the medical and the caring side, and then other people were looking at the activism side... I say that there were two paths, but really there was one path, right? Like, it was impossible to separate the two" (5-6). Mohamed explains further, "Again, it comes back to—where's the love? The core of all of this was love. And I think that that was the core of the activist stream, of the diplomatic stream, and of the care and support stream" (12). What Brooke, Cecill, and Mohamed illustrate is the radical potential of care outside of the medical-industrial complex, which spurred an entirety of activism, and ultimately, an infrastructure that carved out alternative desire lines. These desire lines resisted the isolation experienced by people living with HIV and AIDS, and propelled collectivity in the face of it. These examples illustrate the "ripples" of care that ultimately drive social movements. Equally important, they serve as key examples of the ways in which community care resists the neoliberal responsabilization of people living with HIV and AIDS for their own care needs in the face of neoliberal cutbacks to dominant healthcare models driven by the medical-industrial complex.

The infrastructure of touch comprised of AIDS activism and informal community care networks served as a powerful site of resistance against the medical-industrial complex, its contamination discourses, and the quarantine measures it prescribed. Mingus

importantly opens up a conversation around the radical potential of collective care outside of this dominant structure. She writes,

This offers us tremendous opportunities for coalition and cross-movement work because we all have a shared stake in our individual and collective wellness and healing. If anything, the damage the MIC has inflicted on our planet should be enough for us all to dream and invest in building alternatives. We have so much shared ground when it comes to being able to answer the ever-present question, “*What could true wellness and care look like for our communities?*” (2015 Mingus, blog).

In this passage, Mingus opens up the radical possibility of care outside of the medical-industrial complex—that is, a form of care carried out at community levels. This is first made possible by critically interrogating the effects of the medical-industrial complex on the very bodies that depend upon it. It is by problematizing this form of infrastructure that it is possible to imagine alternative structures of care, and ultimately, other modalities of touch. The informal care networks organized around people living with HIV and AIDS was one such instance of an alternative care model enacted by communities to care for their loved ones, and serves as a powerful example of the field of possibilities that can be imagined outside of the medical-industrial complex.

The role that touch plays in the organization of informal care networks around HIV and AIDS is captured by Sedgwick in her piece “White Glasses,” wherein she describes in intricate detail the sophisticated care network that was organized around Lynch, particularly during his end-of-life care. In this piece, Sedgwick emphasizes the centrality of care teams to AIDS organizing. The acceptance of terminal illness and the eventuality of death is particularly powerful in this piece. For the type of care described by Sedgwick is not cure orientated; rather, it is about easing one’s pain during terminal illness. As Mohamed expressed during his interview, “I know we use the term ‘people

living with HIV or AIDS’ now, but at that time it was people who were *dying* of AIDS” (2). However, the medical-industrial complex is not organized around comfort, but around cure (Clare 2017). As such, medical treatments are often oriented towards the prevention, management, and cure of illnesses and disabilities, overlooking the vital care that goes into tending to illnesses and disabilities that are incurable (Clare 2017; Titchkosky 2009). If terminal illness and many disabilities are everlasting, then they are not states to be overcome. Rather, terminal illnesses and disabilities are states to be accepted and cared for in nuanced ways. This acceptance points to the need for medical models to recognize the complexities of bodies as well as people’s capacities to self-determine care, rather than the containment of bodies to specific illness management and prevention regimes.

Notably, Lynch’s end-of-life care was not provided by the state, but by a broader community that organized to care for him in the absence of state supports, and that remained “beside” him:

After months of grogginess, discontinuous attention, extreme weakness, futile attempts to regain weight and alertness, Michael had decided it was time to die: time to end the assaultive doses of antibiotics, to stop stuffing himself with food he didn’t want, to take the decision about his fate back into the autonomous hands where it belonged. In making the decision to let himself die, refusing food and all but palliative care, Michael was supported by amazing resources of affection, information, and the most mundane personal care from the communities he had himself created, co-created, and fostered in Toronto. Old and new friends, from *The Body Politic*, from AIDS Action Now!, and from the Canadian Center for Gay and Lesbian Studies, the last of these a new organization Michael had founded in response to the Bill Lewis’s death, organized a care team for Michael on what I think is an unprecedented model and scale: twenty-four-hour-a-day attendance by a weekly rota of thirty or so friends, organized through Sunday meetings (often with a nurse), instructed and kept scrupulous track of through a massive logbook... Empowerment to decide, permission to die, the knowledge and tending necessary to do so on his own terms—these turned out to have been, not only among the many gifts from the people who love Michael, but a part of

Michael's legacy to himself from two decades of activism, writing, and what can only be called the work of community (252).

Here, collective care is discussed in relation to Lynch and the community that organized around him in the absence of state supports. Sedgwick's passage outlines the intricacies of this network, which was ultimately comprised of those whose lives Lynch had in some way "touched." At the same time that this care team organized around Lynch, it was Lynch's care that brought together and organized a network of activists, seen for instance in the encounter with Sedgwick described in a February 9, 2014 interview with John Greyson in Toronto, Ontario:

I didn't get really to know Michael until much later, and it was really through the care-team that I got to know him, you know, really in a much richer way, where I would do my shift once a week and it was actually extraordinary, because I was also handing off to just this lovely woman called Eve Sedgwick. Of course, I realized she was Eve Sedgwick, but hadn't read her work at that point, and our conversations were all about how much soup Michael had had, and you know ... and then other stuff, and her time in Toronto, and so yeah, it was just you know very meaningful to be a part of that care team and then that led to me stepping forward when Alex was getting sicker and saying, "We've gotta do this" (9-10).

As captured by Greyson, it was not just that a care team organized around Lynch, but also that care for Lynch served as a focal point for activist responses to inadequate state healthcare supports. Equally important, Greyson's passage demonstrates the rippling effects of care, wherein Lynch's care network served as a model for subsequent care networks in the future work of AIDS activists.

At the same time that Sedgwick captures the intricate care network that organized around Lynch, she importantly locates her own illness alongside of his, envisioning her relationship to him through their matching pair of white glasses:

So often I feel that I see with Michael's eyes—not because we are the same, but because the same prosthetic device attaches to, extends, and corrects the faulty limb of our vision. It is as if we were both the man in the iron mask; different men



in the same iron mask. When I am in bed with Michael, our white glasses line up neatly on the night table and I always fantasize that I may walk away wearing the wrong ones (256-257).

As Sedgwick explains, she does not see with Lynch's eyes, but she can still identify with him through their shared experience of living with a terminal illness. This passage points to the significance of solidarities across differences, and to the radical potential of liberatory access. The power of liberatory access is that it propels collective care that extends solidarity and mutual support across various communities and social movements.

It is important to note, however, that although Lynch's care network represented a beautiful example of liberatory access and a radical alternative to the medical-industrial complex, it was not—and is not—made available to everyone. This is not to critique the care team that organized around Lynch, but rather, is to suggest that such care models should not be the exception, but the rule. In other words, these models serve as one example among many of how marginalized communities organized to provide end-of-life care for people, who otherwise would have experienced ongoing medical neglect. What the care team organized around Lynch demonstrates is that community-based care networks were, and are, vital to disability justice. However, Douglas Stewart importantly points out that much of AIDS activism was geared towards white, cisgender, gay men, and excluded people living with HIV and AIDS with compounding oppressions:

I would sit in meetings and hear some of the people who would talk about this, and really their entry into activism was really through HIV/AIDS. Beyond that, they weren't fighting gay rights struggles, they weren't on the front of any of those movements, but suddenly they had this illness and, "Oh! I'm angry about that!" And so here they were, but many of them were, when you hear what they did in their lives they already were quite privileged in terms of jobs they were able to get, the kinds of communities they lived in, the way they lived. And so their anger was more about frustration with the fact that that was being challenged. And so you're in the room and these are supposed to be our allies in this work, right? And so they struggled sometimes with being open to hearing,

because they still had all those layers of power and privilege that they couldn't see through. "What do you mean race? What do you mean poverty? What do you mean substance abuse? What do you mean sex work? You know, trans what?! And women... How are women...?" So, there was that kind of response that I think all the different groups that were marginalized had to be constantly fighting. But I have to say initially we were there to say, "Yes, their lives were also valuable." Because what we were trying to say was that all kinds of people's lives are valuable that are being missed. And so I think that was a frustration: that we're all there doing the work, making sure that the systems were beginning to shift and change, but for a lot of us it was very slow, and I don't know that it has shifted yet (7).

Stewart illustrates the exclusions generated within AIDS activism, and ultimately, within care networks that centred white, cisgender, gay men. This passage points to a struggle within AIDS activist organizing to recognize issues that dealt specifically with race, as it more often privileged whiteness. It often also did not take gender into account, for example, women's issues were not taken seriously as legitimate concerns often leading to the ongoing violence experienced by women, cis and trans. Again, this is not to critique the care received by these men, but rather, is to problematize the exclusion of certain communities from these networks. As discussed earlier, liberatory access recognizes and challenges entwined oppressions. As Stewart points out, complexity is a vital component of AIDS activism. The limitation of movements to a single identity category illustrates the limits of reach, where certain bodies are put more in reach than others.

As the analysis of AAHP interviews above demonstrates, informal care networks organized around people living with HIV and AIDS ultimately put within reach bodies that the state attempted to put out of reach through quarantine measures. Quarantine measures were directed towards the limitation and elimination of liberatory touch, subjecting people living with HIV and AIDS to acts of forced intimacy within the medical-industrial complex. In the absence of medical healthcare services, forced

intimacy not only included medical touch, but the absence of touch in the first place. Medical acts of touch were carried out in a sterile manner, often encompassing abuse and neglect, or the outright absence of medical care. Forced intimacy ultimately dehumanized people living with HIV and AIDS, framing them as a contaminant rather than as people in need of care. However, informal care networks re-routed normative desire lines, contributing to queer and disability justice world building. The significance of care to AIDS activism is that it served as a principle around which to organize. This organization included solidarity across multiple identity categories, in addition to illness and disability. These acts of access intimacy ultimately contributed to a framework of liberatory access, which not only includes liberation from ableism, but also from multiple forms of oppression.

### **Liberatory Touch and Uncontainable Flourishing**

Importantly, liberatory access in action makes vital interdependent relationships, which challenge quarantine practices of isolation. Quarantine practices represent state attempts to isolate and contain. Clare discusses such attempts by the state as a form of the eradication of difference, referring to attempts as “The un-choosing of disability, one form among many, threatening to create a human monoculture” (134-135). He describes these monocultures as “a clearcut forest replanted with one variety of tree,” going on to state that “monocultures do an immense amount of damage. So much labour and violence goes into creating and maintaining them. Their existence requires hundreds of eradications and removals” (134-135). Monocultures lay the groundwork for systemic violence against all forms of oppression. In the face of such attempts by the state,

informal care networks, and the activism they are entwined with, send a clear message: When the state seeks to separate us, we refuse to be separated. This refusal challenges monocultures with permacultures. As Piepzna-Samarasinha argues,

The more systems are not a monoculture, the more sustainable they will be. The more there are a lot of different kinds of folks giving and receiving different kinds of care, the more there's room for boundaries, ebbs and flows, people tapping out and people moving up. Care doesn't have to be one way. It can become an ongoing responsive ecosystem (website).

As Clare explains, "Part of claiming disability is choosing this messy, imperfect work-in-progress called interdependence" (136). Further, Clare argues that "we need to choose between monocultures and biodiversities, eradication and uncontainable flourishing" (187). In response to quarantine measures that propel containment and the removal of liberatory touch, uncontainable flourishing contributes to radical forms of infrastructure that know no bounds. Touch is political; it can divide, but it can also liberate. In other words, touch exists in multiple modalities.

## **Conclusion**

This chapter argued that access intimacy and liberatory access are powerful acts of resistance against the forced intimacy imbricated in the medical-industrial complex. Where forced intimacy was enacted through quarantine measures, including medical forms of touch or their absence in the first place, access intimacy put people living with HIV and AIDS within reach. This putting within reach importantly laid the groundwork for radical forms of infrastructure that challenged heterosexism and ableism. Following a discussion of access intimacy and the importance of liberatory access, this chapter explored the importance of the "beside" and the putting within reach of people living

with HIV and AIDS in the face of practices that sought to separate them away from the rest of society. The location of care-teams “beside” made possible skin on skin touch, in a context when people living with HIV and AIDS were treated by the medical-industrial complex as “contaminants.” Informal care networks were organized around people living with HIV and AIDS, and went on to inform AIDS activist organizing. In the face of dominant care models directed towards eradication and the creation of monocultures, these care networks contributed towards permacultures that sustain liberatory access and disability justice.

## **Chapter 5: Conclusion**

### **Summary**

This thesis deployed a framework grounded in queer phenomenology and critical disability studies to analyze the various modalities of touch surrounding the 1980s-90s AIDS crisis. In doing so, it argued for liberatory access as a framework for justice that cuts across multiple movements and identifications, while centring the experiences of ill, disabled, and trans people. In doing so, it demonstrated that touch matters to the ways we organize ourselves socially and politically, and that it has the potential to both oppress and liberate. Quarantine measures grounded in the medical-industrial complex isolated people living with HIV and AIDS away from their communities, subjecting them to instances of oppressive touch and forced intimacy behind hospital walls. In this context, liberatory touch—made possible by being beside—was a radical act of resistance that contributed to the mobilization of AIDS activism. The organization of informal care networks around people living with HIV and AIDS is an important example of liberatory access, challenging an “add and stir” approach to disability justice with the centring of ill and disabled people. Importantly, these care networks cut across movements and identifications, which points to the radical potential of liberatory access for challenging multiple forms of oppression.

Chapter 1 introduced the thesis and outlined its methodology, which I located at the intersection of queer phenomenology and critical disability studies. Chapter 2 presented the theoretical framework, which in addition to my methodology, went on to ground my analysis in subsequent chapters. It began with a discussion of Ahmed’s work on desire and spatiality, in which the author examines heterosexism using a

phenomenological lens, as a series of orientations and desire lines. Here, Ahmed suggests that sexuality is a spatial phenomenon, in which subjects are faced in particularly heterosexist directions (69-70). In other words, the spaces we inhabit are structured along the lines of particular hegemonic identities. Ahmed suggests that heterosexism is supported by what she terms “straightening devices” (72). Using McRuer’s analysis of compulsory able-bodiedness—and extending it to include compulsory able-mindedness (Kafer) and cis-genderness—I suggested that hegemonic identities are upheld by a system of interlocking straightening devices. Queer and trans acts of desire disorient these mapped spaces, bringing objects closer that would otherwise be out of reach (92). Missing from Ahmed’s analysis of disorientation is a critical disability lens, for as Titchkosky points out, disorientation carries radical potential, however, it may also prove distressing, necessitating interdependence (67), or what Harbin refers to as “in-this-togetherness” (112).

Next, Chapter 2 engaged with Sedgwick’s work on beside, touch, and texture. Sedgwick identifies the beside as a highly interactive space that exists between bodies in close proximity, which this project extended beyond the material to include feelings of solidarity and collectivity felt between and across identifications. In order for touch to occur in a physical sense, bodies must first be put within reach, which is to say that much exists in the in between. It is when these dualisms collide that touch takes place, in multiple senses. Here, Sedgwick importantly distinguishes between touch and texture, the latter which encapsulates the interactive perceptions of touch (13). Ultimately, what Ahmed and Sedgwick demonstrate is that space matters to touch. Butler’s theories of vulnerability and relationality were next explored, wherein Butler suggests that we are at

root relational beings, wherein we act and are acted upon by others (2004). Lastly Chapter 2 engaged with Gossett, Shotwell, and Campbell to examine memory as relational, and to consider the ways in which queer acts of touch in the present moment are mediated by memories of the consequences of queer touch in the past.

Chapter 3 built on the theoretical framework explored in Chapter 2 to analyze moments of oppressive touch and forced intimacy during the 1980s-90s AIDS crisis. It identified these moments in 1980s quarantine legislation, as well as in AAHP interviews. The chapter began by situating intimacy within a broader framework of desire lines—or what this thesis borrowed from Tang (2016) and Wilson (2016) to define as infrastructure. Ultimately, touch is informed by a broader infrastructure, which in turn, is comprised of a series of desire lines that guide what it should look like, and what it should accomplish, in line with hegemonic identities. This thesis concerned itself with one form of infrastructure in particular—the medical-industrial complex, which as Clare points out, is organized in the pursuit of cure and, therefore, eradication (135). The medical-industrial complex largely informs what Mingus terms “forced intimacy,” (2017) or the moments of intimacy that ill and disabled people do not desire but must rely upon nonetheless in order to get their basic access needs met (2017). It is within the framework of forced intimacy that I identify the idea of oppressive touch, or the acts of voluntary or involuntary touch that people living with HIV and AIDS in the 1980s-90s crisis were forced to rely upon in order to receive basic medical treatment. The chapter proceeds by analyzing quarantine legislation and AAHP interviews using a framework of forced intimacy to understand the various modalities of oppressive touch surrounding HIV and AIDS. Ultimately, the chapter suggests that quarantine legislation—and more broadly, a



quarantine way of thinking about illness and disability—isolated people living with HIV and AIDS away from their communities, ultimately limiting the acts of touch they did receive to its oppressive forms. Sometimes oppressive forms of touch even manifested in its absence altogether. These moments of forced intimacy were informed by the medical-industrial complex, which reframed people living with HIV and AIDS as contaminants.

Chapter 4 analyzed AAHP interviews using a framework of access intimacy to engage with liberatory touch as an act of resistance. It began by borrowing from Mingus to define access intimacy as a shared understanding that exists between ill and disabled people, or between ill and disabled people and abled people, when they immediately understand each other's access needs (2017). Importantly, access intimacy exists across identifications, and can take place, for example, between ill and disabled people and others from marginalized identity categories. Access intimacy is a key component of what Mingus terms “liberatory access,” or the restructuring of society along illness and disability lines, wherein access becomes a collective responsibility (2017). Using this framework, the chapter next identified and analyzed moments of liberatory touch and access intimacy within AAHP interviews. Here, I used liberatory touch to refer to moments of touch that furthered disability justice. The beside factored largely into these moments, where access intimacy often took the form of sitting with someone with HIV and AIDS. One of the most prominent trends in AAHP interviews pertaining to touch was the organization of informal care networks around people living with HIV and AIDS, as seen for instance, in the care team that surrounded Michael Lynch. In this context, skin on skin touch radically resisted quarantine discourses and measures. Ultimately, I argued that liberatory access is so radical because it contains within it the potential for

identifications across and outside of illness and disability. Chapter 5—the current chapter—summarizes my findings and contributions.

### **Contributions and Areas for Future Study**

Above all else, this thesis demonstrated that in its multiple modalities, touch matters to social relations. It can liberate through the provision of access, or oppress through acts of violence. It can separate some, or bring together others. Most importantly, however, it can inspire resistance and a shared sense of responsibility in the face of social injustice. This thesis also demonstrated that queer phenomenology and critical disability studies contribute important lenses, not only to an analysis of touch, but also to the study of social relations more broadly. Specifically, a framework existing at the intersection of queer phenomenology and critical disability studies critically interrogates underlying infrastructures that inform our social relations, putting some more easily in touch than others. This framework also reveals, however, that it is possible to carve out new infrastructures with the potential to redefine how we relate socially.

This thesis built on important analyses of the relationship between compulsory heterosexuality, compulsory able-bodiedness, and compulsory able-mindedness, to contribute the notion of compulsory cis-genderness. In doing so, I argued that heterosexism and ableism cannot be understood apart from cissexism, and in particular, from the social relations and state sanctioned institutions that work to uphold the gender binary. The medical-industrial complex, particularly psychiatry, committed—and continues to commit—violent acts of forced intimacy against many trans people. The categorization of transness as a mental illness, despite the removal of gender dysphoria

from the next edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), illustrates the intersection of compulsory cis-genderness with compulsory able-mindedness. The effects of this discourse exceed single diagnosis, but are present in the ways that those trans people who exist in the messy intersections of disability, mental illness, and transness, are continually denied health coverage for gender-related surgeries and hormones across Canada. This is an important area for future study and activism.

### **Concluding Thoughts**

In the novel *Drag King Dreams* (2006), author Leslie Feinberg illustrates the complexities of identity through the protagonist Max Rabinowitz, who writes to future tenants on his bedroom walls in order to write himself into existence. Feinberg writes, “Human handprints on the ceiling, from the cool cave walls of Pech Merle, wordless, intimate messages sent from a long-forgotten communal past: from the touch of our hands to yours, we exist, we existed” (95). In this passage, Feinberg deploys touch to capture the importance of writing into existence the lives of those who would otherwise be forgotten, lives that often exceed the boundaries of formal written language. Similarly, in her blog aptly entitled *Leaving Evidence*, Mingus asserts that

We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached. Evidence of the wholeness we never felt and the immense sense of fullness we gave each other. Evidence of who we were, who we never should have been. Evidence for each other that there are other ways to live—past survival; past isolation (2018).

Feinberg and Mingus capture a critically important modality of touch—the bringing together of networks of interdependence across identifications and across time. In this sense, one of the most compelling examples of touch captured by AAHP interviews is not

found in one particular interview, but rather, exists in the writing into existence of those whose lives might otherwise be forgotten. These stories put us in touch not only with those who died from HIV and AIDS, but also with the sense of collectivity and interdependency that inspired the informal care networks around them. In light of the interlocking barriers put in place to divide us, these feelings of collectivity and interdependency are vital.



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