

How Does This Happen?:
Settler Colonialism, Anti-Blackness, and Ableism in Places of Unfreedom

by

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ABSTRACT

Deeply entrenched eugenic values overdetermine who is treated with care and dignity and who is treated with violence. These eugenic values inform and are informed by settler colonialism, patriarchy, and ableism. Carceral locales such as nursing homes, hospitals, and jails enact specific kinds of harm onto disabled people and rely on their convoluted and self-serving bureaucratic processes to evade responsibility. Given my interest in the indivisibility of carceral logics, spaces of capture, and ableism, my focus in this dissertation is both the real-life contexts of the individual incidents *and* the systemic, cross-institutional patterns evident in each of the three incidents analyzed.

I take a modified case study approach to three incidents in which disabled people in carceral locales experience tremendous harm. The first incident is about the gross medical neglect and rape of a San Carlos Apache disabled woman at a skilled nursing care facility in Phoenix, Arizona. The second incident occurred at a hospital in Austin, Texas where doctors worked hastily to killing a Black disabled man within only days of his arrival and change his code status to Do Not Resuscitate against his family's will. The third incident focuses on duty of care violations and disability-based discrimination against a white disabled man at a Chicago jail. These situations, when analyzed individually and with/against one another, identify important connections relating to institutional power and cross-institution patterns of harm. I find that the paternal dynamics of medical[ized] facilities, the pervading anti-disability sentiments in US society, and bureaucratic violence make accountability and justice impossible.

key terms: ableism, abolition, bureaucratic violence, duty of care, disability justice, gender, incarceration, medical ethics, paternalism, patriarchy, settler colonialism

DEDICATION

In loving memory of Monika Butkute, Annie Hopkins, Joanna Lagedrost, and Samantha Marcus, four disabled women whose lives and deaths continue to shape me and my understanding of feminist disability justice in profound ways. My life is brighter because of our time together, and I will work for the rest of my life for a kinder, fairer, and more accessible world, a world where disabled women don't have to live in places where they experience harm.

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CHAPTER ONE

INTRODUCTION

Introduction

Ableism cuts across all of our movements because ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability. Ableism set the stage for queer and trans people to be institutionalized as mentally disabled; for communities of color to be understood as less capable, smart and intelligent, therefore “naturally” fit for slave labor; for women’s bodies to be used to produce children, when, where and how men needed them; for people with disabilities to be seen as “disposable” in a capitalist and exploitative culture because we are not seen as “productive;” for immigrants to be thought of as a “disease” that we must “cure” because it is “weakening” our country; for violence, cycles of poverty, lack of resources and war to be used as systematic tools to construct disability in communities and entire countries. (Mingus, 2011, para. 14)

When doctors in medical facilities and sheriffs in jails violate their duty of care¹ to the people under their supervision, they are often protected by their institutions from being held legally culpable. Sick, disabled, mad, and neurodivergent people interface with these institutions at disproportionate rates and are vulnerable to the ways that medical and legal authority position them as less than, as “other” and as disposable – especially those who are poor, racialized as not white, queer, and/or migrants. Sins Invalid, which is a disability justice performance project that centers people of color, queers, nonbinary and trans people with disabilities (<https://www.sinsinvalid.org/mission>), has outlined a list of 10 Principles of Disability Justice (Sins Invalid, 2019). This list of principles is intended to describe the emerging framework of Disability Justice. The 10th principle of Disability Justice, as outlined by

¹ Duty of care refers to the obligation to adhere to a standard of reasonable care and ensure some level of safety.

Sins Invalid is Collective Liberation, the notion that no one can be left behind, that no bodymind² is disposable (Sins Invalid, 2019). This principle guides an analysis that honors the humanity and dignity of people who experience harm *and* encourages different, non-carceral approaches to accountability and justice.

In *The Feminist and the Sex Offender*, Judith Levine and Erica R. Meiners explore the tensions between sexual and gender violence and the impulse to rely on punishment, vengeance, and the carceral state as the response (2020). I think about these abolitionist tensions a lot, especially in situations where the people who are causing harm seem to evade punishment, vengeance, and the carceral state altogether. For example, when police officers harm civilians in the U.S. or when U.S. military personnel harm civilians abroad, they rarely face criminal charges let alone get sentenced to time behind bars; harm is their job. Similarly, when doctors neglect or abuse their patients, they rarely face criminal charges let alone spend time in prison; harm is a risk of their job, for which they have insurance to protect themselves. In situations like these, committing to abolitionist values and resisting a carceral, punitive response can feel as though a step is being skipped, as if the people who experienced the neglect or abuse didn't *get* to have these people, actions, and institutions officially deemed "wrong" or "bad" or "unacceptable."

As I write this, there are numerous state-level attacks being launched nationwide that aim to criminalize medical providers for providing high quality, evidence-based medical care to their patients. There is legislation being proposed related to

² Bodymind is a term popularized by critical and feminist disability studies scholars (e.g., Price, 2015, Clare, 2017, and Schalk, 2018) that resists the Cartesian idea that the mind and body are split. Margaret Price uses this term to refer to, "a sociopolitically constituted and material entity that emerges through both structural (power- and violence-laden) contexts and also individual (specific) experience" (Price, 2015, p. 271).

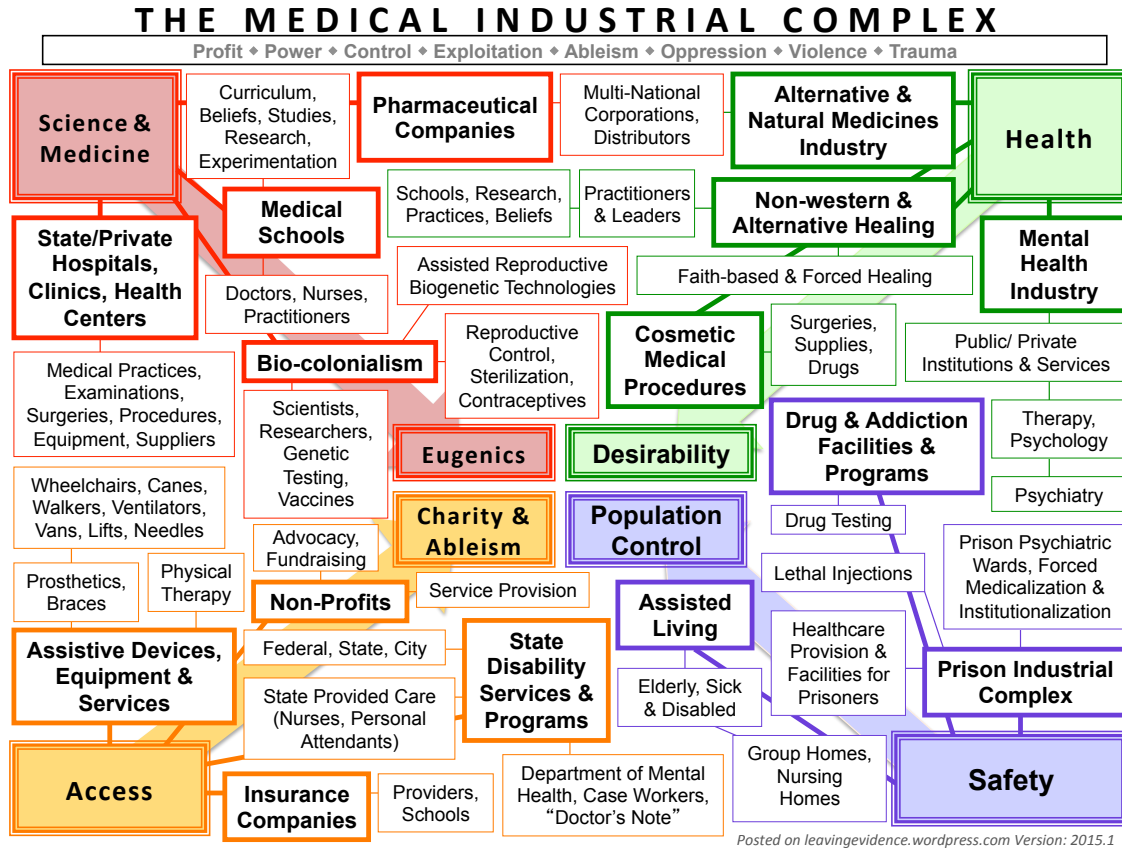
LGBTQIA2S+³ discrimination. Anti-trans bills are being proposed in 34 states, the Florida Senate passed the so-called “Don’t Say Gay” bill, and Texas governor, Greg Abbott, has issued a directive that criminalizes doctors, nurses, teachers, and parents who help young trans people get access to gender affirming medical care. There are also numerous states passing legislation that criminalizes people who seek and/or provide abortion in many cases, and many of these states are simultaneously pursuing legislation that would ban abortion (and therefore, criminalize medical providers) in almost all cases if the U.S. Supreme Court overturns *Roe v. Wade*, the landmark decision that affirms people’s Constitutional right to choose to end their pregnancy (*Roe v. Wade*, 1973). Hospitals in almost every state regularly withhold equitable treatment from patients who cannot pay and engage in the practice of “patient dumping” wherein the hospital transfers or prematurely discharges a patient – typically those who are experiencing chronic homelessness – because of their inability to pay for services. In addition to all of this, the United States does not ensure high quality, affordable, accessible health care for all people living in its colonial and imperial borders, which creates population-level health concerns that doctors do not have the ability (and sometimes the desire) to address.

In every way, providing medical care in the U.S. is a political act, and should be politicized. Regardless of the potentially altruistic reasons people entered health care and its related professions, the Medical Industrial Complex (MIC) is a violently oppressive system, and the decisions that doctors, nurses, case workers, and others in the MIC are tasked to make should be politicized, scrutinized, and criticized.

³ This acronym stands for Lesbian, Gay, Bisexual, Transgender, Intersex, Asexual/Agender, Two Spirit, and the infinite ways people can experience desire for their bodyminds and other peoples’ bodyminds Two Spirit is a term that some people use to refer to Indigenous people who have masculine and feminine spirits.

Figure 1

The Medical Industrial Complex



(Mingus, 2015)

“[The image shows a visual layout of the Medical Industrial Complex, which is written at the top in large letters. Just under it, there is a thing, long box that contains the words: Profit, Power, Control, Exploitation, Ableism, Oppression, Violence, Trauma. There are four main quadrants, each in a different color with large matching colored arrows connecting the outer broad categories to inner underlying motives: “Science and Medicine” is connected to “Eugenics;” “Access” to “Charity and Ableism;” “Health” to “Desirability;” and “Safety” to “Population Control.” Subcategories and main categories within each quadrant, are listed in large and small boxes that are all connected to each other with lines, forming a web-life effect, filling the entire page.]” (Mingus, 2015, Image Description). A full visual outline is available at <https://leavingevidence.wordpress.com/2015/02/06/medical-industrial-complex-visual/>

Mia Mingus, who is a writer, educator, and the founder of SOIL: A

Transformative Justice Project, writes,

The Medical Industrial Complex is 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. (2015, para. 3).

This dissertation focuses on three instances of harm that occurred in three different locations, each of which was enabled by multiple tentacles of the Medical Industrial Complex and sanctioned by multiple, related institutions.

Ruth Wilson Gilmore describes abolition as a theory of social change, a way to understand what can be made instead (Petitjean, 2018). I understand the Medical Industrial Complex to be different from the other, interrelated prison-industrial and military-industrial complexes, because where the latter two serve only to enact violence and harm in the service of imperialism, colonialism and white supremacy, the MIC is complex in its harm. I argue that while carceral punishment and militarism have no place in our society (and therefore, should be abolished entirely), many of the products, services, and facilities that make up the MIC are crucial for survival. There are institutions that prioritize profit and encourage eugenic logics, but these institutions also provide access to important medications, therapies, procedures, and equipment. There are clinicians allowing, enacting, and profiting from pain, suffering, and death, and there are clinicians navigating these violent institutions and figuring out how to offer compassion and support within and against their institutional constraints and infusing non-Western healing practices into their work. I use abolition as a guide for how to reimagine the MIC

and a framework for understanding the resistance and subversion already occurring within and outside of it.

How did this happen? What needs to change so this does not happen again? I find myself returning to these questions over and over again. A San Carlos Apache disabled woman is raped and becomes pregnant while living at a skilled care nursing facility in Phoenix, Arizona that has a checkered history of neglecting and abusing the disabled people who live there. Nobody at the facility notices or reports anything until she gives birth, and no doctor is held responsible for wrongdoing. How did this happen? A Black disabled man is denied life-sustaining treatment and has his code status forcibly changed to Do Not Resuscitate (DNR) by hospital in Austin, Texas that has a history of quality-of-care complaints. Nobody at the hospital publicly expresses any remorse for what they did to this patient, and no doctor is held responsible for wrongdoing. How did this happen? A white disabled man is denied the medication and disability accommodations ordered by a doctor at the Cook County Jail, a Jail that regularly receives and settles civil rights complaints regarding disability discrimination and unsafe conditions. Nobody at the Jail is held responsible and no fundamental changes occur. How did this happen? This dissertation uses a variety of critical perspectives, which I will detail in the Methodologies and Methods chapter, to analyze these three incidents individually and with/against one another.

Study Overview and Research Questions

Dr. Jonathan Rosa redirects student researchers to avoid the colonial, capitalistic, and policing practice of finding a research topic we think is undiscovered, claiming individual ownership over it, and then working fiercely to protect it from theft (Rosa,

2020). He argues that, instead, researchers should consider why scholars have avoided studying these issues and what function(s) such avoidance has served. In this project, I acknowledge the insidious and pervasive ways that ableist notions of desirability and disposability seep into every aspect of human life, including academic research. I do not associate the overwhelming avoidance of a meaningful analysis of disability or the absence of a clear and consistent anti-carceral analysis in feminist activism and scholarship as an indication of malice. Nor do I associate the race-evasive, colonial tendencies in disability-related activism and scholarship as indications of moral failing. I hope that by continuing in the critical and feminist tradition of analyzing the connections between ableism and other systems of oppression, this dissertation can provide contextualized exemplars that amplify intellectual and political action to increase resources and access to life chances, especially for people who are targeted for state violence (Lawston & Meiners, 2014).

This exploratory study considers three research questions. What can be learned from using feminist, disability justice, and abolitionist approaches together to think about how ableism informs medical[ized] and legal decisions, especially regarding the institutional harm enacted onto disabled people interfacing with these institutions? How does this harm keep occurring? And how do institutional paternalism and so-called medical “expertise” contribute to who is (and is not) treated as having – and being capable of having – a life worth living?

Key Terminology

Many key terms in this dissertation are expansive, plural, and contested. While definitions of terms and concepts are woven throughout each chapter as applicable, below are some brief descriptions of a few key terms/concepts in alphabetical order.

Ableism. Talila L. Lewis is an abolitionist lawyer, educator, organizer, and the founder of HEARD (<https://behearddc.org/>). My understanding of ableism is directly informed by Lewis' most recent 2022 definition:

The system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systematic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism. (para. 3).

Abolition. Importantly for this research, I share in Dylan Rodríguez's conception of abolition that it is inseparable from its feminist and queer roots in Black liberation and Indigenous anticolonialism/decolonization (Rodríguez, 2019). Embracing an expanded understanding of incarceration, one that considers places of confinement that a) are disabling, sickening, and maddening, and b) confine disproportionate numbers of disabled, sick, and mad people, abolition involves a direct rejection of and reimagination of the carceral state, which refers to the various forms of institutionalization of targeted human capture (Rodríguez, 2019).

Anti-Blackness. In their online glossary, The Movement for Black Lives offers the following definition for anti-Blackness:

The Council for Democratizing Education defines anti-Blackness as being a two-part formation that both voids Blackness of value, while systematically marginalizing Black people and their issues. The first form of anti-Blackness is

overt racism. Society also associates un-politically correct comments with the overt nature of anti-Black racism. Beneath this anti-Black racism is the covert structural and systemic racism which categorically predetermines the socioeconomic status of Blacks in this country. The structure is held in place by anti-Black policies, institutions, and ideologies. The second form of anti-Blackness is the unethical disregard for anti-Black institutions and policies. This disregard is the product of class, race, and/or gender privilege certain individuals experience due to anti-Black institutions and policies. This form of anti-Blackness is protected by the first form of overt racism. (Racial Equity Tools, n.d., para. 6).

In this dissertation, I use anti-Blackness to refer primarily to “the covert structural and systemic racism which categorically predetermines the socioeconomic status of Blacks in this country.”

Anti-Black Racism. I use this term to refer to the beliefs, attitudes, prejudice, and/or discrimination against Black people (broadly defined) that categorically predetermine their socioeconomic status. This discrimination is actualized through individual people *and* institutional policies, particularly in institutions relating to health care, education, criminal justice/punishment, and the economy.

Bureaucratic violence. The term *legal violence* refers to the harm enabled by legal policies, particularly for members of specific groups (Abrego & Menjivar, 2011; Menjivar & Abrego, 2012). Dean Spade uses the term *administrative violence* to identify the harm trans people experience as they interface with the multiple institutions and bureaucratic processes that they are forced to navigate in order to accomplish tasks such as adjusting information on their state sanctioned identity documents, accessing health care, registering at shelters and other so-called public services (Spade, 2011).

Bureaucratic violence is used to refer to how, when laws and policies cannot target a specific group or officially intend to cause harm, bureaucracy and convoluted bureaucratic processes can accomplish that harm. Carina Heckert uses this term to refer

to the harm caused by the convoluted process that pregnant immigrants must navigate in order to secure health care that is *technically* available to them but difficult to access because of the bureaucracy (Heckert, 2020). I use the term bureaucratic violence in reference to ways that faulty documentation processes, whether falsified medical charting in a Phoenix nursing home, unethically simple paperwork procedure to change a patient's code status in a Texas hospital, or the inability to effectively convey a doctor's orders in a Chicago Jail, enable harm in ways that seem particularly adept at avoiding accountability. A key aspect of this dissertation involves a distinguishing feature of bureaucratic violence: its seemingly non-violent nature (Norberg, 2021).

Carceral ableism. Abolitionist scholar and activist, Liat Ben-Moshe, describes carceral ableism as, “the praxis and belief that people with disabilities need special or extra protections, in ways that often expand and legitimate their further marginalization and incarceration” which often results in increasing resources for carceral expansion overall (Ben-Moshe, 2020, p. 17).

Disability. Throughout this dissertation, “disability” is used to refer to a category of being, a political identity, and an analytical lens. Some scholars use “dis/ability” to draw attention to the relationship between the ability/disability binary (e.g., Goodley, 2014), and some scholars use “(dis)ability” to visually represent how this relationship is shifting, contentious, and contextual (e.g., Schalk, 2018). In this dissertation, while I do not intend to affirm the binary or ignore the contextual nature of the term, I use “disability” as a broad term and address important differences and distinctions as they come.

Disability Justice. As articulated by the Sins Invalid Collective, a Disability Justice framework recognizes that all bodies are unique and essential, all bodies have strengths and needs, all bodies are confined by inseparable systems of oppression such as ableism, white supremacy, gendered oppression, capitalism, militarized imperialism, and settler colonialism (Sins Invalid, 2019). This framework recognizes how legacies of systemic harm inform each other and contribute to how bodyminds become understood – or not – as having lives that are institutionally recognized as worth living and as, at the very least, *capable* of having a life that is worth living.

Paternalism. The practice of someone (often a person with institutional authority) infringing on the rights, freedoms, and/or autonomy of a person (or groups of people) based on the paternal notion that the person is *incapable* or *less* capable of making a so-called ‘good’ decision for themselves than is the authority figure(s). This infringement is often touted as benevolent or in the alleged best interest of the person but typically replicates larger patterns of power and oppression such as sexism, ableism, and ageism.

Sanism. This term typically refers to prejudice and discrimination against people with mental health care needs, so-called mental “illnesses,” mental disabilities, and/or psychiatric disabilities (see Chamberlin, 1978; Perlin, 1992). I use sanism to refer to the system of assigning value, credibility, and capability to a person (or group of people) based on societally constructed ideas of normalcy, intelligence, fitness, and rationality, which are all rooted in eugenics, anti-Blackness, misogyny, settler colonialism, and capitalism. These values are assigned and legitimized through individual actions and institutional practices, and you do not have to have a mental health care need or a

psychiatric disability to experience sanism. In everyday life and in the legal process, sanism contributes to what people and behaviors are considered deviant, dangerous, emotional, unstable, unfit, and unintelligent (Perlin, 2013).

Settler colonialism. In 1999, Patrick Wolfe wrote that settler colonialism should be seen not as an event but as an ongoing structure because the logic, tenets, and identities produced by settler colonialism persist and continue to shape other social and cultural formations into the present (Wolfe, 1999; 2006). Evelyn Nakano Glenn and J. Kēhaulani Kauanui (Kanaka Maoli) share this analysis and caution against the liberal impulse to work for inclusion rather than liberation (Glenn, 2015; Kauanui, 2016). This study is guided by an ethos of anticolonial, intersectional feminism. I recognize that “Decolonization is not a swappable term for other things we want to do to improve our societies,” it is instead a fundamental challenge to a settler future, to the colonizing assumption that the future existence of the United States is inevitable (Tuck & Yang, 2012, p. 3).

Organization of the Dissertation

This chapter is intended to serve as an introduction to the issues and ideas that are at the heart of this dissertation. The next chapter provides information about the methodologies and methods I engaged with during the research process. Chapters 3, 4, and 5 offer in-depth information about each of the incidents. Each of these three chapters is organized into semi-short sub-sections (to increase accessibility, predictability, and clarity) and begins with a timeline of key events, contextual information about the events, people, and location(s) relevant to each incident. Chapter 6 combines a cross-chapter analysis and concluding comments.

A Note on Sensitive Content

The pages that follow are hard to read; they were hard to write. In chapters 3, 4, and 5, I analyze incidents of rape, killing, incarceration, and institutional violence in three different but extreme spaces of unfreedom. Although I highlight relevant activist efforts and successes in an attempt to remind us that resistance and possibility for change are everywhere and already occurring, this dissertation is – and should be – deeply upsetting to read. Many pages of this dissertation were written with angry tears in my eyes and a deep ache in my heart. Even now, I still cannot read through the abridged timelines at the beginnings of chapters 3, 4, and 5 without a lump forming in my throat. But generations of freedom fighters have insisted on the necessity of specifically naming the sources of harm, and I believe this is a revolutionary – and necessary – practice to keep. A specific analysis of how institutions cause harm, justify the harm they cause, and evade responsibility/accountability for their continued role in enabling that harm allows for an informed and specific approach for transformative justice. What comes in the pages that follow should be deeply activating for us all, some more than others. As you read through chapters 3, 4, and 5 especially, I encourage you to take care of your bodymind in whatever ways you need.

CHAPTER TWO
METHODOLOGIES AND METHODS

Introduction

Feminist researchers hold a commitment to paying attention to the differential effects of power and share a common goal of effecting some sort of change, often relevant to a particular group of people or community. Some of the central tenets of feminist epistemologies and methodologies include 1) recognizing how knowledge is powerful and that although it can have liberatory possibilities, it also has the capacity to oppress (Fonow & Cook, 2005), 2) working to identify everything as being situated within larger socio-politico-economic intersecting structures of power (Duggan, 2003; Fine, 2003; Spade, 2010), and 3) addressing how power affects people differently (based on social and political contexts, geographic location, etc.). Guided by these tenets, this dissertation focuses on three incidents that, when analyzed individually and with/against one another, identify important connections relating to institutional power and cross-institution patterns of harm.

In the spring and summer of 2020, disabled and sick people living in nursing homes, assisted living facilities, rehabilitation centers, and other palliative care facilities in the U.S. were placed under extreme isolation and lockdown protocols for extended periods of time under the guise of safety, infection control, and risk management. These types of facilities (many of which continue to operate with increased restrictions for residents) experienced alarmingly high rates of infection, hospitalization, and death that rivaled their local jail and prison counterparts (Harvard Global Health Institute, 2021; Prison Policy Initiative, 2020). As could be expected, isolation or distancing efforts in

these types of facilities had little effect on curbing the spread, and employees in these facilities continued to introduce and spread the coronavirus in these facilities.

Despite the 1999 SCOTUS decision of *Olmstead v. L.C.*, which bans the unjustified segregation of people with disabilities, many disabled people continue to live in places where they are segregated from their families of origin, social circles, and opportunities for recreation and/or employment. Throughout the pandemic, COVID-19 related infections, hospitalizations, and deaths in the residential/carceral facilities where many disabled people live have been rampant. While I was researching for this dissertation project, I was also researching the COVID-19 safety protocols of two facilities where some of my disabled friends live to better advocate with and for them, and I spent a lot of 2020 trying to support people living in two Western Illinois facilities - one a rehabilitation center and the other an assisted living facility. These friends were scared of what would happen to them inside their living facilities *and* what would happen to them if they had to be transferred to a hospital. This compelled me to include what happened to Michael Hickson in this research; this is the focus of Chapter 4.

This dissertation project has occurred entirely within, alongside, and, in many ways, because of the COVID-19 global pandemic. While I was designing this research project in the spring of 2020, rates of new COVID-19 infections and deaths were higher in the Navajo Nation and the White Mountain Apache Tribe than anywhere in the U.S. (Curtis, 2020; Silverman et al., 2020). As a settler scholar, I had been hesitant to include the incident at Hacienda HealthCare in my research but witnessing the U.S. government's genocidal neglect of tribal nations during this pandemic compelled me to use this dissertation as a platform to amplify the violence of settler colonialism and affirm a

commitment to justice against the U.S. settler state into this work; this is the focus of Chapter 3.

I had originally intended to select three situations occurring in what might be traditionally considered to be “medical” facilities (e.g., hospitals and rehabilitation centers), but the surge of racial justice uprisings in the US motivated me to select a situation occurring in a traditional, “carceral” facility (e.g., jails and prisons). During the summer and Fall of 2020 Black activists in the U.S. were protesting police killing Black civilians and introducing numerous people to ideas about what transformative justice might be in cases of physical harm. During that same time, as I prepared to defend the proposal for this study, I was researching COVID-19 infection rates at an Illinois prison where my longtime Black & Pink pen pal and friend (<https://www.blackandpink.org/>) was being held. This confluence of thinking about the physical and psychological harm enabled and carried out by/in carceral facilities prompted me to include an analysis of how these facilities pose specific kinds of harm onto disabled people in their custody. Although the overwhelming majority of people in the Cook County Jail are Black and Latino, what happened to Michael Joseph Borys – and the unusually high settlement that followed – exemplifies the Jail’s inability to prevent harm to those caged inside, even to white people; this is the focus of Chapter 5.

Case studies – used as methodology, method, or both – can produce detailed qualitative accounts that describe a real-life environment and explain the complexities of these real-life situations in ways that might not be as easily captured through experimental or survey research (Zainal, 2007). Qualitative case studies can afford researchers opportunities to explore or describe a phenomenon in context using a variety

of data sources (Baxter & Jack, 2008). Yin (2003) explains that a case study design is most useful when the focus of the study is to answer “how” and “why” questions, the researcher seeks to incorporate contextual conditions believed to be relevant, and/or the boundaries between the phenomenon being studied and the context(s) are unclear. As identified in the title, the question that guides this research is “How does this happen?” and focuses on the broader sociopolitical contexts that allow these incidents to occur with little to no culpability or accountability, especially in places that have been under scrutiny for allowing similar incidents to occur in the past.

During a lecture given at The University of Chicago, Angela Y. Davis explained, Feminist methodologies impel us to explore connections that are not always apparent. And they drive us to inhabit contradictions and discover what is productive in those contradictions. Feminism insists on methods of thought and action that urge us to think things together that appear to be separate, and to de-segregate things that appear to naturally belong together (Davis, 2013).

Given my interest in the indivisibility of carceral logics, spaces of capture, and ableism (Ben-Moshe, Chapman, and Carey, 2014), my focus in this dissertation is both the real-life contexts of the individual incidents *and* the systemic, cross-institutional patterns evident in all three exemplars. Thus, my approach to and analysis of the three exemplars, although not bounded by the tight parameters of a traditional “case study,” most closely resemble a blend between two types of case studies: descriptive and multi-case.

Descriptive case studies enable the researcher to [better] describe a phenomenon and the real-life context in which it occurred, and multiple-case studies enable the researcher to explore and compare connections and contradictions between cases (Yin, 2003).

Methodology is the theory(s) driven framework for how a project should proceed (e.g., what ethical/procedural considerations should be made, what methods might be useful, what data analysis strategies will be most useful/applicable). Method is the technique for gathering evidence in that research project (e.g., survey, archive, participatory, interview, oral history, observation). The next section will explain bricolage research. Then, I discuss the methodologies that guide this project, followed by four sections that detail the procedural methods used for each exemplar. This chapter ends with a discussion of ethical considerations and reflexivity.

Bricolage

I am inspired by Julie Kaomea, a Native Hawaiian scholar and educator, and her use of what she names *methodological eclecticism*. In a 2013 article, Kaomea discusses how her research in and with Native Hawaiian communities reflects a “trench coat” approach rather than the more traditional, scientific “lab coat” approach. She explains that in her research on the settler curriculum being taught in Hawaiian schools, she acted as a detective whose job was to survey the scene of the crime, ask questions, and interpret clues in order to reconstruct the missing narrative of what *really* happened. Kaomea explains, “Rather than specializing in a single investigative method, private detectives are methodological bricoleurs (Berry, 2006) who utilize methods ranging from suspect interrogation and document analysis to analytical chemistry, footprint examination, and decoding ciphers” (2013, p. 614).

The three incidents that are the focus on in this study are similar in some important ways and unique in other, important ways. They each have different types and amounts of materials available to analyze and different contexts to account for. Bricolage

research is a critical, multi-perspectival, multi-theoretical, multi-methodological approach to inquiry (Denzin & Lincoln, 1999; Kincheloe, 2001; Berry, 2006; Rogers, 2012). As a “clever assemblage of interpretive tools and empirical materials that together provide us with new perspectives on old and enduring social, political, and educational challenges” (Kaomea, 2016, p. 102), bricolage enables researchers to use the ideas and tools that are a) most relevant and/or b) more available. In this study, I utilize a variety of ideas and tools in order to address the specificity of each incident while also attending to the larger patterns and connection that connect them all together. I ask detective-like questions such as “How does this happen?” and follow Kaomea’s strategy of using a pragmatic variety of methods to analyze evidence on the three incidents. Abolition feminism, critical disability studies, and intersectionality are the three perspectives that guide this research, and, when used together, they inform my analysis.

My assemblage of interpretive tools included different kinds of qualitative analysis. I draw from critical content, discursive, archival, popular media, and feminist legal analysis of primary and secondary sources that represent a variety of perspectives such as court documents, press releases, news reports, and meeting transcripts. Although much of this research process has been done in physical isolation, I have been able to talk through my findings and analysis with friends, peers, and students. Using three methodological and theoretical lenses, I have followed my deep, critical reads of relevant archival data by writing drafts and having conversations with faculty, individual graduate students, and a group of graduate students who regularly convene to solicit/provide writing support. My chair, Dr. Beth Blue Swadener, and I engaged in deep, frequent dialogue, and created a rhythm of drafting chapters, revising chapters, and discussing

those revisions. Additionally, my classmate and friend, Danielle Lucero (Isleta Pueblo) provided me with invaluable feedback on Chapter 3. Personal, political, and intellectual commitments to Disability Justice and decolonization have informed how I assembled, analyzed, and wrote each chapter.

Methodologies

Power practices *through* knowledge (Foucault, 1990), and scientific and medical so-called expertise invisibilize this power and how institutions shape the ways people live and die (Hubbard, 1988; Spade, 2010). I use a complementary combination of three methodological approaches and four methods not to ‘create new knowledge’ but rather to illustrate what critical perspectives can move into the spotlight when specific historical and political contexts are foregrounded. Feminist research can be distinguished by its commitment to producing knowledges that disrupt hegemonic practices and resist gender injustices (Jaggar, 2008), and Native and Indigenous feminists have articulated that feminist methodologies need to directly account for – and challenge – settler colonialism and the pervasive logics of genocide that undergird Western thought practices (Arvin, Tuck, & Morill, 2013). Intersectionality, critical disability studies, and abolition feminism form the theoretical and methodological bricolage on which this study is based.

Intersectionality

As a methodology, intersectionality is “a way of understanding and analyzing the complexity in the world” (Collins & Bilge, 2016, p. 2), one that helps me think about how systems of power work within and beyond identity claims *and* the material effects these systems of power have (Schalk, 2018). An intersectional approach holds me accountable to what Native feminist theorists have pressed settler researchers to do:

question academic participation in Indigenous dispossession (Arvin, Tuck, & Morrill, 2013). Intersectionality is especially important for this study because it foregrounds an analysis of how systems of power inform each other in ways that contribute how people experience institutional and interpersonal harm.

Critical Disability Studies

Julie Avril Minich explains that a critical disability studies methodology “emphasizes its mode of analysis rather than its objects of study” (2016, para. 5). In this study, I engage multiple objects of study in order to offer a comprehensive analysis of what leads to (or allows for) the harm that disabled people in carceral locales routinely experience *and* how these circumstances often remain largely unaffected and unchanged, regardless of the outcome of bad publicity and settlements/lawsuits. “It must be a methodology that proceeds to radically disrupt the multiple sociopolitical ideologies that assign more value to some bodies and minds than to others” (Minich, 2016, para. 11). Critical disability studies as a methodology guides the analysis to focus on the sickening, disabling, and debilitating circumstances, on the anti-disability values held by individuals and upheld in institutions, and the differential treatment the ability/disability binary enables. It embraces a goal of “producing knowledge in support of justice for people with stigmatized bodies and minds” (Minich, 2016, para. 6) and enables a more capacious recognition of bodyminds that are devalued and pathologized and the structures that cause this dehumanization and stigmatization to occur.

Abolition Feminism

Ruth Wilson Gilmore describes abolition as a theory of social change (Petitjean, 2018) and Dylan Rodríguez explains that abolitionist praxis “addresses carcerality as a

logic of power that generates multiple, overlapping, and differently scaled carceral regimes” (Rodríguez, 2019, p. 1612). As a methodology, abolition feminism pushes researchers to embrace complexity, undermine the carceral state, and build new sources for safety, repair, and accountability (Davis, Dent, Meiners, & Richie, 2022). Abolition feminism positions the state (in this case, its many institutions and everyday practices) as a source of harm, as the premier barrier to safety, wellness, and justice, especially for people who experience the compounding effects of systemic oppression. Using abolition feminism as a methodology enables me to consider the complexities of the three exemplars in this dissertation and imagine different imaginations of safety and accountability that do not enhance the carceral state or the legitimacy of any of its related ideologies and institutions.

Methods

A hallmark of case study research is the use of multiple data sources (Yin, 2003) and a pillar of bricolage research is the employment of a multi-method approach (Rogers, 2012). Typically, a case study approach is used to understand one phenomenon and the complex, multi-dimensional contexts of that phenomenon. Using a modified case study approach to better understand connections between three separate incidents, I used feminist content analysis, discursive analysis, and narrative analysis of primary and secondary documents. This multi-method approach allowed me to select a method that is fitting for the data source in order to get basic information about each incident, learn different perspectives about each incident from key stakeholders related to each situation, assess how disability, gender, and carceral logics are being mobilized, and identify opportunities for abolitionist interjections.

Critical Thematic Analysis (CTA) is a qualitative research method used to examine the interrelationships between qualitative data, social practices, ideologies, and power relations (Lawless & Chen, 2019). CTA is a particularly useful qualitative research method because it enables researchers to analyze qualitative data and everyday discourses from critical standpoints and works toward social justice goals. In total, I analyzed 204 pages of material. My analysis involved reading transcripts, court documents, and news reports several times to promote familiarity, and my descriptive coding and memo-writing was inductive, semi-collaborative, and occurred simultaneously with data collection.

As a graduate student and new parent who is geographically bound, financially constrained, and trying to safely and responsibly navigate the COVID-19 global pandemic, convenience and purposive selection were used to select the three situations I focus on in this dissertation. I purposefully selected three situations that I believe exemplify how different kinds of institutions pose similar, specific, and direct threats to the disabled people in their custody. The circumstances surrounding each of these incidents are ripe for a critical analysis of the specific kinds of harm each institution enables *and* the mechanisms through which these institutions evade responsibility and accountability for those harms. I used a variety of ideas and tools in order to address the nuances of each incident and also identify broader patterns that connect all three. All of these situations occurred in the U.S. between 2014-2021.

My process of analysis occurred in four stages. First, I reviewed the materials related to each incident to familiarize myself with events in order to build the case for the reader, organizing important information into a chronological order. Second, I worked to

identify the identities, titles, and relationships between key parties and discern relevant contextual factors. Third, using a bricolage approach, I did three passes of analysis for each incident, each pass analyzing the information from a different perspective: feminist and critical legal perspective, decolonial/anti-racist perspective, and a Disability Justice perspective. The process of having three phases of analysis was especially useful because it ensured that each situation was analyzed from all three critical perspectives, even when those perspectives might not seem as applicable for a given incident. For example, a decolonial/anti-racist lens was used to consider what happened to a Native woman in Phoenix *and* what happened to a white man in Chicago. Fourth, I compared findings from these phases across all three incidents to illuminate key distinctions of each incident as well as patterns of power relations. Some of these patterns include civil rights violations, breaches in institutional and interpersonal duty of care obligations, dynamics of power and control reminiscent of settler colonial and anti-Black racism, and medical authority being used to justify disposability.

Exemplar 1

To understand what happened to a San Carlos Apache disabled woman at a residential skilled care nursing facility in Arizona, I reviewed and analyzed a variety of documents: 1) minutes from Arizona Medical Board meetings as well as transcriptions of those meetings, 2) public statements given by leaders in the San Carlos Apache Nation and disability-focused groups such as the Arizona Center for Disability Law and The Arc, 3) court documents from Nathan Sutherland's case, 4) local and national news reports—including tribal news outlets, and 5) documents related to the legal and extralegal proceedings that followed the incident. Together, these documents total 68 pages.

Exemplar 2

To understand what happened to Michael Hickson in a Texas hospital, I reviewed a variety of documents pertaining to the incident: 1) legal and extralegal proceedings, 2) news reports that covered Hickson's death in real-time as well as a few longform journalism pieces that provided multiple perspectives and reflections from key stakeholders, 3) press releases from the hospital, Family Eldercare, Inc., and numerous disability-focused organizations, 4) the legislation put forth by Texas Representative Smithee (R-Amarillo), and 5) transcriptions of the recorded conversation between Melissa Hickson and Dr. Vo. Together, these documents total 98 pages. I researched and familiarized myself with other examples of medical ethical violations pertaining to end-of-life decisions where guardianship has been appointed to a paid third party, and I compared the legislation put forth by Representative Smithee (R-Amarillo) with other legislation regarding guardianship responsibilities and end-of-life decisions. Unfortunately, since the Texas Medical Board did not investigate or deliberate on the providers who took active measures to withhold treatment from Michael Hickson with the goal of ending his life, there was no opportunity for me to analyze how the Board assessed different aspects of what happened.

Exemplar 3

To understand what happened to Michael Joseph Borys while he was incarcerated at the Cook County Jail in Illinois and how incidents like this happen time and time again, I reviewed 1) the complaint filed on his behalf, 2) public statements made by disability and prisoner advocacy organizations, 3) recent lawsuits about the duty of care responsibilities that jails and prisons have to people in their custody (specifically,

disabled people in their custody), 4) local news reports that covered his story after the settlement amount was released, and 5) key court decisions that provide context for Borys' high settlement amount. Together, these documents total 38 pages. Unlike with the first two incidents, the violence Borys experienced was not caused, enabled, or encouraged by medical providers. There are very few news articles or press releases from when the incident occurred, and the news reports related to this incident primarily focus on the high amount of his settlement and the numerous civil rights settlements the County approves on a regular basis. Simply put, there are fewer available primary and secondary sources for me to analyze for this exemplar than there are for the other two. Whereas the incident at Hacienda HealthCare garnered national and international press (i.e., more available news reports) and involved multiple state medical board decisions, Borys' situation did not.

Ethical Considerations

Aside from Michael Hickson and Phillip Gear Jr., every person named in this dissertation – from the disabled people who were harmed by the institutions to the doctors, prison guards, and judges involved in their cases – is alive as far as I know. The San Carlos Apache's woman's name has not been publicly released, so I honor that decision by referring to her using other descriptors (i.e., San Carlos Apache disabled woman). Although everything that might be considered personal information about these people is easily accessible in publicly published court reports, news articles, press releases, public records, and other online sources, I recognize that I am a stranger to the people named in this dissertation, and if they were to read their own names or the details pertaining to these difficult incidents might be jarring. For this dissertation, I did not

reach out to the people and/or families of the San Carlos Apache woman, Michael Hickson, and/or Michael Joseph Borys. In the future, as I work to edit this dissertation into a book manuscript, I plan to reach out to these families and explain my intentions of publishing my analysis of what happened to them and their loved ones, provide drafts for them to read, discuss their comfortability, and hopefully, come to a mutual agreement about how to best respect their loved one's experience in the book (which might very well end up being to not include it at all).

Another ethical consideration regards how I should refer to the three focal individuals. Throughout the writing process, I have returned to the question: "How might this phrasing/framing come across to this person or someone who has been personally affected by this incident?" News articles, press releases, court documents, and anecdotal comments made by implicated parties (doctors, hospital administrators, sheriffs, etc.) offer conflicting descriptions of these people. Whether using a harmful and dehumanizing description such as "vegetative state" or referring to Michael Hickson simply as a "quadriplegic man" (as opposed to using person-first language: man living with quadriplegia), these phrases presuppose a value judgment regarding how these people exist/ed in the world and focus on specific medical diagnoses. For Michael Joseph Borys, instead of guessing or presuming his relationship to the category of "disability," I refer to him simply as a man who experienced seizures and a man who now lives with a variety of long-term injuries and care needs.

Some sources describe the San Carlos Apache woman as unable to communicate, but her tribe, family, and attorneys say she *could* communicate. Similarly, doctors at St. David's South Austin Medical Center described Michael Hickson as unable to

communicate in the days leading up to his untimely death, but his wife and family insist that he *could* communicate. In the US, the settler colonial and anti-Black efforts to render Native, Indigenous, and Black people incapable, unfit, and unworthy is part of a larger project of silencing, removal, and elimination. As an abled white settler, whose communication style is socially and institutionally recognized (e.g., English, verbal speech, easily pick up on social cues and facial expressions), I make the intentional, political decision in this dissertation to refrain from imposing subjective, potentially harmful descriptors.

Disability is a complex, dynamic, personal, and political identity category. While some feel a positive connection to the term disability and to their own bodymind more generally, others, especially those who have acquired their disabilities slowly, later in life, or as an injury, a result of state violence or other forms of debilitation, might not feel that positive connection as easily. Although there are times when I choose to include personal/medical information about people related to these incidents that I consider to be pertinent to understanding the situation, I avoid prescribing medical, cultural, or political identities to the people whose experiences form the core of each exemplar.

Finally, the ethical consideration I have struggled with the most: [how] can I, a white, abled, settler scholar who is not and has not been incarcerated/institutionalized do justice to and make recommendations on these issues? A key dynamic/intention of feminist research is that it should have an action orientation and try to change political policy (Fonow & Cook), but my research process has not been participatory or included the experiential knowledge of people who are or have been in similar situations to these three incidents. As a result, I feel a great sense of hesitancy to suggest actions/changes

without having engaged a wide variety of perspectives from people who are the most negatively affected by ableism, anti-Blackness, institutionalization, settler colonialism, paternalism, etc. The phrase/ethos popularized by disability activists “Nothing About Us Without Us” is instructive for policymaking practices as well as how I proceed in the research process. I have relied on a combination of critical methodologies and Sins Invalid’s 10 Principles of Disability Justice (Sins Invalid, 2019) to guide me so that I – to the best of my ability at this time – follow the leadership of the most impacted for all recommendations I make.

Reflexivity

All research has political implications, and as a feminist settler researcher, I work to recognize these implications and be forthcoming about my agenda (Fonow & Cook, 2005; Hawkesworth, 2006). I welcome Corbett Joan O’Toole’s (2013) invitation to disclose and be transparent about my relationship(s) to disability, which are personal, familial, social, professional, and political. While much of how I understand ableism, sanism, and the Medical Industrial Complex has come from learning from disabled activists and years of academic training in Feminist Disability Studies, I would be remiss if I did not address – however vaguely – how formative the personal relationships I have with people who are disabled, sick, and mad have been for me. As will become [more] clear in the pages that follow, ableism plays a leading role in the extent to which medical professionals, for example, consider a person’s life to be livable or, worth living/saving. Some of the most impactful and instructive relationships I have to “disability,” as it were, involve people who do not publicly disclose their relationships to disability, diagnosis,

and/or care needs precisely because of their fear(s) of how ableism and paternalism might affect them more/differently if they publicly disclose.

It is important to name that I do not live with “the traits we think of as disability” (Garland-Thompson, 2005, p. 1558), and although I find it compelling (and in many cases, useful) to trouble the binaries often associated with disability and sanity, this is not the place for that. While not intending to reify these harmful binaries, it is important to acknowledge that at this moment and for my entire life so far, I have been and continue to be an abled and saned white ciswoman. These intersecting relations of power that position me as at least somewhat *capable* and *deserving* of a life that is considered livable and worth living are directly related to – and in many cases, directly contribute to – the ways that other people are positioned as *incapable* and *undeserving* of a life that is considered livable and worth living. I am hesitant when I interact with a medical professional, but I am not scared for my life, as many people are. I grew up with health insurance and although I have lived without health insurance during parts of my adult life, I have always had the cultural capital necessary to successfully navigate complex medical[ized] systems as I have needed. My inquiry and analysis embrace a crip politic and foreground an intersectional feminist disability approach because incarceration and/or the looming threat of being made to live in a place where one experiences harm disproportionately affects people who do not benefit from the combined gender, racial, colonial, class, ability, and sanity privileges that I do.

Alcoff and Potter (1993) explain that one of the central tenets of dominant Western epistemologies is to aim for objective, detached knowledge, and create what Sandra Harding identifies as a “dispassionate researcher,” one who engages in research

that is seemingly politically “neutral” (Hawkesworth, 2006). A feminist revision to this is to specifically name the dimensions of my life that make me a passionate researcher who is not neutral to the issues discussed in this dissertation. As Michelle Fine argues, “As researchers, we need to position ourselves as no longer transparent, but as classed, gendered, raced, and sexual subjects who construct our own locations, narrate these locations, narrate these locations, and negotiate our stances with relations of domination” (Fine, 2003, p. 142). While I have not been incarcerated or institutionalized, I am in deep, lifelong relations with people who are and/or have been.

For sixteen years, I have been involved with a variety of not-for-profit organizations – some that buy into and further a charity/pity model and some that embrace a more transformative, community-building model. I have many friends who live with disabilities, illnesses, and care needs that affect where they live: some live in residential facilities (e.g., group homes, nursing homes, “care” facilities, rehab centers) where they are subjected to surveillance, restriction, dehumanization, and other kinds of violence and some live with family members who restrict their physical, political, social, and financial autonomy. These friendships and my sense of accountability to these friends compel/enable me to take a careful, nuanced, and informed approach to this research.

I recognize that my lived experiences and close friendships give me a distinct relationship to this research. My personal and political commitment to changing the popular and institutional narratives that enable the harm of disabled people in carceral spaces affects everything I do, and this research project is no exception. The four disabled women named in the dedication section each were put into situations where they

experienced harm that was not inevitable but instead the direct outcome of deep, sustained, permissible, and even, intentional institutional violence. In the research, analysis, and writing stages, I have used intersectionality as a methodology to help me think critically about my connections and engage in a structural analysis of my own relationship(s) and investment(s) to power.

Finally, this entire research process has occurred within, alongside, and because of the deadly and ongoing COVID-19 global pandemic. The incidents I focus on in Chapters 3 and 5 occurred in 2014 and 2018-19, but the focus of Chapter 4 is on an incident that occurred during the early months of the pandemic, which as of the time of this writing, is still ongoing. I try to offer statistical information about the pandemic and its preliminary effects on different populations, but I find it difficult to reflect on my own experience in a pandemic that is still very much ongoing. I take seriously a collective responsibility to mitigate the spread of this virus, and I support policy initiatives suggested by activist organizations – especially those that are Black, Indigenous, disabled, and/or queer-led – that direct resources to people who various social structures have made more vulnerable to infection and/or general hardship related to the pandemic. At the time of this writing, I do not fully know how this pandemic has affected me or will affect me, and therefore, it is difficult for me to offer critical reflections about how my interests and values related to the pandemic have affected this research.

As I work to challenge settler colonialism and anti-Blackness, in myself, my social circle, and my research, and commit myself to the 10 Principles of Disability Justice (Sins Invalid, 2019), I continually revisit my institutional and personal relationships to settler colonialism, racism, and ableism. This feminist act of repetition

compels me to find new or different ways to challenge the deep seeded and shameful investments I have been strategically socialized to have. By following the leadership of the most impacted and embracing critical frameworks, I hope to mitigate the harm my research does and cultivate a transparent agenda that is guided by and aligned with visions of justice put forth by peoples who have experiential and embodied knowledge that I lack and may learn from.

CHAPTER THREE

SETTLER COLONIALISM IN THE MEDICAL INDUSTRIAL COMPLEX

An Abridged Timeline

- **December 2018:** A San Carlos Apache woman who was a longtime resident/patient at a Hacienda Healthcare facility gives birth. The staff at this skilled nursing facility in Phoenix, Arizona denies any knowledge of her pregnancy or the rape that led to it. This full-term birth indicates at least one incident of rape occurring earlier in the year, sometime between March and April.
- **January 2019:** Following a positive DNA match to the newborn baby, Nathan Sutherland (a Licensed Practical Nurse at Hacienda Healthcare) is arrested and charged with one count of sexual assault and one count of vulnerable adult abuse. Sutherland voluntarily surrenders his nursing license the day before being arrested. The Arizona Health Care Cost Containment System temporarily suspends Dr. Thanh Nguyen, the woman's most recent primary care provider.
- **February 2019:** Nathan Sutherland pleads not guilty on both counts.
- **May 2019:** The Arizona Board of Nursing votes unanimously to dismiss complaints against three nurses who had been working at Hacienda: Valerie Brehm (Director of Nursing), Kathryn Del Real (Chief Operating Officer for Clinical Services), and McKenzie Gillies (Director of Patient Services).
- **June 2019:** The San Carlos Apache woman's family files a \$45 million notice of claim against State of Arizona, showing 83 missed opportunities for the woman's primary care providers, Drs. Phillip Gear Jr. and Thanh Nguyen, to diagnose her pregnancy.

- **October 2019:** After a 5-4 vote, the Arizona Medical Board dismisses the complaint of possible wrongdoing against Dr. Thanh Nguyen, who had been providing care for the woman starting in September of 2018. The Chair of the AZ Medical Board, Dr. R. Screven Farmer, MD, concludes the Board's discussion by saying, "I would also emphasize for the record that there are concerns that you know this was a 5-4 vote so there is certainly some level of concern and I think the physician will probably take note of that and conduct himself hopefully in the future accordingly." Per the Board's vote, no advisory letter is issued.
- **November 2019:** Dr. Phillip Gear Jr., who had treated the woman from 1992 (when she was three years old) until September 2018, voluntarily surrenders his medical license to the AMB and retires following a consent order to surrender his license and not contest the matter in court.
- **Summer 2020:** The State of Arizona settles for \$7.5 million.
- **December 2020:** Phillip Gear Jr. dies.
- **June 2021:** Judge approves \$15million settlement against Phillip Gear Jr. in a lawsuit by the woman's parents.
- **September 2021:** Nathan Sutherland pleads guilty to both charges, facing up to 10 years in prison and a lifetime of probation.
- **December 2021:** Judge Margaret LaBianca sentences Nathan Sutherland to 10 years in prison, after which he must register as a sex offender and be on probation until he dies. Sutherland remains the only Hacienda HealthCare employee to be held responsible for any wrongdoing related to this situation.

A timeline of all the relevant information that pertains to this case is difficult for me to create because the rape of a Native disabled woman living in a private, state-funded medical facility has many dimensions to consider and a variety of places to begin. For example, it could begin as it appears above: when the woman gave birth. But, since the criminal charges are for sexual assault and abuse of a vulnerable adult, the timeline might also begin in March 2018, when at least one instance of this assault and abuse took place, resulting in the pregnancy. To add to the dimension of criminal charges, the timeline could include information about the fraud scheme charges the former CEO of Hacienda HealthCare pleaded guilty to in June 2021, after a mass exodus of Hacienda administrators beginning in early 2019.

The timeline might also begin in 2002 when reports were made to the Phoenix Police Department alleging sexual assault happening at Hacienda HealthCare, after which the woman's mother repeatedly negotiated with Hacienda to have her daughter treated only by female employees. It could begin in 2001 with the Letter of Reprimand the Board of Medical Examiners in the State of Arizona issued Dr. Phillip Gear Jr. for "gross negligence, repeated negligence, repeated negligence or negligence in harm or death of a patient."

All of this points to a historical reckoning such that in order to show the context of why a San Carlos Apache woman was receiving medical care at a private facility in Phoenix, Arizona, the timeline would need to include the Indian Health Care Improvement Act of 1976 and the creation of The Indian Health Service in 1955. This timeline could also date back to the 1927 SCOTUS decision of *Buck v Bell*, wherein the Constitutional rights of institutionalized disabled women and their reproductive

autonomy was decided (*Buck v. Bell*, 1927). It could also begin with the Snyder Act of 1921 because of its legislative importance for healthcare, education, and civic participation for Native people.

My point is, this timeline could go back to the late 1400s, when European imperialism and settler colonialism began, and each preceding event included on the timeline would contribute to a more comprehensive context for what happened in 2018 and the absence of accountability that has followed. The totality of how settler colonialism enabled this could never be fully captured by events I include on a timeline. For this chapter, the abridged timeline above will serve as a basic guide for key events occurring between 2018 and 2021. I will provide information about other events as needed.

Process

Judith Levine and Erica Meiners define abolition feminism as “a melding of anti-racist prison abolitionism – which is part of the Black radical tradition – and feminism. It grows out of the recognition of the shared ideologies that undergird state violence and interpersonal gender violence and the official and cultural conflation of vengeance with justice.” (Levine and Meiners, 2020, p. 183). I have considered many questions about what happened at Hacienda. Some questions have been as straight-forward as “What procedural errors allowed for the assault, pregnancy, and labor go allegedly unnoticed by all staff members, including and especially her primary care providers?” Whereas other questions explore the abolitionist and feminist possibilities that Ruth Wilson Gilmore pursues in response to Vladimir Lenin’s question: “What is to be done?” (Gilmore,

2011). I combine intersectionality and abolition feminism to create the conceptual framework I rely on to address these two questions.

In order to consider the different possible realms for accountability and punishment (individual and institutional, criminal, civil, and regulatory), I reviewed a variety of archival policy materials including Arizona Medical Board meetings, statements from leaders in the San Carlos Apache Nation and disability-focused groups such as the Arizona Center for Disability Law and The Arc, as well as court documents from Nathan Sutherland's case. In addition, I reviewed news reports from local and national news media outlets – including tribal news outlets. I analyzed the decisions made by the AMB to learn about what factors were important to these two regulatory bodies as they made their decisions on what should be done. I also considered how gender, disability, Indigeneity, violence, and accountability are presented in various news reports about the numerous lawsuits, complaints, and audits that Hacienda Healthcare has been at the center of over the last few decades.

As I demonstrate in this chapter, settler colonialism, specifically in the form of the U.S. government's paternal and genocidal disinvestment in Indian Health Service facilities, creates the conditions for a San Carlos Apache disabled woman to be housed in a notoriously negligent institution in Phoenix, Arizona where she experienced sexual abuse and medical neglect. The Arizona Medical Board's lack of members who are Native and/or disabled, not to mention members of the San Carlos Apache Nation who are living in facilities similar to Hacienda HealthCare, directly contributes to the negligent decision-making practices and deeply biased perspectives of the Board. I argue that the paternal dynamics of medical[ized] facilities such as Hacienda HealthCare and

the deeply entrenched ableist and eugenic values held by medical professionals contributed to the sweeping lack of accountability for what happened to the woman who gave birth in December 2018.

Central to my analysis is decolonization, which is as much about returning land, affirming tribal sovereignty, and upholding treaty rights as it is about ending the harms that colonization brought, especially capitalism, ableism, and patriarchy (Deerinwater, 2021; Tuck & Yang, 2012). Sovereignty is a form a gender justice (Aikau, et. al, 2015; Deer, 2015; Kauanui, 2008). A focus of this chapter is to demonstrate how capitalism, ableism, and patriarchy contribute to the settler colonial goals of harm and dispossession. As Scott L. Morgensen (2011) explains,

We are all caught up in one another, we who live in settler societies, and our interrelationships inform all that these societies touch. Native people live in relation to all non-Natives in the context of the power relations of settler colonialism, though they never lose inherent claims to sovereignty as Indigenous peoples. (p. 1).

The medical-industrial complex is one venue where these interrelationships remain largely unchallenged and settler colonial power relations remain largely unchanged.

Health Justice Commons describes the medical-industrial complex as being comprised of entangled institutions that are complicit with, give rise to, and profit from people being sick and disabled (Health Justice Commons, 2021). The harm enabled and allowed in one institution (e.g., Hacienda Healthcare) affects the harms enabled and allowed in other, entangled institutions (e.g., the Arizona Medical Board). Guided by the demand for settler scholars like me to question and challenge [our] academic participation in Indigenous dispossession (Arvin, Tuck, & Morrill, 2013), this dissertation

rejects the inevitability of U.S. occupation and searches for accountability possibilities that do not legitimize or expand settler colonial violence.

Hacienda HealthCare, Inc

Created in 1967 with the original name of Hacienda de los Angeles, Hacienda HealthCare, Inc. offers a variety of social and healthcare services to children and adults in Arizona living with chronic illnesses, complex medical needs, and intellectual and developmental disabilities (<https://www.haciendainc.org/about-us/our-mission-and-vision/>). One of the ways they offer these services is through a skilled nursing facility located on occupied Akimel O’odham (Pima) and Pee Posh (Maricopa) land, otherwise known as Phoenix, Arizona. When someone living at the facility gave birth in December 2018, spurring a series of investigations into Hacienda Healthcare, it was revealed to the public that because the State of Arizona had not required intermediate care facilities to be licensed with the Arizona Department of Health Services since 1997, this facility had been operating without oversight for decades and has had numerous allegations of neglect and abuse during this time.

As I will argue in this chapter, settler colonialism, specifically in the form of the U.S. government’s paternalism and genocidal disinvestment in the Indian Health Service, creates the conditions for a San Carlos Apache disabled woman to be living in a notoriously negligent institution in Phoenix, Arizona where she experienced sexual abuse and medical neglect. Colonial understandings of who deserves care, paternal dynamics of medical[ized] facilities such as Hacienda HealthCare, and ableist values held by medical professionals all contributed to the sweeping lack of accountability for what happened to the woman who gave birth in December 2018.

The Arizona Medical Board

Established in 1913 by the Arizona State Legislature, and originally named the Board of Medical Examiners, the Arizona Medical Board (AMB) has three central responsibilities: examining and licensing all allopathic physicians in the state of Arizona, renewing medical licenses, and protecting the public (Arizona Medical Board, n.d.). The AMB is comprised of 8 physician members and 4 public members (one of whom must be an experienced and credentialed nurse). All members are appointed by the Governor. The AMB is a member of the Federation of State Medical Boards and, similar to other state medical regulation boards, is mandated to “protect the public’s health, safety and welfare through the proper licensing, disciplining, and regulation of physicians” (Federation of State Medical Boards, n.d.).

The COVID-19 global pandemic has shifted how the Board has been conducting meetings, but they traditionally hold their regular meetings every other month. During these meetings, the Board discusses cases that have been brought to their attention and decides, for example, if a physician’s licensure should be continued, suspended, or revoked. Importantly for this chapter, the Board spent less than fourteen minutes discussing whether or not Dr. Thanh Nguyen should face disciplinary action for the so-called ‘surprise’ birth of his patient at the Hacienda HealthCare facility in December of 2018.

Some Information about the San Carlos Apache Disabled Woman

The focus of this chapter is not on the personal details of the woman who experienced rape and medical negligence. Terms such as sexual assault, sexual abuse, and rape are often used interchangeably. In this chapter, I will use rape whenever possible

because, as Sarah Deer (Mvskoke) suggests, it reframes what happened as a political issue (MPR News, 2015). While many news reports attempt to describe her intellectual level and capacity for communication, my focus is on the events surrounding the incidents of abuse and negligence and who has – and has not – been held accountable. Questions about her intellectual capacity and how alert, aware, and communicative she might or might not have been while living in the facility are rife with ableism, sanism, and settler colonial misogyny. While multiple news outlets covering this situation have described this woman in a variety of dehumanizing ways, my analysis remains centered on how the abuse and negligence she experienced has been [mis]handled.

The San Carlos Apache Nation

The U.S. federal government officially recognizes 574 tribes, and 22 of those tribes are located within the colonial boundaries of what is currently known as the State of Arizona. The San Carlos Apache Nation is one of these federally recognized tribes and was established by executive order in 1871 to contain the Chiricahua Apache people and surrounding Yavapai and other Apache bands that had removed from their original homelands by order of the U.S. government. Over 15,000 live on the San Carlos Apache Indian Reservation, which spans more than 1.8 million acres and is located about 130 miles east of Phoenix. Settler colonial decisions that have contributed to the climate crisis (rising temperatures, wildfires, water scarcity) pose significant threat to people living on or near the San Carlos Apache Indian Reservation.

On this reservation lies a sacred site called Chich'il Bildagotee by the Apache People and Oak Flat by local settlers, a site whose significance has been recognized by the U.S. government and is listed on the National Register of Historic Places. In 2014,

Congress authorized Oak Flat to be transferred to the private control of Resolution Copper, a large, foreign-owned mining company (<https://www.saveoakflatws.com/>). The mining process that Resolution has proposed will mine copper from 7,000 feet below Chich'il Bildagotee / Oak Flat and create an estimated 1.6 billion tons of toxic material (i.e., acid-generating toxic tailings) to be piled in a nearby area. Since then, Apache people and their supporters have resisted the construction of this mine and garnered so much support that there are currently two bills in Congress that would repeal the transfer: H. 665 and S 173. The woman whose experiences are at the center of this chapter is an enrolled member of the San Carlos Apache Nation.

Figure 2

Comprehensive Map of Arizona Indian Reservations



NATIVE PEOPLES OF ARIZONA
COMPREHENSIVE MAP OF ARIZONA INDIAN RESERVATIONS



SOURCES:
American Indian Tribes and Communities in Arizona.
http://www.epa.gov/region9/air/maps/images/AIR1100040_2g.gif
Arizona Tribal Lands and Reservations
http://www.epa.gov/region9/air/maps/images/AIR1100040_2g.gif

(American Indian Tribes and Communities in Arizona, n.d.)
Image description: A yellow map of Arizona with all Indian reservations shaded in orange and dark orange. Everywhere included in the current colonial borders of Arizona was originally Indigenous land before becoming colonized by Mexico and now the United States. It appears that currently, these reservations account for about 25% of the land in Arizona. Text on the lower left side of the image reads: “Native Peoples of Arizona Comprehensive Map of Arizona Indian Reservations”

Intersectionality

The first principle of Disability Justice, as outlined by Sins Invalid, is intersectionality: the understanding that systems of oppression work together in ways that have rendered a majority of the world “invalid” and therefore disposable (Sins Invalid, 2019). Black feminisms and woman of color feminisms have long used intersectionality as an analytical framework to interrogate and identify the complexities of how these systems of oppression (and the subject categories they create) work together and how they are relational (Brown, 1992; Collins & Bilge, 2016; Crenshaw, 1989). Just as privilege and oppression are complicated, interrelated, and always experienced in our gendered, fleshy bodyminds, so too are care/harm and safety/violence. The relationality and violence at the core of this chapter elicits an observation Cherríe Moraga made decades ago about how clinging to privileges inevitably makes other people’s lives more vulnerable to violence (Moraga, 1993). The logics of settler colonialism rely heavily on patriarchal, ableist, and sanist ideas of intelligence and capability, and every time these ideas go unchallenged is an attempt to dehumanize Native people, especially Native people who are also disabled and thus, more likely to experience violence.

Settler colonialism subjects Native peoples to specific - and exceptional - dimensions of vulnerability and violence, including the forced transnational migration to access medical[ized] services and other types of care. Ableism and capitalism are dehumanizing, disabling, and debilitating systems of power that make people who have ongoing medical[ized] care needs vulnerable to institutionalization and captivity. IHS is historically and chronically underfunded since its inception in 1955. For every “American Indian,” IHS spends roughly \$4,078 per person (Indian Health Service, 2020), compared

to the national average of \$12,530 per person (Centers for Medicare & Medicaid Services, n.d.). Simply put, IHS is unable to provide adequate facilities and healthcare for Native people who are sick and/or disabled. For Native people that rely solely on IHS facilities and services this underfunding and the inadequate facilities provide the conditions for continued violence and dehumanization. About 70% of Native Americans (classified by the U.S. Census as American Indians and Alaska Natives) live in urban areas, but only 25% of these urban dwelling Native peoples live in counties where they can easily access federally funded Indian health programs (Indian Health Service, n.d.). This means that Native people in need of healthcare have three options: purchase private insurance so that they can be seen at facilities within their living area, or (and more often the case) travel excessive distances to go to an IHS hospital/facility, or lastly, forego medicalized healthcare services.

Drawing attention to the vast archipelago of carceral institutions, Liat Ben-Moshe explains, “When thinking of disability and incarceration from an intersectional perspective...it is important to think about incarceration in a variety of locales that disabled and/or non-normative bodies and minds are being swept into, such as psychiatric hospitals, residential institutions for those with intellectual and developmental disabilities, and prisons” (Ben-Moshe, 2014, p. 255). I consider Hacienda HealthCare - and other so-called care facilities - to be one of these locales. While their website names the facility in question as an “all-inclusive residential care facility,” it has the four main characteristics Erving Goffman said constitutes a total institution: batch living, binary management, the inmate role, and the institutional perspective (Goffman, 1961). This Hacienda HealthCare facility is a total institution, meaning it has partial or total control

over every aspect of the daily lives of the people who live there. This insular structure makes it easier to evade accountability when harm and neglect [repeatedly] occur. Just as guards in a prison (another total institution) are rarely held accountable or disciplined for the harm they allow or enact onto incarcerated people (Small, 2019), the doctors who were supposed to ensure the health, safety, and well-being for the woman at Hacienda HealthCare were not held accountable and received no discipline for their extreme medical negligence in 2018.

Ben-Moshe uses intersectionality to illuminate the similarities among the carceral logics that organize a variety of locales of incarceration (prisons and facilities like Hacienda HealthCare) as well as the day-to-day similarities of captivity experienced in these types of facilities. Writing about the experiences of Native American women imprisoned at the Women's Correctional Center in Montana in the 1990s, Luana Ross (Salish and Kootenai) shows how the incarceration of Native women enables and is enabled by racialization, patriarchy, and loss of sovereignty (Ross, 1999). Similarly, writing about the experiences of a Dakota woman and other institutionalized – or incarcerated – Native peoples at the Canton Asylum for Insane Indians in South Dakota in the early 1900s (Burch, 2014), Susan Burch explains the U.S. government used medical/psychiatric authority to justify the involuntary and often indefinite psychiatric confinement of Native peoples in the Canton Asylum.

In this chapter, I use intersectionality to focus not only on the experiences of an institutionalized, disabled San Carlos Apache woman at Hacienda HealthCare but also about how those experiences were shaped by interlocking systems of power such as settler colonialism, capitalism, patriarchy, and ableism.

Where to Live

The woman whose experience lies at the heart of this chapter is an enrolled member of the San Carlos Apache Nation, one of the twenty-two federally recognized tribal nations in Arizona. She had been under the care of Hacienda HealthCare since she was a young child. In *Allies and Obstacles* (2020), Allison C. Carey, Pamela Block, and Richard K. Scotch describe the complicated roles that parents of disabled children play, including the decision to institutionalize [or not] their children. Whether aligned with disabled-led fights for autonomy, interdependence, and justice or not, many parents with disabled children experience not being able to meet their child's physical, medical, financial, emotional, and/or social care needs. For Native parents of disabled children living on reservations, not having adequately funded and staffed local IHS facilities makes ensuring their child's care needs even more difficult. Native parents of disabled children are faced with an impossible decision to either relocate from their homelands and extended network of support (family, community, and clans) or struggle to provide the necessary care their child needs at home on the reservation. Displacement and relocation have been tools of the U.S to assimilate and steal Native land. This impossible condition of inadequate healthcare only further contributes to the ubiquitous nature of the settler colonial project.

Sara E. Green is a sociologist who studies disability and the mother of a disabled adult woman. The bulk of her scholarship focuses on the social and cultural dynamics that affect how parents of disabled children care for those children and how they *feel* about caring for their children. Contrary to the ableist and eugenic assumptions that position the presence of disability or illness as the source of burden, Green finds that for

many parents, financial constraints, not knowing what rights or services their child is supposed to have access to, prior inexperience with disability/illness, not having adequate networks of support, and having to interact with intimidating medical, educational, and or social service professionals are the burden, not their child's diagnosis or care needs (Green, 2007).

As Marta Russell and Liat Ben-Moshe have each explained, although disabled people might not participate in the paid labor market, when they are warehoused in nursing homes, group homes, and other so-called care institutions, they serve as the raw materials and their presence therefore becomes productive (and therefore, profitable) in a capitalist system (Ben-Moshe, 2011; Russell, 2019). This economic incentive creates a situation wherein parents of children who have ongoing care needs often end up relying on residential facilities like Hacienda HealthCare to provide care and streamlined services for their family members because individual families rarely have the resources to provide these expensive and time-consuming services themselves. The people who live in these facilities who receive disability benefits are subjected to a government-imposed 'resource limit' and are not allowed to have more than a few thousand dollars in countable resources (i.e., total dispossession), but many have far less than that, if any at all.

Jess L. Cowing challenges Feminist Disability Studies scholars to formulate a scholarly praxis that acknowledges how land theft generates uneven points of access to health and wellness (Cowing, 2020). I understand settler colonial contexts (i.e., land theft, forced displacement, and resource theft/manipulation) as generating the uneven points of access to healthcare options and outcomes that disabled Native people have. The

presence of disability and illness is inextricably linked to the violence of settler colonialism (Lovern, 2017), including the violence of land theft and woefully inadequate funding of Indian Health Service which aid in the disablement and debilitation of Native peoples in the U.S. Jasbir K. Puar (2017) explains that settler colonialism, capitalism, and militarized imperialism create the conditions for debility and disablement. Years of her mother's fierce and persistent advocacy had resulted in the San Carlos Apache disabled woman's Individualized Service Plan specifying that no male employee was to ever be alone with the woman without the presence of another, female employee, but court documents show that Nathan Sutherland was likely alone with this woman countless times. This broken agreement between Hacienda and the woman's family, which led to extreme [and in some ways, preventable] violence and neglect, is reminiscent of the numerous broken treaties between the U.S. federal government and tribal nations.

Maile Arvin (Native Hawaiian), Eve Tuck (Unangaâ), and Angie Morrill (Klamath) explain that highlighting the connections between heteropatriarchy and settler colonialism is generative intellectually *and* politically (Arvin, Tuck, & Morrill, 2013). This framework brings me to think about what factors affect the San Carlos Apache Nation's ability to ensure the safety and well-being of all members, specifically disabled members who are living off the reservation but are still entitled to the rights afforded to tribal members. As I discuss below, the gross and chronic underfunding of the Indian Health Service, which affects if and how Native people are able to receive services on reservations, and the San Carlos Apache Nation's lack of jurisdiction over the incident are two of these key factors.

Questions and Findings

Why is Nathan Sutherland the only person involved with the situation at Hacienda HealthCare being held responsible? How is the overwhelming lack of accountability being justified? What are the contributing factors that have affected the outcomes of this situation? These questions can be addressed by my four key findings: 1) the San Carlos Apache Nation's lack of jurisdiction and the role the underfunding of The Indian Health Service plays; 2) the U.S. criminal justice system's narrow scope of what constitutes a criminal act; 3) administrative violence enacted by and through the Arizona Medical Board; and 4) the deeply rooted anti-disability bias that pervades all of U.S. society.

Finding 1: Lack of Jurisdiction

Although the Indian Health Service is responsible for providing members of federally recognized tribal nations with medical and public health services, IHS facilities typically operate with budgets far below calculations of expected cost. Decades of settler colonial policies and broken treaties have left tribal nations with under-resourced Indian Health Service facilities, lack of clean and available water, and many people living with chronic health conditions. According to the National Congress of American Indians, "The average IHS per user spending in 2013 was only 59 percent of calculated full costs. The actual percentage varies between IHS areas, with some funded at much less than 59 percent of need" (National Congress of American Indians, 2016, p. 56). As Jen Deerinwater (Cherokee) explains, "As so often happens with disabled, Black, and Brown womxn, the federal government used IHS to sterilize anywhere from 25-50% of womb carrier patients in the 1970s. Despite the devastatingly high rates of sexual assault and violence that our women, children, and Two Spirits face the majority of our IHS facilities

lack sexual assault nurse examiners, birth control, abortion, and STD/STI prophylactics” (Deerinwater, 2020). So, regardless of whether or not Native women and Two Spirits – especially those living with disabilities and/or chronic illnesses – live near an IHS facility, they are not likely to receive adequate, accessible care.

The gross and chronic underfunding also affects the ability to, “recruit, retain and train staff, and facilities deteriorate resulting in safety being compromised” (National Indian Health Board, 2020, p.12). When local IHS facilities are unable to uphold the U.S. federal government’s trust responsibility and provide the care Native people need, they either go without the care they need or they move to other, often urban areas to seek services at either another, better-equipped IHS facility, or a private facility such as Hacienda HealthCare. This transnational migration is a form of settler colonial displacement and dispossession, and the San Carlos Apache disabled woman who might otherwise have lived on her reservation near her family ended up living in a place where her tribe has no legal jurisdiction.

That last sentence, however accurate it is, might make it sound like there *are* places where her tribe has jurisdiction. There are no places where the San Carlos Apache Nation has absolute and unquestioned jurisdiction over the rape of one of its members. Depending on location and the type of crime as well as the races of both the offender and the victim, criminal jurisdiction can go to federal, state, or tribal governments. This is, of course, an example of the imposition of colonial law and how it continues to make it possible for the United States (and Canada) to “reduce Indigenous political authority....by judicially proclaiming their own criminal behaviors as lawful” (Stark, 2016).

The U.S. federal government has exclusive jurisdiction over certain major felony crimes – including rape – that take place on tribal reservations. As Sarah Deer explains, the Major Crimes Act of 1885 takes all criminal jurisdiction away from tribes and gives it to the U.S. federal government, which has specific, gendered implications for Native women because they experience sexual violence at rates much higher than non-Native women (Deer, 2015). So, even if Nathan Sutherland had raped a member of the San Carlos Apache Nation on the reservation, the tribe still would likely not have had any jurisdiction over any part of the investigation, trial, or sentencing of the case because the case would have automatically been tried in federal or state court, not tribal court.

Part of recognizing settler colonialism as a structure, not an event (Kauanui, 2016; Glenn, 2015; Wolfe, 1999; 2006), means understanding how current settler colonial contexts are being maintained, and in settler states such as the U.S., “the justice system is an integral component of settler colonial warfare against Indigenous peoples” (Toronto Abolition Convergence, 2020). The San Carlos Apache Nation, like all other tribal nations, does not have full criminal jurisdiction over crimes that occur off and in many cases on their respective reservations. As settler colonialism would have it, however, Nathan Sutherland’s case would not have been fully under the tribe’s jurisdiction, regardless of whether or not it occurred on or off the reservation. In the 1978, the U.S. Supreme Court decided in *Oliphant v. Suquamish Indian Tribe* that tribal nations do not have criminal jurisdiction over non-Indians (*Oliphant v. Suquamish Indian Tribe*, 1978). In 2013, the Violence Against Women Reauthorization Act gave federally recognized tribes criminal jurisdiction for some domestic violence cases where a non-Indian perpetrated the crime(s). Since the San Carlos Apache disabled woman member was

living in Phoenix to receive medical[ized] services, she was not living on the reservation, thereby enabling this case to become a matter of state jurisdiction. More specifically, in the case of rape and vulnerable adult abuse that occurred at Hacienda HealthCare, criminal jurisdiction was given to the Arizona state government.

Eli Clare says that searching for people who have been disappeared into institutions is “a kind of resistance...a brilliant imperfection in the face of erasure” (Clare, 2017, 114). For people labeled disabled, sick, and/or mad, this disappearing happens in the variety of locales that Ben-Moshe explains disabled and/or non-normative bodies and minds are commonly swept into. For Native disabled women, however, this disappearing occurs in a specifically genocidal context, wherein Native women must always be disappearing, whether via death, institutionalization/ incarceration, or other forms of displacement (Burch, 2021; Ross, 1999). Disappearing via incarceration is particularly important for this case because, as abolition feminism reminds, it’s essential to avoid conflating vengeance with justice. Whether Nathan Sutherland had been tried in a federal court or a tribal court, the myriad of conditions/factors that allowed for the rape(s) and ongoing medical negligence would not be fundamentally transformed. Sending Drs. Gear Jr. and Nguyen and all administrators at Hacienda HealthCare who allowed male caretakers to be alone with the woman at any time despite its clear violation of her Individualized Service Plan to prison is vengeance. Ensuring the San Carlos Apache Nation has the resources needed to enact full jurisdiction is a place to start for justice. Directly addressing the root causes for why this woman was living in a private facility in Phoenix where her Individualized Service Plan was repeatedly violated might be a place to start for justice.

Importantly, fundamentally changing the structure and process of the Arizona Medical Board might be a way to create a more just process, but it would require a slew of important considerations (i.e., adequate funding for social services, community support, and so on). Although the Arizona Advisory Council on Indian Health Care exists to serve as a resource for Tribal governments and the State of Arizona in order to help meet the unique health care needs of Native people in Arizona, it played no role in helping the San Carlos Apache Nation, the State of Arizona, or the Arizona Medical Board figure out how to address this situation. For any case that comes before the Board involving a Native person, the Board should ensure an Indigenous perspective at every stage of the investigation. If anyone involved is an enrolled member, a liaison from their tribe should be appointed by their tribe and granted decision-making power. The Board should fund a permanent, paid position for a tribal liaison.

Finding 2: Narrow Scope of Crime

Two medical doctors, three nurses working in administrative/supervisory positions, and numerous other employees of Hacienda HealthCare were employed to carry out the care needs of all people living at the facility, but in every news article, court document, and transcript of meeting minutes I reviewed, all employees reported being shocked when the woman gave birth. Not one employee indicated to any media outlet or investigator that they had suspected any instance of sexual violence, let alone noticed the woman's pregnancy at any time preceding the December 2018 labor and delivery.

The only person who has been held responsible and/or received any measure of disciplinary action is Nathan Sutherland, a low wage-earning Haitian migrant. This is important for three major reasons: 1) the U.S. criminal justice system – and the people

who uphold it – have preconceived notions of who is and is not a “criminal” as well as who does or does not have the capacity to commit violent sexual crimes; 2) sexual violence and gender-based violence against Native women has been and continues to be a leading strategy of U.S. settler colonialism; and 3) the errors and negligence that occurred at Hacienda HealthCare are relegated to regulatory bodies that operate with little oversight.

First, one outcome of chattel slavery in the U.S. is that Black boys and men are widely imagined as dangerous sexual predators (Smiley & Fakunle, 2016) and are overrepresented in jail and prison populations (Nellis, 2021). From Emmett Till in 1955 to Antron McCray, Kevin Richardson, Yusuf Salaam, Raymond Santana, and Korey Wise in 1989 (known by some as the Central Park Five), there is a long history of young Black boys and men being accused and convicted (via legal and extralegal means) of committing sexual violence. At the same time, there is also a long history in the U.S. of xenophobic fears regarding the sexual and/or reproductive intentions of migrants and border crossers. The rape, undiagnosed pregnancy, and a myriad of other procedural errors at Hacienda HealthCare are clear indications of gross negligence by numerous staff members. Yet, aside from one instance of sexual abuse and one instance of vulnerable adult abuse, no other negligence or wrongdoing was pursued in criminal court, and Nathan Sutherland is the only person being held criminally responsible for anything related to the December 2018 birth.

Second, the rape of Native women has notoriously been a leading strategy for U.S. settler colonialism (Deer, 2015). Whether enshrined in military strategy or embraced by settlers through media and policy, the longevity of this strategy has translated into the

notion that Native women are rape-able, or at least *more* rape-able than other women. Important, tribally specific differences exist regarding the rates, causes, and contexts of domestic and sexual violence experienced by Native women (Hamby, 2005), but according to a 1998 study, rates of violence experienced by San Carlos Apache women are alarmingly high, mirroring statistics of more broadly categorized Native American women (Hamby & Skupien, 1998). The patriarchal violence that settler colonialism has inflicted upon and introduced to tribal communities is evident in the extraordinarily high rates of domestic and sexual violence American Indian and Alaska Native women experience. Recent data suggests that more than 50% of American Indian and Alaska Native women have experienced sexual violence and Alaska Native women experience domestic violence at up to 10 times higher than women in the rest of the U.S. (Rosay, 2016; Indian Law Resource Center, n.d.).

In a contemporary U.S. society that prospers from and through inflating its scope of authority and incarceration and expanding what can be criminalized in order to increase possibilities for punishment, only one person was found to have done something illegal. A simple example of how U.S. society has expanded what can be criminalized in order to increase possibilities for punishment within the criminal justice system is felony murder: a rule wherein people can be convicted of first-degree murder in situations where the death was caused by someone else. According to the Restore Justice Foundation, “forty-four states, Washington D.C., and the federal government have codified some form of the felony-murder rule” (Restore Justice Foundation, n.d.). This example is not to suggest that felony murder is useful, ethical, or laudable in any way, it is simply to show one way the criminal justice system can and does strategically weaponize punishment in

a variety of ways. While the rape of this disabled San Carlos Apache woman *was* criminally prosecuted and Nathan Sutherland sentenced to the maximum amount of prison time, nobody who contributed to the circumstances that allowed the rape to occur and the assault and pregnancy to go unnoticed and undiagnosed has been held responsible for their role(s).

Why did the State of Arizona not pursue any other wrongdoing related to what happened at Hacienda HealthCare or attempt to take further disciplinary action against anyone besides Nathan Sutherland, the low-wage Black im/migrant who is now incarcerated for the next ten years? Did the commonly assumed benevolence of medical providers, anti-Black and xenophobic ideas that conflate Blackness and migration with danger and predation, and systemic dehumanization of Native women and disabled women affect the state's decision not to conjure up charges? As of 2018, with an incarceration rate of 868 per 100,000 people, the Prison Policy Institute reports that Arizona locks up a higher percentage of its people than any democracy on earth, and a total of 145,000 Arizona residents are behind bars or under criminal justice supervision (Jones, 2018). So, when the state of Arizona decided to not seize the opportunity to press criminal charges against either Dr. Gear Jr. or Dr. Nguyen with, it begs the question: why not?

Third, the AMB operates with little oversight and no meaningful or measurable accountability to people who are most impacted by their decisions. Although Dr. Phillip Gear Jr. did not comply with the directives in her Individualized Service Plan to ensure that the woman was never to be cared for by male employees, or at least not without the accompaniment of a female employee at all times, he did not perform the required

physical examinations, and did not properly review her medical chart (including and especially information regarding her menstrual cycles), the Board allowed Gear Jr. to voluntarily surrender his medical license and retire. Although court documents show that staff members documented signs/symptoms of pregnancy seventy-three times during the months leading up to the birth, Dr. Thanh Nguyen (who assumed care of the woman a few months before she gave birth), did not order an ultrasound of her abdomen until the day before she gave birth. Since the actions and inactions of Drs. Gear Jr. and Nguyen were not pursued in criminal court, the Arizona Medical Board was the only possible domain for any semblance of accountability, responsibility, and/or discipline for these two physicians. Still, after only fourteen minutes of discussion during their meeting in October 2019, the Arizona Medical Board voted to dismiss the case against Dr. Nguyen noting that although there was “concern” among Board members, “the physician will probably take note of that [concern] and uh conduct himself hopefully in the future accordingly.”

Finding 3: Administrative Violence and The Arizona Medical Board

In *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of the Law*, Dean Spade explains how institutions and bureaucratic processes affect life and livability (Spade, 2011). Although his focus is on the procedural hold ups and administrative gate keeping practices that most directly affect trans, nonbinary, and gender non-conforming people, I find Spade’s analysis of how these processes affect livability to be generative for thinking about the overwhelming lack of accountability following the Hacienda HealthCare incident(s). Since neither doctor received criminal charges, the Arizona Medical Board assumed sole authority over whether and how Drs.

Gear Jr. and Nguyen were to be reprimanded or held responsible for their respective roles in what happened. Court documents related to the criminal case the state filed against Nathan Sutherland and the civil case the woman's family against the State of Arizona, both doctors, and two private medical companies indicate severe medical negligence and numerous procedural errors. Yet, multiple members of the Board repeatedly justified the errors and went so far as *commiserating* with the difficult situations doctors who work at/for facilities like Hacienda – like Dr. Nguyen – are often put in.

In *Feminist, Queer, Crip*, Alison Kafer explains how medical professionals enacted and carried out a larger cultural disinvestment in the reproductive potential and bodily autonomy of young disabled women and girls by suggesting and performing procedures on a young disabled girl's body to prevent it maturing during and after puberty. Kafer's framing is useful for understanding how, through their gross and repeated negligence, Drs. Gear Jr. and Nguyen effectively carried out a larger cultural and colonial disinvestment in this disabled Native woman's safety, sexual health, and bodily autonomy. Understanding how the Arizona Medical Board responded to their roles in this disinvestment provides a deeper understanding of how state medical boards are one of the entangled institutions that make up the medical-industrial complex and the settler colonial state.

The woman's family sued both doctors and two medical companies as well as the state of Arizona for being "grossly negligent" in overseeing and assessing Hacienda's operations, and while the State agreed to pay \$7.5 million dollars to settle the lawsuit, the Arizona Medical Board did not find either doctor to have been negligent enough to deserve severe sanctioning by the Board. Just as the City of Louisville agreed to pay

Breonna Taylor’s family \$12 million dollars to settle their wrongful death lawsuit but have yet to find anyone directly responsible for the wrongful death, the State of Arizona agreed to settle the suit without finding anyone directly responsible for being “grossly negligent” and creating the conditions for this situation to have occurred. By segmenting different aspects of this situation into different court systems and relegating the fate of the doctors solely to the Arizona Medical Board, the gross negligence that the State agreed occurred does not get meaningfully addressed.

In the U.S., being a medical professional – especially a physician – is traditionally and commonly lauded as an altruistic profession, making it difficult to identify/accept how doctors are positioned within the medical-industrial complex in ways that allow them to enact immense power and authority over individuals who are structurally positioned in ways that make them [more] vulnerable to violence. Not one person who was present at the October meeting of the Arizona Medical Board verbally disagreed that Dr. Nguyen’s medical charting errors and quality of care issues were noteworthy. The Board also noted that there was an “unacceptably long delay” in the examination that should have occurred soon after Dr. Nguyen assumed care of the woman. Additionally, although multiple members agreed that the copy-and-paste nature of the notes exhibited on the woman’s medical charts make it hard to know if the required examination or other standard examinations occurred at all, the Chair of the Board, Dr. R. Screven Farmer said the cut and pasted medical notes “raise a little bit of an integrity issue.” Yet, despite this damning evidence that Dr. Nguyen did not properly or ethically fulfill his professional obligation to keep accurate medical records of his patient, five of the nine present Board members voted to not issue an advisory letter.

While discussing the issues surrounding the mandated physical examinations the woman was entitled to when Dr. Nguyen assumed responsibility for her care, Board member Dr. Lois E. Krahn described the “unacceptably long delay” and Dr. Bruce Bethencourt said that because of Dr. Nguyen’s medical charting errors, “We [the Board] really don’t know if the appropriate examinations occurred.” The Board’s internal investigation showed that contrary to the standard protocol that physicians perform an in-person physical examination prior to calling in phone orders for a patient, Dr. Nguyen did “a lot” of phone ordering for this patient before performing the standard physical examination. Although this “unacceptable” delay in examination and Dr. Nguyen’s verifiably inaccurate medical records were not disputed by the Board, the Chair of the Board, Dr. Farmer, focused on whether or not they could have changed the outcome rather than focus on the obvious negligence they indicate. He said, “It’s certainly difficult to know whether doing the exams earlier on would have affected the outcome um but maybe ultrasound would have been ordered earlier.” Members also discussed the fact that Dr. Nguyen had ordered an ultrasound for a so-called mass in the woman’s abdomen but that the staff did not complete the ultrasound. The Board members spoke of this element of the situation as having been unfortunate but ultimately not a wrongdoing or oversight on Dr. Nguyen’s part because he in fact *had* noticed something in his patient’s abdomen and ordered an ultrasound accordingly. Shamefully, however, not one person on the Board mentioned that Dr. Nguyen ordered the abdominal ultrasound only one day before the woman gave birth.

Finally, the demographic makeup of the Board does not reflect the populations of patients in the State of Arizona. Part of the value of having regulatory boards that are

comprised not only of physicians but also nurses and community members is that there will always be some degree of diversity in how members relate to (or not) the cases that come before them. The Board, however, bears little resemblance to the racial, gender, class, age, sexuality, or nationality demographics of the people who live in Arizona. As stated earlier, the State of Arizona has 22 federally recognized tribal nations as well as numerous other tribes that are not federally recognized, Mexican and Central American migrants, vibrant queer communities filled with trans and nonbinary people, and disabled people living in care facilities run by private companies like Hacienda HealthCare. Yet, the Board lacks members whose social locations and life experiences position them as having to experience the medical-industrial complex – including individual clinicians – in distressing and even, dangerous, ways. The Board lacks members who are disabled and living in institutions, tribally affiliated, trans or nonbinary, Black, undocumented, and poor. The disparity between the embodied experiences of who is on the Board and the totality of who seeks medical care in the State of Arizona is incredible and inequitable.

“Nothing about us without us” is a phrase made popular by disabled activists in the Disability Rights Movement in the U.S. in the 1970s and 80s and remains a pillar of disability activist work (Charlton, 2000). “Leadership of the most impacted” is a core principle of the Disability Justice Movement (Sins Invalid, 2019) that emphasizes how transformative (and necessary) it is to make sure people who are directly impacted and *most* impacted are in decision-making positions. Both phrases identify how essential it is for decision-making practices to foreground the perspectives of people who are most directly affected by the intersecting and compounding power dynamics in a given situation. The demographic makeup of the Arizona Medical Board directly affects how

members of the Board analyze the cases that come before them, the perspectives brought up (or not) in their Board meetings, and the decisions they ultimately make about what behaviors, errors, and harm are permissible and which are worthy of disciplinary action. Since the Arizona Medical Board was given sole authority over if and how Dr. Nguyen should be held accountable for his key role in what happened, the biases of individual Board members and the Board as a whole determine what degree of medical negligence is acceptable for disabled Native women living in institutions.

Finding 4: Anti-Disability Bias

Since 1927, the phrase “three generations of imbeciles are enough” has reverberated throughout all kinds of institutions in the United States and has affected dominant cultural understandings of disabled women. Justice Oliver Wendell Holmes made that remark after he and his benchmen made the 8-1 decision that the Constitution did not protect Carrie Buck, a disabled incarcerated woman who was living in the Virginia Colony for Epileptics and Feebleminded, from being forcibly sterilized (*Buck v. Bell*, 1927). In a society where this decision remains a key legal precedent regarding the sexual and bodily autonomy of disabled women living in institutions, it is no surprise that the settler colonial logics of elimination follow this paternalistic violation of a disabled Native woman’s sexual and bodily autonomy. Nearly 100 years after these harrowing remarks were made, nobody is being held responsible for the extreme and prolonged negligence the woman at Hacienda HealthCare experienced. Since the decision has never been formally overturned, the eugenic values memorialized in Justice Holmes’ comment reflect the ableist and patriarchal sentiments both then and now.

Summary

In a news release from January 9, 2019, The Coalition to Stop Violence Against Native Women explains that Native women and women with disabilities are both demographics that are known to experience high rates of sexual violence (CSVANW, 2019). This chapter has attempted to address the question: how does medical negligence against disabled people living in spaces of extreme unfreedom occur, and how does it to continue to occur? I believe settler colonialism, failure of the U.S. criminal justice system, the Arizona Medical Board's carelessness, and the deeply rooted anti-disability bias that pervades all of U.S. society are four key factors that explain how this happened and contribute to the potential for something very similar happening again.

Given the notorious reputation of IHS for hiring and employing medical professionals who have demonstrated unsafe and/or unprofessional decision-making skills (e.g., the U.S. government has had to pay nearly \$55 million in settlements as the result of 163 malpractice suits at IHS hospitals in the last 13 years), even if the Arizona Medical Board *had* reprimanded Dr. Nguyen in some way, he very well may have been able to find a job at an IHS facility and continue [mis]practicing medicine on Native women. Building on this critique of how medical professionals violate their own ethical principles and enact gross medical negligence, the next chapter will discuss what Harriet A. Washington explains as a key reason to resist medical authority: "how race, culture, and economics have trumped medical and scientific truths at every turn" (Washington, 2006, p. 9).

CHAPTER FOUR

ANTI-BLACK ABLEISM AND MEDICAL BIAS

“Race has been, and continues to be, a fundamental issue in American medicine, as it is in other American institutions” – Vanessa Northington Gamble, *Making a Place for Ourselves*, xviii.

“Ableism is connected to all our struggles because it undergirds notions of whose bodies are considered valuable, desirable, and disposable” – Mia Mingus, Leaving Evidence blog on February 12, 2011.

An Abridged Timeline

- **February 21, 2020:** While awaiting a hearing to decide who should be granted permanent guardianship of Michael Hickson, his wife or his sister, a Texas judge appoints Family Eldercare, Inc. as temporary guardian.
- **June 2, 2020:** Michael Hickson is admitted to St. David’s South Austin Medical Center to be treated for recurring health issues (not COVID-19)
- **June 5, 2020:** With the expressed consent of Family Eldercare employee Jessica Ann Drake, Dr. Viet Vo abruptly decides to end all life-sustaining treatment, including nutrition and hydration, and change his code status to Do Not Resuscitate (DNR).
- **June 11, 2020:** After 6 days without proper nutrition and hydration, Michael Hickson dies alone at St. David’s South Austin Medical Center.
- **July 2020:** The National Council on Independent Living, along with eight constituency organizations, files a Complaint of Disability Discrimination with

the Department of Health and Human Services (DHHS) and Office for Civil Rights (OCR) and requests an investigation be opened regarding the illegal discrimination by St. David's South Austin Medical Center, its two parent organizations, and Family Eldercare, Inc. ADAPT of Texas also files a complaint with the DHHS and OCR requesting they investigate multiple aspects of the situation.

- **March 2021:** Representative John Smithee (R-Amarillo) sponsors House Bill 3063, which requires private professional guardians to consult next of kin and disability advocacy organizations in the process of making end-of-life and critical care decisions concerning an adult ward. Melissa Hickson files a petition against Family Eldercare, Inc. and the two employees who dealt with Michael Hickson's case most directly and requests \$1 million as monetary relief.
- **June 2021:** Melissa Hickson files a complaint for a wrongful death lawsuit against the hospital both doctors who treated her husband, Carlyle Cantu and Thanh Vo, citing anti-disability discrimination and gross medical negligence (among others).

St. David's South Austin Medical Center

St. David's South Austin Medical Center is a large, acute care medical hospital that can accommodate up to 368 patients at a time and has a Level II trauma center and a helipad. The facility has been the center of numerous quality of care lawsuits over the last decade.

Figure 3

St. David's South Austin Medical Center



(CAS Austin, n.d.)

Image description: A plain, gray, cement building with a white sign that reads: “St. David’s South Austin Medical Center”

#NoICUgenics and #NoBodyIsDisposable in the United States

In the spring of 2020, many hospitals in the U.S. began drafting and instituting care rationing protocols as Intensive Care Units (ICUs) became overflowed with patients sick with COVID-19. Instead of offering guidance for how to provide fair, nondiscriminatory protocols when allocating scarce resources (e.g., ventilators, medications, provider time, bed spaces), these care rationing protocols enable providers to discriminate based on disability, age, and body size. Not only do these discriminatory protocols rely on prejudiced ideas of who can live a good life, who deserves to live a good life, and who should get the chance to try, they allow providers to make unilateral, largely unchecked decisions they are not normally tasked to make. These prejudiced and

ableist ideas affect the kind of care people who were being treated for COVID-19 received as well as those who were not but needed a ventilator (e.g., Michael Hickson). Although providers from all over the globe have agreed that involving people with disabilities and chronic illnesses in the process of creating care rationing protocols and disaster response strategies can enhance efforts to reduce anti-disability prejudice, many U.S. hospitals do not explicitly recruit people with disabilities and chronic illnesses nor are they guided by disability ethics (Singh, 2020).

The COVID-19 pandemic has exacerbated pre-existing issues of access resulting from anti-Black racism, capitalism, and ableism, resulting in extreme [health] disparities. These extremely disproportionate outcomes encompass everything from who has had – and not had – access to free and reliable COVID-19 testing, employment and housing stability, free, early, and convenient access to vaccines, and, importantly for this chapter, access to high-quality, dignified health care. The institutional responses during this global pandemic have been a large-scale reflection of what many have already known: medical authority in the United States has always been a tool of and for violence. As the No Body is Disposable campaign explains, “disabled people, fat people, elders, and people with AIDS or other illnesses are being specifically targeted for denial of life-saving care during care rationing” (No Body is Disposable, n.d.). Through older activist movements such as Not Dead Yet and more recent campaigns such as #NoBodyIsDisposable and #NoICUGenics, disabled activists and their supporters continue to resist medical authority and so-called expertise that threaten, shorten, and end disabled people’s lives.

My analysis in this chapter is guided by the 10th Principle of Disability Justice, as outlined by the Sins Invalid collective: no one can be left behind, and no body is

disposable (Sins Invalid, 2019). Stacy Milbern offers a politicized understanding of ableism as being “a system of oppression that favors able-bodiedness at any cost, frequently at the cost of people with disabilities” (Berne & Milbern, 2017). For Michael Hickson, the Black disabled man whose experience is the focus of this chapter, doctors at a Texas hospital relied on deep-seated anti-Black ableism and rendered him disposable and his wife unworthy of compassion amidst the difficult COVID-19 no-visitor protocols in place. I broadcast the differential treatment Michael Hickson received in the hospital because eugenic logics of desirability and disposability are relational: a trait/ability/bodymind can only be *undesirable* in relation to a *more* desirable trait/ability/bodymind. I argue anti-Blackness, capitalism, and ableist values held by medical professionals overdetermined the kind of treatment and end-of-life decisions made for Michael Hickson at a Texas hospital in June 2020.

Health Care Disparities in the United States

In 1966, Reverend Dr. Martin Luther King, Jr. told reporters outside of the annual meeting of the Medical Committee for Human Rights, “Of all the forms of inequality, injustice in health is the most shocking and the most inhumane because it often results in physical death” (King, Jr., 1966). Nearly sixty years later, the health and health care disparities the United States remain extreme and shameful. These disparities are, of course, to be expected in a settler colonial nation that has embraced slavery and segregation and refuses to provide universal healthcare to all who live here. Whether represented in national statistics or personal testimonies, most people living in the United States experience barriers to accessing affordable and affirming health care from providers they feel are invested in their wellness.

While the focus of this chapter is on how anti-Black ableism is upheld in and by medical[ized] institutions, I feel compelled to note that people who use drugs (Myerson et al. 2021), queer and trans people (Spade, 2003; Sharman, 2016), people experiencing homelessness (Greysen et al., 2013), fat people (Gardiner, 2020), and intersex people (Davis, 2015; Rubin, 2017) are all subjected to similar and interrelated bias and discrimination when seeking medical[ized] services. Native and Indigenous people continue to decry the substandard care that underfunded Indian Health Service facilities often provide American Indian and Alaska Native people (Walker, 2019) and the extreme health disparities among Native Hawaiian and other Pacific Islanders (Mokuau, DeLeon, Kaholojula, Soares, Tsark, & Haia, 2016). Disabled, fat, neurodiverse, mad/Mad, deaf/Deaf, and people with chronic illnesses have reported and resisted the harmful eugenic practices that medical institutions uphold, wherein disability and bodily difference are understood as “an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate” (Garland-Thomson, 2005, p. 1557). In the case of Michael Hickson, doctors were unable to cure or eliminate his disabilities and ongoing care needs, so they eliminated him.

Ruth Wilson Gilmore defines racism as, “the state-sanctioned and/or extralegal production and exploitation of group-differentiated vulnerability to premature death” (Gilmore, 2007, p. 247). Centuries of racism, harm, neglect, and gross mistreatment have left many Black Americans with little, if any, trust in medical institutions and the clinicians who uphold them (Gamble, 1995; Roberts, 1999). In her book, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, Harriet A. Washington coins the term “Black iatrophobia”

(translating to fear of medicine) to refer to Black people's keen hesitancy of the ways that medical institutions create and increase vulnerability to premature death (Washington, 2006).

The toxic power dynamics that are foundational to medical research and treatment in the United States are so disturbing and shameful that despite continuous efforts to redress these inequities, harm remains a regular occurrence. This happens, in large part, because medical professionals and the institutions that train, accredit, and employ them refuse to deeply examine and challenge how racism and other forms of implicit bias affect clinical practice (Brooks, 2015). As is clear in the case of Michael Hickson and his bereaved family and friends, clinicians can make unilateral decisions that determine disposability, as long as they say their decisions were based on medical expertise and not social/cultural factors such as white supremacy, patriarchy, classism, and ableism.

Michael Hickson

In 2020, as COVID-19 was affecting – and killing – lower income Black and Indigenous people at rates far higher than their higher income white peers, it was also spreading rapidly in congregate living facilities such as prisons, jails, and nursing homes. The high rates of staff turnover, infeasibility of physical distancing, and large numbers of high[er] risk people housed in these carceral locales directly contributed to the disproportionately high numbers of cases and deaths in these facilities (Harvard Global Health Institute, 2021).

Michael Hickson was a forty-six-year-old Black disabled man in Texas who had been living in one of these congregate living facilities for the last three years, where his wife of eighteen years, Melissa, and their five children visited him often. Hickson had

been a National Merit finalist and was a proud Morehouse College graduate. Melissa told a reporter from The Washington Post that Michael had a brilliant mind, enjoyed Octavia E. Butler's *Parable of the Talents*, and loved being a father. In 2017, Hickson experienced cardiac arrest in the car after dropping some of his children off at their school and had been living with quadriplegia, vision loss, and a brain injury ever since. He lived with ongoing and somewhat complex medical care needs as a result of this incident but never lost his sense of humor or love for his family.

After testing positive for COVID-19 in his nursing home facility on May 8, 2020, Hickson was transferred to St. David's South Austin Medical Center in Austin, Texas on June 2, 2020 where he was to be treated for sepsis, pneumonia, and a urinary tract infection. He tested negative for COVID-19 a few days before being admitted and had been treated for these same issues at St. David's only three months prior. But on June 5, 2020, Hickson's doctors, Dr. Viet Vo and Dr. Carlyle Mabry Cantu, decided to end antibiotic treatment, withhold nutrition and hydration, designate him as Do Not Resuscitate, and place him on hospice. As a result, Michael Hickson died on June 11, 2020. Despite Melissa Hickson vehemently advocating against it, medical professionals at St. David's South Austin Medical Center sought the consent of Hickson's temporary guardian, Family Eldercare, Inc., and used their medical authority to end Michael Hickson's life. These medical professionals relied on anti-Black ableism and racialized understandings of his disabled masculine gender to determine that a) Michael Hickson did not have what they considered to be much of a quality of life, and b) it was not medically responsible to save him. During a recorded conversation Melissa Hickson had with Dr. Viet Vo, she advocated for her husband's quality of life and challenged the

ableist overtones of such a rash, lethal decision, but Dr. Vo insisted that Hickson's quality of life was different from other patients because unlike other patients who were being treated for COVID-19 and related complications, Hickson did not walk or talk. Unfortunately, when a disabled person does not have a DNR as their medical order, it is not uncommon for doctors to question it and even, as in the case of Michael Hickson, advocate to override that order and instate a DNR (Shapiro, 2020).

The hospital's Chief Medical Officer, DeVry Anderson, described it as a "very sad and complex situation," gesturing toward the profound and untimely loss of this man, husband, and father. But a few weeks later, the National Council on Disability issued a statement denouncing St. David's denial of life-saving care and expressed grave concern over the hospital using anti-disability bias to assess that Hickson had a low quality of life on account of his disabilities and violate his civil rights by withholding their services. In their statement, the Council insisted,

The presence of a disability does not lessen a person's value, nor should it warrant a person's abandonment by the medical facilities they rely on for care. When a medical facility makes a decision to deny medical care to a person with a disability that is based on, or influenced by, biased views about life with a disability, it runs afoul of federal civil rights laws. (2020).

A year after his untimely death, Melissa Hickson filed a wrongful death lawsuit against St. David's South Austin Medical Center and Drs. Vo and Cantu, citing gross medical negligence and disability-based discrimination, among eight other counts.

Process

For this chapter, I reviewed the legal and extralegal proceedings related to what happened to Michael Hickson at St. David's South Austin Medical Center, press releases from the hospital, Family Eldercare, Inc., and numerous disability rights organizations,

and familiarized myself with other examples of medical ethical violations pertaining to end-of-life decisions where guardianship has been appointed to a paid third party. I also examined news reports that covered Hickson's death in real-time as well a few longform journalism pieces that provided multiple perspectives and reflections from key stakeholders. I compared the legislation put forth by Representative Smithee (R-Amarillo) with other legislation regarding guardianship responsibilities and end-of-life decisions. Unfortunately, the Texas Medical Board did not investigate or deliberate on this situation, so there was no opportunity for me to analyze how the Board assessed different aspects of what happened.

Anti-Disability Sentiments in the U.S. are Multidimensional

Intersectionality, with a specific focus on a Black feminist disability framework (Bailey & Mobley, 2019), reveals the complexity and interconnectedness of a system of oppression such as ableism. In the wrongful death lawsuit, the first count listed is "Disability-Based Discrimination under Section 504 of the Rehabilitation Act of 1973" due to a) the intentional and deliberate denial of hospital services, and b) the nondiscriminatory mandates of Section 504, which St. David's was subjected to because it receives funding for Medicare and Medicaid programs. In fact, between May 2011 and January 2018, St. David's was cited with ten miscellaneous violations by Medicare/Medicaid (Painter, 2018). Given the specific, non-intersectional terms of this count, it is important to provide some context about the ways that anti-disability sentiments have been enacted by medical providers claiming medical expertise. Hospitals cannot legally and openly discriminate on the basis of race or ethnicity, but when doctors

use their alleged expertise to make vague, coded, and often unfounded claims that a patient has a ‘low chance of recovery or rehabilitation,’ they often go unchallenged.

Within the anti-disability bias that fuels efforts to prevent, mitigate, or cure disability, and to eliminate people who live with disabilities, there is immense complexity and nuance, making it hard to use a single word to encompass it all. When referring to “disability,” I understand that it “cannot easily be accepted as a self-evident phrase referring to a discrete group of particular people with similar essential qualities” (Kafer, 2003, p.78). Attempts to prevent disability are futile because, “...many disabilities are not detectable genetically, and...no amount and no degree of prenatal screening or in vitro engineering will produce a world free of people with cerebral palsy, autism, or pneumonia, not to mention people who are hit by cars.” (Bérubé, 2013, p. 107). Nevertheless, prenatal genetic screening, selective abortion, forced sterilization, and coercive contraception are all tactics used to prevent the presence of disability, illness, neurodivergence, and other modes of existence that do not align with rigid medical parameters of a ‘standard, healthy person.’ For many people who live with disabilities and chronic illnesses, a “healthy” or “non-disabled” past never existed and a “healthy” or “non-disabled” future might not be possible (Clare, 2017).

In the wrongful death lawsuit, the section that details the count of disability-based discrimination very clearly notes that since both Drs. Vo and Cantu were acting within the regular scope of their jobs, the hospital is vicariously liable for their acts and omissions. This is important because it recognizes both the individual power that these doctors held in terms of making the life-or-death decision about whether or not they thought Michael Hickson had the potential to have a “healthy” or “non-disabled” future

as well as the institutional power that this hospital enacts by determining the scope of what kinds of lethal decisions are (or are not) permissible for their employees to make. Family Eldercare had been serving as Michael Hickson's temporary guardian and although no employee had visited Michael for nearly two months, they were quick to agree to DNR code change recommended by doctors at St. David's.

Racialized and Gendered Ableism

Resisting a common presumption in Disability Studies that the medical model of disability and the social model of disability are mutually exclusive, Alison Kafer has proposed a political/relational model of disability, one that attends directly to how medical discourses/practices *and* social environments affect how our racialized, sexed, gendered, and classed bodyminds move through space and time (Kafer, 2013). Since disability is a non-discriminatory reality, any theories that deny or discount the non-discriminatory reality of race fail to adequately represent disability (Dunham et. al., 2015). Writer and activist Imani Barbarin poignantly demonstrates the importance of accounting for the reality of race by saying, "white disabled people's desire to constantly position their marginalization as on par with racism comes from a resentment that they don't GET to exercise whiteness in the same way as their abled white peers" (Barbarin, 2020).

Although the works of women of color have not traditionally been included in the citational canon of Feminist Disability Studies, feminist theorists such as Audre Lorde, Gloria Anzaldúa, and Cherríe Moraga all theorized deeply about how gendered and racialized dynamics affect our material, fleshy bodies in generative ways. Priya Kandaswamy, like many other intersectional feminist theorists, explains how processes of

racialization actually change the way people experience gender (Kandaswamy, 2012). These contributions are especially important for thinking about Michael Hickson's experience at St. David's, not as a person who was Black and a man and disabled but as a Black disabled man, whose experiences of anti-Blackness, patriarchy, and ableism were fully and fundamentally interconnected.

Racialized and gendered ableism are fueled in large part by larger systems of oppression that work together to uphold abled white male wealth. A critical, intersectional disability studies framework ensures that what happened to Michael Hickson at this Austin hospital is tied to these place-based histories of violence. Texas is a state in the U.S., where healthcare is a key dimension of U.S. white colonial power (Health Justice Commons, 2021) and millions of people live without healthcare and lack access to affordable, high-quality health care. Michael Hickson was disabled Black patient whose life was ended by hospital clinicians in the capital city of this formerly Confederate state that enslaved Black people until June 19, 1865, years after the U.S. Civil War had officially ended. This same area of Texas is also the ancestral homelands of the Tonkawa peoples and is well-known for having been an important migration area for the Comanche and Apache peoples. Settler colonialism is an eliminatory logic, while Native and Indigenous peoples experience the most intense and direct attempts of elimination, Black bodyminds are also dehumanized and debilitated as the U.S. nation state tries to establish power and claim legitimacy.

Race, disability, and gender are three key factors that affected the level of humanity and dignity that hospital providers decided was appropriate for Michael Hickson. Despite Melissa Hickson's desperate plea for more time, more consideration,

and more compassion for her husband, the raging COVID-19 pandemic and subsequent implementation of rationing protocols gave the hospital an enticing incentive to stop spending hospital resources on someone like Michael Hickson. A Black feminist disability framework enables an analysis that accounts for the roles that Hickson's race, gender, sexuality, age he was at the onset of his disability(s), and how he acquired his disability(s) could have played in how he experienced racialized and gendered ableism (Bailey & Mobley, 2019). Although Michael Hickson was a smart, consistently employed, loving husband and father who lived the majority of his life without disabilities, he was treated as a multiply disabled Black man and presumed to have a low quality of life.

There is no way to minimize how the deep anti-Black cultural biases regarding Black men and Black fathers in the U.S. affected how Michael Hickson's life was regarded by medical professionals during his hospital stay. In a society where Black Americans' civic participation is relatively new and voter suppression is enacted in every state, it comes as no surprise that Michael Hickson's safety and autonomy were disregarded by hospital staff. Racialized ableist patriarchy devalues men who are Black and/or disabled. Notions of who can (and cannot) be a good father, a provider for his family, and a valuable/valued member of society are central to the statements doctors and hospital administrators made about how Hickson did not have much of a quality of life to return to and how complex his medical needs were. For doctors at St. David's, his needs exceeded his worth and the quality of life he and his family had become accustomed to since he acquired his disabilities in 2017 was written off as not worth returning to. Similar to the kinds of public statements often made by police chiefs when their officers

kill civilians, hospital administrators acknowledged there was sadness to the situation but ultimately used their positions of authority to defend his killing.

Of course, there are certainly doctors and administrators who are reimagining their roles and responsibilities as advocates for social justice (Grzanka & Brian, 2019). All over the world there are doctors who are committed to equity and whose goals – both personal and professional – lie in the wellness and dignity of all patients. But in a capitalist society such as the U.S., where most people are structurally prevented from having easy access to the kind(s) of medical[ized] and/or preventative care they might need, it is impossible to separate the financially lucrative and culturally revered position doctors enjoy from the for-profit medical care system currently in place. A recent survey of 714 U.S. physicians revealed that 35% know little or nothing about their legal responsibilities pertaining to the ADA and 71% do not know who determines a person's reasonable accommodations (Iezzoni et al., 2022). Providers do not have to consciously use their status or alleged medical/psychiatric expertise in order to enact violence and uphold structural discrimination; this can and does happen regardless of individual intent, sometimes as an honest result of ignorance. Racialized and gendered ableism can be perpetrated by anyone with access to institutional power.

It is necessary to note that Michael Hickson was not the only person in this heartbreaking and maddening situation whose experience was undoubtedly affected by larger, cultural biases. As a Black woman in the U.S. South who was vocally and repeatedly disagreeing with her husband's doctors as they attempted to devalue his life and speculate on whether or not it was worth the resources to try to save, the wrongful death lawsuit Melissa Hickson filed asserts that the hospital repeatedly denied her access

to her husband. Although this occurred during a time when restricting visitors to curb the spread of COVID-19 was a common practice among all types of medical facilities, the hospital refused to allow Melissa to video chat at any point during the last three days of his life. There is no way to ignore the prevalence of misogynoir, what Moya Bailey has defined as the ways that anti-Black and misogynistic representations have shaped and continue to shape ideas about Black women (Bailey & Trudy, 2018; Bailey, 2010; Bailey, 2021) or the endurance of the controlling image of an angry, sassy, emotional Black woman (Collins, 2000). Was the hospital's refusal to allow Melissa to video chat with her dying husband, a courtesy that seems like the most basic level of compassion, a punishment for the trouble she had given the hospital as she attempted to advocate for her husband and demand answers for the hospital's perplexing decision to withdraw all life-sustaining care? While it is unlikely the hospital and any of its staff would respond to such a question, it is clear that the reductive and unfounded controlling images and stereotypes of Black women have real-life effects.

As Bettina Judd explains, “the angry Black woman trope is a distortion of Black women's knowledge” (Judd, 2019, 178). So, when Michael Hickson's sister – who is also a physician – made public comments about how Melissa's judgment regarding Michael's care and prognosis was clouded due to her love for her husband, she was adding to and drawing on ableist legacies of women, especially non-white women, being treated as unable to make logical, rational, “good” decisions: a form of epistemic violence. In *Are Prisons Obsolete?*, Angela Y. Davis explains that women have been incarcerated in psychiatric institutions more than in prisons, women are more likely than men to be institutionalized in mental facilities, and whereas deviant men get constructed as criminal

and end up in jails and prisons, oftentimes, “deviant women have been constructed as insane” (Davis, 2003, p. 66). Renee Hickson reflected on the intense care needs her brother had needed since the incident in 2017 and told the Washington Post, “Unfortunately, you have to let go of the life you thought you were going to have...you have to live in reality” (Cha, 2020). The implications of a medical doctor like Renee Hickson claiming that someone is out of touch with reality and unable to make decisions others might deem ‘sensible’ or ‘good’ are very dangerous because of the intense authority and power given to medical professionals.

Along with able-sanism and stereotypes of angry Black women, Melissa Hickson was subjected to medical elitism where people without formal medical training and credentials after their names cannot be considered knowledgeable. If, as Ruth Wilson Gilmore has observed, “Capitalism requires inequality and racism enshrines it” (Gilmore, 2019, p. 240), then able-sanism and medical authority serve to justify that racism. A key reason that Family Eldercare had been granted temporary guardianship over Michael Hickson was because the court still needed to decide who would be the best, most fit guardian: his emotional, passionate, advocate of a wife or his doctor of a sister. Had Melissa Hickson’s sanity and decision-making abilities not been called into question by so many parties, she would have been the court’s obvious choice for guardianship and the doctors at St. David’s would not have been able to legally end Michael Hickson’s life.

A Livable Life / A Life Worth Living/Saving

For as long as there have been doctors who wield medical authority, there have been people who challenge how that authority permits doctors to make largely unchecked decisions. In addition to receiving biased medical training, doctors in the U.S. are like

anyone else: they experience lifelong socialization into systems of oppression. Disability Studies scholarship has typically focused on how ableism and anti-disability sentiments are the premier source of oppression and disenfranchisement that many disabled people experience. More recent Critical Disability Studies scholarship highlights how settler colonialism, racial capitalism, cisheteropatriarchy, and militarized imperialism create unlivable conditions which sets the stage for ableism and anti-disability sentiments to thrive. In attempt to highlight the importance of including disability (as an embodied identity and as an analytical category), prominent Feminist Disability Studies scholar Rosemarie Garland-Thomson has explained that disability is important – as a political identity and an analytic category – because it affects everyone who lives long enough (Garland-Thomson, 2012). The last few words of that sentence form the beginning of an acknowledgement that entire populations of people are targeted for violence, making it less likely that they will not live long enough to experience this conceptualization of disability.

In *A litany for survival* (Griffin & Parkerson, 1995) Audre Lorde recognizes how the intentional debilitation of entire populations is not an exception to the norm but is instead the intended outcome of interlocking oppressive systems. She explains that some people – especially those who are Black, queer, low-income, and sick – were/are never meant to survive these systems. This analysis helps understand the implications of a doctor at St. David's South Austin Medical Center saying to Melissa Hickson that they did not believe her husband had much of a quality of life. This is a painful example of the deadly consequences that arise when powerful institutions embrace the [incorrect] cultural conflation of disability, life expectancy, and quality of life (Johnson, 2005). Part

of this conflation, as Sunaura Taylor explains, occurs because, “disability is presented as pitiable, always in need of a cure, and a barrier to a full life” (Taylor, 2017). Hickson’s Blackness, physical and cognitive disabilities, and recurring illnesses could have each been medically and culturally justified as being barriers to a full life. United Nations human rights experts have publicly decried the common claim that disability, old age, or living with a disabling condition are reasons to enable access to medically assisted dying because everyone has the “right to life on an equal basis” (United Nations, 2020).

Medical expertise typically identifies any presence of disability as a problem and locates that problem within the individual, obscuring the historical, institutional, social, and political anti-disability sentiments that position the presence of disability as a problem in the first place. On March 28, 2020, after the Office of Civil Rights posted their guidelines for the civil rights considerations medical providers needed to be upholding when making decisions during a time of emergency, the Office’s director, Roger Severino, expressed concern that stereotypes about disabled people that conflate living with a disability with a poor quality of life might be improperly used to justify disabled people from equal access to care and resources.

By determining and distinguishing what is to be considered *normal* and *abnormal*, medical professionals (researchers and providers alike) form and justify the anti-disability sentiments upheld in broader U.S. society. Tobin Siebers (2008) has theorized what he calls *the ideology of ability*, wherein ability is socially and institutionally favored over disability. Eli Clare (2017) has theorized what he calls *the ideology of cure*, wherein disability, illness, and impairment are socially and institutionally understood as needing to be cured, fixed, and eradicated. Eunjung Kim (2017) has theorized what she calls

curative violence, which encompasses the intended and unintended violence that destroys disabled subjects in the unquestioned quest for a cure. So, what happens when the disabled person cannot be *cured* of their disability and their medical needs might not be able to be rehabilitated or remedied? And what happens, especially in the case of Michael Hickson, when the disabled person is Black and already dehumanized in ways that position him as not worth the effort or resources to cure?

Black bodyminds (and non-white bodyminds more generally) have never been unquestionably considered to be capable of having valuable, livable lives. Gestational health disparities, mortality rates of Black women and Black birthers, infant death rates, life expectancy differences, and HIV/AIDS mortality rates are all clear indications of inequitable medical care in the U.S. Sometimes this inequitable care comes in the form of overtreatment or overdiagnosis, and sometimes it comes in the form of undertreatment, underdiagnosis, and misdiagnosis. The eugenic logics of which traits are or are not desirable, which informs notions of which *people* are or are not desirable, were not left behind in the 1930s. When institutions make decisions about who should be protected, by a doctor in a hospital, an officer on the street, or a judge in a court, they enact eugenics. When institutional power and so-called medical expertise are leveraged to justify racialized and gendered ableism, they enact eugenics. When Drs. Cantu and Vo decided to withhold all life-sustaining treatment from Michael Hickson and abruptly change his code status to Do Not Resuscitate, they enacted eugenics. Drawing on their own biased opinions of what constitutes a life worth living, they decided Hickson's life was not worth living and therefore, not worth saving.

Violating All Four Major Principles of Medical Ethics

There are four commonly accepted principles of health care ethics that have been widely influential in medical ethics training: respect for autonomy, nonmaleficence, beneficence, and justice (Beauchamp & Childress, 1979/2013). None of these four principles are intended to routinely be considered as more/less important than the others, but providers will undoubtedly find themselves in situations where they are responsible for determining which principle carries more weight in that particular situation (McCormick, n.d.). Although the COVID-19 pandemic and resulting care rationing protocols (and triage mentality of providers) might have made certain aspects of Hickson's treatment plan more complex than other patients in the hospital during that same period of time, what St. David's did to Michael Hickson violates each of these principles. Below I will outline each principle, provide specific examples of how providers at St. David's violated each of these ethical principles, and offer some of the feminist revisions for these principles that Campella & Feinsinger (2020) have suggested should be emphasized and further parsed out in medical school ethics curriculum. Although the ableist implications in each of these widely accepted ethical principles can and should be troubled, my intention in this section is to demonstrate how the actions of Drs. Vo and Cantu violated their *own* profession's ethical commitments.

The first principle is of respect for autonomy and it is the basis for the practice of informed consent. This principle means that, whenever possible, patients should be provided the necessary information so they understand different aspects of the situation and their various options as well as be protected from controlling influences that might affect their ability to make a free and voluntary decision. When a third party is being paid

to assume guardianship over a patient like Michael Hickson, it becomes impossible for providers to respect the patient's autonomy. Drs. Vo and Cantu made quick, life-ending decisions that went directly against the wishes of his wife and his full code status. In the lawsuit Melissa Hickson filed, it shows that after two days of withholding antibiotic treatment, nutrition, and hydration, Michael Hickson expressed hunger and was given a small amount of nutritional drip through his feeding tube. This example proves that, at least on some level, doctors were aware that Michael Hickson a) was aware of his needs, b) could effectively communicate his needs, and c) had a desire to continue living.

Campella & Feinsinger (2020) explain that *relationality* and *relational autonomy* are more generative ways for providers to make considerations because they highlight key relationships and create space for addressing interdependent relationships a patient likely has. Although Michael Hickson was not legally able to make his own medical decisions, he *was* capable of effectively communicating a key medical need. Additionally, there are egregious differences between how Melissa Hickson describes his cognitive and emotional states and how his doctors describe them. Guided by a principle of relationality, Hickson's doctors would likely have taken Melissa Hickson's experiential knowledge of her husband's care needs into consideration and thought more carefully about the degree to which a newly appointed third-party company could/should make such major, life-ending decisions for Michael Hickson.

The second principle is of nonmaleficence and it forms the fundamental commitment for health care professionals to do everything they can to protect patients from harm or injury. This principle means that providers should provide a proper standard of care that avoids risk or harm to the patient as much as possible. After only

three days in the hospitals, Drs. Vo and Cantu changed Michael Hickson's code status from full code, meaning the hospital should do everything possible to save his life, to DNR, meaning the hospital is not responsible for trying to resuscitate/save him. Their decisions to end his antibiotic treatment and withhold all nutrition and hydration were likely the most harmful decisions they could have made at that juncture in his care. Not only did these doctors not practice the principle of nonmaleficence, Dr. Vo's recorded comments demonstrate a clear motive for *why* he and his colleagues decided to forego their ethical commitment to do everything they could to protect Michael Hickson from harm or injury. Without Melissa Hickson's unwavering advocacy, these comments would not have been recorded and shared with the public, which would make it nearly impossible to prove disability-based discrimination occurred.

It is no secret that people who live in institutions are more likely to experience more physical and social isolation than people who live in community settings, among friends and family, etc. During the initial months of the COVID-19 pandemic, shelter-in-place directives were enacted around the U.S. and extreme lockdown protocols were implemented at facilities such as nursing homes, jails, and prisons. For many people with disabilities living in different kinds of residential care facilities, all visitation was banned, getting food delivered was forbidden, and social interactions among residents and staff severely limited. Reporting extreme feelings of isolation during this pandemic has been common among people with disabilities, regardless of where they live (Reber et al., 2022). Although the principle of nonmaleficence typically refers to a provider's commitment to avoid enacting direct, bodily harm to a patient, St. David's repeated refusal to accommodate Michael Hickson's access needs so that he could have virtual

visitation with his family *is* a form of harm. Although St. David's was taking active measures to end his life, they did not value his life or honor his close relationship to his family enough to offer this incredibly simple act of compassion.

The third principle is of beneficence and it affirms that the premier duty of health care providers to be a benefit to patients – and society more broadly – and be proactive about preventing and removing harm. Where nonmaleficence is something all providers should always be practicing, beneficence can become tricky in situations of urgency, when multiple patients need the same treatment at the same time. This principle also serves to reassure patients that their providers are invested in their health, rehabilitation, and overall well-being, they their providers will use their expertise and experience to benefit them. Although there were likely resource constraints and a sense of urgency due to COVID-19, the slew of deadly decisions that Drs. Vo and Cantu made were unrelated to such possible resource constraints. His antibiotics and feeding tube nutrition were not terminated because there was a critically low supply and other patients needed that same treatment at the same time. They violated their premier duty and withheld these life-sustaining treatments because they determined Michael Hickson's quality of life was low and therefore, not worth expending the resources to attempt to return to.

Finally, the fourth principle is of justice and fairness, and, in times of limited resources, a fair method of determining who gets what needs to be determined. Like the principle of beneficence, this fairness is intended to ensure the fair treatment of individual patients as well as entire populations of patients. This principle hinges on the idea that people who are equals should qualify for equal treatment, which leaves a lot of room for biased opinions about who are and are not equals. It is, however, impossible to

completely avoid the biased opinions about which patients are (or are not) equals that settler providers at a highly profitable hospital that is located on stolen Indigenous land where Black people continue to experience interpersonal and institutional violence have been socialized to have. Dr. Vo's recorded comments that Michael Hickson's quality of life was different than that of other patients because he was not "walking, talking" like they had been shows that Dr. Vo did not consider Michael Hickson to be "equal" to other patients and therefore, undeserving of equal treatment. Dr. Vo allowed deep-seeded anti-disability bias to justify why he was not ethically responsible for treating Michael Hickson with fairness.

Feminist commitments can provide direction for questioning power relationships between patients and providers (Warren, 1989). Campella & Feinsinger's final revision is about *epistemic justice*, which directs providers to directly address how medical knowledge held by providers is often privileged over the experiential, embodied knowledge of patients (and, as in the case of Michael Hickson, loved ones advocating on their behalf). This privileging of alleged medical expertise can lead providers to make decisions that do not adequately consider patients' perspectives, which can lead to inadequate care and/or inappropriate treatment decisions (Campella & Feinsinger, 2020).

The violations of each of these four well-established principles of health care ethics occurred quickly, in rapid succession, and have since been defended vigorously in multiple arenas (lawsuits, press statements, etc.). Although the ongoing and deadly COVID-19 global pandemic has had disproportionate effects on Black and/or disabled populations, all of the ethical violations seem to exist outside of COVID-19-related scarcities.

No Accountability and No Change (Yet)

In the case of Drs. Phillip J. Gear Jr. and Thanh Nguyen and the Arizona Medical Board, neither doctor was found to have been medically negligent or deserving of Board-sanctioned discipline. In the case of Drs. Viet Vo and Carlyle Mabry Cantu and the defining roles they played in ending Michael Hickson's life, they were never brought before the Texas Medical Board. Not one person involved has been held criminally responsible, St. David's has not changed its position on this case, and Melissa Hickson's lawsuit is still pending.

The multifaceted prejudices infused in medical school curriculum and clinical training, biases held by individual practitioners, and discrimination allowed/enabled by medical institutions all contribute to the levels of humanity, effort, and compassion afforded to patients who live with disabilities and/or complex or ongoing medical needs. When protocols, individual providers, and institutions are not held responsible or accountable for wrongdoing that results in disparate health outcomes, nothing changes. Although I believe the complaint Melissa Hickson filed offers a powerful and detailed condemnation of what St. David's did to her husband and the ethical violations that occurred throughout his entire hospital stay, it is unlikely that an outcome of the lawsuit will effectively address anti-Black ableist bias in medicine. The court might agree that it was a wrongful death, there was gross medical negligence, and Michael Hickson experienced disability-based discrimination during his stay at St. David's. But, similar to the incident(s) at Hacienda HealthCare, none of the medical providers who made that death, negligence, or discrimination possible will be held responsible or accountable for the death, negligence, or discrimination.

At present, no measurable change has occurred as a result of Melissa Hickson's fierce advocacy and no one has been held accountable for the gross medical negligence and disability discrimination that Michael Hickson experienced while hospitalized at St. David's. Melissa Hickson's lawsuit against St. David's might not create widespread, fundamental change, but if it is determined in her favor, it might serve as a useful referent for other bereaved loved ones who find themselves in an impossible situation similar to hers. The tension amongst hospital employees who have been affected by this situation – however minimally – might lead to different internal practices when it comes to making end-of-life calls for disabled patients. HB 3063 could provide stricter guidance for providers – in and out of Texas – who are responsible for making decisions. Melissa Hickson's love for her husband and continued disability advocacy has opened up several avenues for accountability and change. Without knowing the outcome of these loose ends, I do not know how small- or large-scale that accountability and change might be. It is clear to me, however, that she and her attorneys have worked diligently to not let her husband be one of the many disabled people who disappear in institutions or Black people whose presumed value disappears at the direction of medical providers.

CHAPTER FIVE

BUREAUCRATIC VIOLENCE AND CARCERAL ABLEISM

An Abridged Timeline

- **October 12, 2014:** Michael Joseph Borys, a 32-year-old white man who experienced seizures due to a long battle with brain cancer, is booked on a misdemeanor charge for pretrial detention into Cook County Jail (CCJ).
 - That afternoon, a Cermak Hospital physician confirms his history of seizures, orders Borys an anti-seizure medication to be taken that day and directs jail personnel to assign him a bottom bunk. Despite these orders, Borys does not receive anti-seizure medications in a timely manner and Guard R. Senese and/or Commander A. Garcia violate the physician's orders by assigning Borys a top bunk for the night.
 - That night, CCJ Guard R. Senese observes Borys "not acting normal" but takes no action.
- **October 13, 2014:** Around 2:30 a.m., Borys has a seizure and falls violently from the top bunk that he had been incorrectly assigned. The bodily damage resulting from his seizure and fall was so extreme that he was put into a medically induced coma for a week and underwent two brain surgeries and one surgery to address sinus issues resulting from the incident. His fall left him with fractured orbital bones, a fractured skull, permanent blindness in one eye, and a Traumatic Brain Injury (TBI) that permanently altered his cognitive functioning.
- **January 2015:** Due to his ongoing cognitive limitations, Michael Joseph Borys' father, Michael Jay Borys, is granted guardianship of his son.

- **October 2015:** Local Chicago disability rights organization Equip for Equality and attorneys representing Borys' father/guardian on Borys' behalf file a federal lawsuit against Cook County Sheriff Tom Dart, Cook County, and Correctional Officers R. Senese and A. Garcia claiming violations of the federally protected rights that Section 504 of The Americans with Disabilities Act affords to disabled people like Michael Joseph Borys when they require a reasonable accommodation (e.g., a lower bunk).
- **October 2017:** \$4.75 million settlement is reached (about \$2.8 to Borys, the rest to his attorneys).
- **November 2017:** This settlement is approved by the Cook County Board along with approximately \$7 million in other settlements, one of which being a \$3.25 million payout to a woman who was sexually assaulted in a Markham courthouse cell by two men who guards let into her cell to use a toilet. Cook County Board President, Toni Preckwinkle, expresses concern over the amount and frequency of [mostly] civil rights complaints brought against the county, many of which end in taxpayer dollars being used in settlements.

Cook County Jail

Cook County, Illinois is home to over 5.2 million people (which is more than 40% of the total number of residents in Illinois), making it the most populous county in the state and the second most populous county in the United States (U.S. Census Bureau, n.d.). With sizable Black, Latino, Asian, Native American, and immigrant populations, Cook County boasts the highest levels of diversity on many fronts. The Cook County Jail is located in Chicago, Illinois and is the largest single site jail facility and the third largest

jail system in the U.S. The massive jail complex is the size of 72 football fields. Typically, there are approximately 7,500 people being detained at the jail on any given day, with more than 90% of those people being held on pretrial detention, meaning they have not been convicted of any crime and in most cases, cannot afford their bail amount (Coalition to End Money Bond, n.d.a). Additionally, on a typical day there are 2,000 people who are not in the jail but are on electronic monitoring (sometimes called ‘community corrections’) and therefore subjected to heightened surveillance and only one misstep away from becoming formally incarcerated at the jail. This means that on a typical day, there are more people incarcerated in the jail or living under supervision than there are in 67% of cities in the state of Illinois (Illinois Demographics, 2020).

The successful organizing efforts of Chicago Community Bond Fund, the Coalition to End Money Bond, and other organizations in Illinois have resulted in a reduced number of people held captive by CCJ and an increase in public awareness of the unconstitutional and inhumane natures of money bond and pretrial detention. As a result, population numbers and demographics have been shifting over the last few years. In addition, like all other prison and jail systems in the U.S., CCJ has done a shamefully bad job of managing the COVID-19 global pandemic and protecting its inmates, causing jail numbers to fluctuate throughout the pandemic (Staudt, 2020; Herring & Sharma, 2021).

Despite this fluctuation, the demographic makeups of who is physically behind bars at CCJ and who is on electronic monitoring – or digital incarceration – are nearly identical to each other. About 95% are male, with approximately 75% being Black and about 17% being Latino and 65% under the age of 35 years old (Cook County Sheriff, 2021). According to self-reported, one-year data from people incarcerated at Cook

County Jail, over 73,000 children under the age of 18 were affected by parental incarceration in the jail (Governor’s Office of Early Childhood Development, 2021). Offering intersectional demographic data about disability is difficult, partly because of how demographic information is documented by the jail and partly because “disability” is a broad umbrella term that has a variety of meanings depending on the context. One example of how demographic data about disability are often erased is that although people with disabilities account for one-third to one-half of all the people killed by law enforcement (Perry & Carter-Long, 2016), race and/or gender are often the only victim demographics that get emphasized by news outlets and activist groups alike. The compounding effects of white supremacy, capitalism, ableism, and patriarchy are usually not fully accounted for and so the full scope of who is being harmed at disproportionate rates (by police, in hospitals, in jails, etc.) is not meaningfully addressed.

Two other important statistics that are difficult to offer about Cook County Jail – but are closely related to disability and essential for understanding who is most affected by the jail – are a) the percentage of people in the jail who have experienced housing insecurity and/or homelessness before their first stay at the jail, *and* b) the percentage of people who experience housing insecurity and/or homelessness after their formal incarceration ends. Those who struggle the most to secure housing are people in poverty with disabilities who need accessibility accommodations. The overwhelming majority of housing options are not affordable or accessible to people with disabilities, and those options become drastically reduced if the person with a disability has been charged with or convicted of a crime (Access Living, 2019).

Figure 4

Cook County Jail



(Ortiz VII, 2018a)

Image description: The tops of three jail buildings are partly visible behind a tall, gray cement wall that spans beyond the entire width of the photo.

Along with the L.A. County Jail system in California and Rikers Island in New York City, CCJ is commonly referred to as the largest or one of the largest mental health care facilities in the nation. While this designation incorrectly suggests that the jail is one of the nation's largest *providers* of mental health care services, it does highlight a major issue: the jail is filled with criminalized people who have mental health care needs that a) were not met prior to their incarceration at the jail, b) are affecting or being affected by their experience in jail, or c) might affect their ability to avoid becoming incarcerated again in the future. On any given day, about 30% of the people being caged at CCJ have a

documented mental health care need, with many more whose physical and mental health are being actively distressed (Cook County Sheriff's Office of Mental Health Policy & Advocacy, n.d.). While some say that people with disabilities or mental health care diagnoses/needs and people who use drugs should be diverted toward medical treatment rather than punitive incarceration, thereby denying how sickening, disabling, and maddening any length of jail/prison stay can be, a crip/mad of color critique positions these so-called treatment and care options as no less coercive and violent than other forms of incarceration (Aho, Ben-Moshe, & Hilton, 2017; Ben-Moshe, 2020). Cook County Jail is, in every way imaginable, one of the carceral locales that Liat Ben-Moshe identifies where sick and disabled people are swept into at disproportionately high rates and experience coercive and violent environments.

One of the institutional mechanisms that enables the disproportionately high rates of people with mental health care needs in Cook County Jail has been pretrial detention. If Michael Joseph Borys had not been held in pretrial detention, he would not have been booked into the Jail and thus, would not have been subjected to the unsafe and unaccommodating environment that led to his injuries. In January 2021, the Illinois legislature passed the Pretrial Fairness Act, written by organizers with the Coalition to End Money Bond and the Illinois Network for Pretrial Justice. This comprehensive act's nine key accomplishments are that it: 1) abolishes money bond in Illinois, 2) limits eligibility for pretrial incarceration, 3) regulates risk assessment tools, 4) authorizes release by law enforcement, 5) reduces penalties for violation of pretrial release conditions, 6) requires reconsideration of detention and release conditions, 7) ensures credit and movement for people on electronic monitoring; 8) reforms the warrant process,

and 9) ensures transparency and oversight through data collection and publication (Coalition to End Money Bond, n.d.b.).

The Coalition to End Money bond explains that money bond and pretrial detention criminalize what some might call mental illness while simultaneously harming the mental health of people who are currently or formerly incarcerated as well as their loved ones (Coalition to End Money Bond, 2022). The money bond system in the U.S. fuels inequality because a person's financial situation and ability to access money quickly becomes a leading determinant in where they get to live before their trial: in jail or not in jail (Scott-Hayward & Fradella, 2019). Instead of spending an average of \$300 million per year to incarcerate people pretrial, many of whom at the Cook County Jail, local governments in Illinois could redirect that money and address key issues that contribute to the disproportionate incarceration of people with disabilities, mental health diagnoses, and/or chronic health conditions: community-based mental health care services, affordable and accessible housing, education and employment opportunities (Coalition to End Money Bond, 2022).

Disabled in Jail

Incarceration is sickening and disabling, and the criminal punishment system in the U.S. is debilitating. Prisons (and jails) are especially dangerous places for people who are racialized as non-white and disabled (Ware, Ruzsa, & Dias, 2014). Regardless of one's previous physical or mental health care needs, and whether held captive in an adult or juvenile jail, a state, federal, or immigration prison, or civilly committed to a psychiatric institution, the experience of penal incarceration is designed to be a debilitating system that is damaging to the bodyminds of all affected parties (e.g.,

incarcerated person, their family, their community, etc.). In a 2015 report, The Vera Institute of Justice explains, “even a brief stay in jail can be destructive to individuals, their families, and entire communities” (Vera Institute of Justice, 2015, p. 2). All incarcerated people are routinely subjected to environments that are sickening and disabling and inhumane (e.g., unclean drinking water, rodent and/or pest infested living spaces, poorly circulated air, abuse from guards) (Oberholtzer, 2017; Vallas, 2016). But in court and in jail/prison, disabled people are routinely refused their federally protected right to accommodation (e.g., an ASL interpreter for someone who is deaf/Deaf/hard-of-hearing or a lower bunk for someone who have a history of seizures).

Cook County Jail is a sickening environment wherein physical and mental health care needs arise and worsen, but language, context, and the debilitating jail environment make it difficult to offer precise statistics about disability-related data on the jail’s population. Additionally, the ability/disability binary actually serves to bureaucratically discriminate against many groups of people, including those who cannot gain access to the State-defined category of ‘disabled’ and those who do not recognize themselves as ‘disabled’ and therefore do not claim that identity. Someone might not self-identify as disabled but if they rely on a mobility device such as a walker or a cane to move around, how should an institution like CCJ document these mobility needs? For many low-income people and communities, someone might not have had access to adequate mental health care services and therefore never received a formal [accurate] diagnosis; without a documented diagnosis, how might CCJ document mental health care need(s)? What about someone who lives with chronic pain or a non-apparent disability that is not officially recognized or validated by the Jail? What if someone has been subjected to biopsychiatric

violence and overdiagnosed or misdiagnosed? What about the many people who develop mental health care needs, respiratory issues, and/or other health-related issues after spending time in CCJ and carceral places like it?

These questions and their myriad of answers demonstrate how official data about how many people with disabilities are in the jail is very difficult to discern. The number of lawsuits filed against the county each year that focus on accommodations and medical negligence, however, is a clear indication that people with disabilities are in the jail and mistreated in the jail on a very regular basis. And, as Jasbir K. Puar has emphasized, whether a person is officially recognized as disabled or whether a person claims the identity of disabled, they can (and do) experience the population-level debilitation that racial capitalism, settler colonialism, neoliberalism, and militarized imperialism cause (Puar, 2017).

Illinois has an incarceration rate of about 564 incarcerated people per population of 100,000, meaning that Illinois imprisons more of its people in jails, prisons, immigration detention, and juvenile justice facilities, than many wealthy democracies throughout the world (Jones, 2018). Similarly, the United States does not ensure health care for everyone, so millions of people live with unmet health care needs, which in many cases, can develop into conditions that negatively affect their daily life (i.e., what the government considers at a given time to be a ‘disability’). According to the 2011-2012 National Inmate Survey, 40% of individuals in jail self-reported having a disability, and of this group, 53% self-reported having a co-occurring chronic condition (Bronson, Maruschak, & Berzofsky, 2015). According to the Coalition to End Money Bond, 44% of incarcerated people in U.S. jails in 2017 had a mental health diagnosis (Coalition to End

Money Bond, 2022). Additionally, incarceration disproportionately affects people who have been diagnosed with what psychiatrists currently consider to be a “serious mental illness” with nearly 40% having been held captive in a jail or prison at some point in their lives (Torrey, Kennard, Eslinger, Lamb & Pavle, 2010). Despite these numbers, only about 32% of people in jails throughout the U.S. who live with chronic conditions receive at least one medical evaluation while incarcerated (Wilper et al., 2009).

Another population of incarcerated people that can be difficult to identify in a statistic is people who are Deaf/deaf/hard-of-hearing. People who are Deaf (and communicate using sign language and identify culturally and often, politically, with their deafness) and people who are deaf and hard-of-hearing experience extreme and often, dangerous disadvantages during every stage of the carceral process. Jails and prisons often do not screen for hearing abilities or keep updated records on the hearing needs of their incarcerated population, making it difficult to identify how many people at a given facility are Deaf/deaf/hard-of-hearing. Since there are consistently lawsuits in every state regarding the denial of accommodations that people who are Deaf/deaf/hard-of-hearing need to access and/or participate in the various aspects of the carceral process (e.g., arrest, trial, meetings with attorneys, interactions with jail/prison staff), we know this is an issue. In Illinois, the routine denial of access and accommodations for incarcerated Deaf/deaf people was so widespread that in 2018 the State of Illinois settled a class action lawsuit regarding its treatment of Deaf/deaf/hard-of-hearing incarcerated people in the custody of the Illinois Department of Corrections (IDOC).

Seven years after the suit was originally filed, the State of Illinois agreed to settle *Holmes v. Baldwin* (2018) which mandates the IDOC to provide sign language

interpreters for disciplinary hearings, medical visits, counseling sessions, and other “high stakes interactions.” Under the settlement, the IDOC is supposed to increase access for educational and vocational programs for deaf and hard-of-hearing people. This settlement was projected to affect over 300 people incarcerated at that time, but that number was only an estimate since IDOC had not previously screened for hearing abilities/needs. Unfortunately, however, in 2020 a federal judge ruled in *Holmes et al., v. Jeffreys* (2020) that the IDOC was in violation of the settlement agreement and granted the plaintiff’s motion to enforce the settlement (National Association of the Deaf, 2020).

The Prison Litigation Reform Act of 1996 requires people who are incarcerated in jails and prisons who have experienced civil rights violations to exhaust all possible administrative remedies – and pay a fee - before they are allowed to file a lawsuit. In the 2016 SCOTUS decision *Ross v. Blake*, it was determined that an incarcerated person only needs to exhaust the administrative remedies that are *actually* available to them (Ross v. Blake, 2016). Incarcerated disabled people, however, as indicated in *Holmes v. Baldwin* (2018) and *Holmes et al. v. Jeffreys* (2020) in Illinois, are routinely denied the accommodations and support necessary for them to access, let alone exhaust, the administrative remedies meaning they are often unable to bring civil rights violation claims against their captors (Vallas, 2016). The grievance process is not bereft of the jail or prison’s asymmetrical power dynamics and, depending on who is trying to lodge a complaint and their reason for doing so, initiating the grievance process results in retaliation. For incarcerated transgender and intersex people in particular, the very act of trying to file a grievance often results in retaliation (Sylvia Rivera Law Project, 2007).

I consider the convoluted paperwork process that is often inaccessible and dangerous to be a form of bureaucratic violence, or violence that occurs when institutions require a complicated and discouraging complaint process that makes it difficult for individuals to successfully lodge a complaint against the institution. As a result, the institution is rarely, if ever, held responsible or accountable for the harm it causes. Since a cash settlement is often the end of the procedural road for lawsuits against the County, Sheriff, and Jail, even when cases *are* successful and plaintiffs receive a large amount of money, there are typically no mechanisms in place for enacting transformative changes that would address what caused or allowed for the incident to occur in the first place. Incidents of civil rights violations, breaches of duty of care, and disability-based discrimination rarely effect changes that are widespread and/or sustainable.

Another dimension regarding the rights of people with disabilities who are incarcerated in jails and prisons is the 1999 U.S. Supreme Court decision of *Olmstead v. L.C.* (*Olmstead v. L.C.*, 1999). This decision affirmed the Americans with Disabilities Act of 1990, which requires states to provide community-based services so that disabled people have access community-based services, even in situations of financial constraint of the individual, and attempted to end the then-common practice of states moving people with disabilities from community settings into isolated, hospital settings. Attorney Jamelia N. Morgan has written extensively about the liberatory possibilities that *Olmstead* holds for disrupting the disabling conditions in jail and prison settings (e.g., solitary confinement, inaccessible programming) and reducing the extraordinarily high numbers of disabled people behind bars (Morgan, 2020). Since the *Olmstead* decision obligates states to not use hospitals as a dumping ground for people with disabilities,

many states have begun to use jails and prisons to house their disabled residents (McDonough, 2021).

Attorney Margo Schlanger explains that most people in jails have at least one disability: about 40% live with a chronic condition, about 60% live with what psychiatrists and psychologists would likely consider to be a mental illness, and many more who are blind, deaf, and/or use mobility devices to get around. For Schlanger, these high statistics signal that “choices relating to disability are central to the operation of U.S. carceral facilities” (Schlanger, 2017, p. 297). Civil rights violations in Cook County Jail are an everyday occurrence. From pretrial detention and for-profit money bond to physical, psychological, and sexual abuses, CCJ has been a notoriously dangerous and unfair place. As many have publicly lamented over the last few decades, the culture of brutality, violence, and negligence at CCJ is as unacceptable as the inaction of politicians and top administrators to address these issues (Roderick and Solange MacArthur Justice Center, 2014). For people who are living with disabilities, impairments, and/or chronic conditions, people who are neurodivergent and/or aging, and people who have physical and/or mental health care needs, any length of a stay at CCJ can be damaging, and sometimes, deadly. Michael Joseph Borys was incarcerated in CCJ for less than 24 hours before he suffered a serious accident that resulted in lifelong injuries, disabilities, and impairments.

Process

This situation received significantly less public and legal attention than did the previous two situations. Whereas what happened at Hacienda HealthCare and St. David’s South Austin Medical Facility garnered national and international press and resulted in

more lawsuits, what happened to Michael Joseph Borys at CCJ culminated in one filed complaint, a few press releases from key stakeholders, and local news reports that focused most of their attention on the high settlement amount rather than the egregious rights violations perpetrated by CCJ. I reviewed a total of 38 pages of relevant documents, which include the complaint filed on his behalf, public statements made by disability and prisoner advocacy organizations, similar lawsuits about the duty of care responsibilities that jails and prisons have to people in their custody (specifically, disabled people in their custody), and local news reports that covered his story after the settlement amount was released.

Michael Joseph Borys: One Among Many

When Michael Joseph Borys was booked into Cook County Jail for pretrial detention, his medical needs and disability accommodations were verified by the medical provider who performed his medical intake screening/evaluation but not communicated to and/or carried out by CCJ correctional officers. In this jail and in many other U.S. jails, medical negligence, civil rights violations, and disability-based discrimination like this are commonplace, sometimes resulting in lifelong emotional and psychological trauma, sometimes resulting in worsened conditions or permanent injury, and sometimes resulting in death. Although the grievance process is convoluted, inaccessible, and often discouraged by jail staff, numerous lawsuits are filed against CCJ each year and millions of taxpayer dollars are spent settling these suits.

Figure 5

Bunk Beds in Cook County Jail



(Ortiz VII, 2018b)

Image description: Bright fluorescent lights illuminate a large open dormitory type room filled with bunk beds that are spaced only a few feet apart. The floor looks to be concrete and there is a large “L” painted on one of the yellow walls. This room is part of Division 4 at the Cook County Jail. The bunks shown in this photo are similar to, if not the same as, the bunk Michael Joseph Borys fell from on his first night in CCJ.

Borys’ case garnered a lot of publicity, in part, because of how quickly the incident occurred after he arrived and how serious and permanent the consequences of the jail’s negligence were/are on his bodymind. But much like Rikers Island and the L.A. County Jail system, people with disabilities and other health care needs at CCJ are unlikely to have their needs and accommodations met at all, let alone in a timely matter. In recent years, Cook County has been sued many times for the Jail’s demonstrated

inability to provide a safe and accessible environment, for both the people it incarcerates and the people it employs. Although his injury and resulting lawsuit garnered a lot of local publicity, he is only one of many people who have been denied disability accommodations, had their federally protected civil rights violated, and/or acquired illness, pain, trauma, disabilities, and/or injuries as a result of the jail's harsh environment. Importantly, however, he was one of a very small number of people who have received large settlements; the majority of civil rights settlements the County Board approves are for \$1,000 or less (Puentes, 2017).

Intersectional feminist theory is particularly useful when thinking about how interacting systems of power affect who is (and is not) incarcerated, what they are incarcerated for, how long they remain in jail and/or under the Sheriff's supervision, and the experiences they have while in jail or under supervision. Some people (such as Michael Joseph Borys) are successful in the grievance process and awarded large settlements for their mistreatment while others are unable to access the grievance process and/or do not have the outside support to follow through with a lawsuit. Multiple, intersecting factors affect if and when the County acknowledges, however tacitly, a person's claim of rights violations and/or undue harm. Borys' whiteness, maleness, and outside support from family and a well-known and well-connected local disability rights organization (Equip for Equality), along with the visibility of his injuries and the Jail's legacy of documented negligence, all contributed to Borys' ability to overcome the Jail's bureaucratic violence and successfully navigate the grievance process, ending in a large cash settlement.

Two of the four counts in the lawsuit focus on how not assigning Borys a bottom bunk was a form of disability discrimination under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. The other two counts, however, claim Defendants Dart and Cook County 1) “maintain policies and practices that allow detainees with disabilities to be given bunk assignments without consideration of their need for accommodations,” and that 2) their “conduct was intentional and deliberately indifferent to Michael’s federally protected rights.” These last two counts are of particular significance because they signal a recognition that Borys’ situation was not a one-time accident that was the result of unusual staff error or technology failure. Rather, they indict the entire Cook County criminal punishment system for how it breached its duty of care to Borys by willfully and wantonly disregarding his medication and accommodation needs.

In lawsuits, willful and wonton indicates that the incident in question is either the result of intentional actions *or* the result of circumstances that exhibit a reckless or conscious disregard for safety (Siemer v. Nangle, 2011; Henslee v. Provena Hospitals, 2005). So, although the County did not officially admit fault in the settlement, their willingness to settle for \$4.25 million demonstrates their tacit recognition that the Cook County Jail either a) knowingly employs staff that intentionally caused harm to Michael Joseph Borys, or b) maintains circumstances that enable such harm to occur.

Between 2015 and 2017, the Board approved about 230 settlements \$1,000 or less related to civil rights violations for lower amounts (Puente, 2017) in addition to numerous multi-million-dollar settlements. Settlements are approved by the Cook County Board of Commissioners, and the Board’s President, Toni Preckwinkle, and other Commissioners

have voiced concern over the number of civil rights cases regarding CCJ that are brought against the County *and* settled by the County. In addition to the concern about civil rights violations being a regular occurrence at the Jail, Commissioner Larry Suffredin (D-Evanston) went on record in 2017 emphasizing that a premier goal of the Board is to protect taxpayer dollars (Puentes, 2017). Since saving taxpayer dollars is a major, stated concern of the Board, I understand their routine approval of numerous settlements of all amounts to be a tacit acknowledgement that the Jail is and continues to be an environment where harm regularly occurs.

Duty of Care

A key aspect of the lawsuit Michael Joseph Borys' father filed on his behalf focuses on how the Cook County Jail breached their duty of care to Borys by failing to provide his anti-seizure medication in a timely manner and assigning him a top bunk after a physician ordered the jail to assign him a bottom bunk (Borys v. Dart, 2017). In legal matters, duty of care refers to the responsibility for the health, safety, and well-being of a person or group of people. Depending on the situation, this duty of care falls on different parties: medical providers, employers, parents, guardians, jail/prison officials, etc.

Although the physician who conducted Borys' initial medical screening accurately and explicitly identified the medication regimen and disability accommodation Borys needed, Cook County and Sheriff Tom Dart failed to provide and/or ensure adequate and effective channels for communication between medical providers and jail staff. In 1994, the U.S. Supreme Court ruled that inhumane prison conditions violate the Eighth Amendment and that prison officials can be held liable for harm that occurs as a result of

their “deliberate indifference” to a substantial risk of serious harm (*Farmer v. Brennan*, 1994).

A question that an intersectional feminist disability approach – supplemented with a commitment to abolition feminism – helps illuminate: Is it even possible for jails/prisons to oblige a duty of care for the people they hold captive? Architectural design, extreme and chronic underfunding, and social/cultural values regarding carcerality make jails terrible, sickening places. These are examples of and barriers to jail county and jail officials successfully fulfilling a duty of care to the people incarcerated in their jail(s). During the COVID-19 global pandemic, incarcerated people and their non-incarcerated supporters have forced conversations about the duty of care that the County, Sheriff, and Jail have – but are not fulfilling – to the people in their custody regarding their health, safety, and well-being. Chicago Appleseed is a volunteer-led, collaborative non-profit organization that advocates for fair accessible, and anti-racist courts in Chicago, Cook County, and the state of Illinois (Chicago Appleseed, n.d.). In March 2020, Chicago Appleseed emphasized that Cook County officials were neglecting the population to whom they bear the most direct duty of care: people in custody at Cook County Jail (Staudt, 2020).

Liat Ben-Moshe (2020) questions the relationships between carceral locales that are legitimized by "care" (e.g., nursing homes and psychiatric hospitals) and those legitimized by "punishment" (e.g., jails and prisons). Unlike the extreme medical negligence at Hacienda HealthCare and the negligence and discrimination that occurred at St. David's South Austin Medical Center, the medical provider who performed Michael Joseph Borys' medical screening/evaluation *did* uphold their ethical obligations

to Borys by identifying his medical needs and disability accommodations. The failure/harm in this case occurred when officers at CCJ did not follow through with the doctor's prescription order and accommodation directive. Had the medical provider not accurately identified Borys' medical needs and disability accommodations, his lawsuit against the County and Sheriff might not have been as successful.

By approving a settlement of \$4.25 million, the County Board decided Borys' claims that the Jail disobeyed/disregarded the doctor's orders and failed to provide the proper and recommended accommodations to minimize the risk of serious injury had so much merit it was most strategic for the County to settle the case rather than fight a lawsuit in court. In the effort to identify how CCJ failed to establish adequate/effective communication channels between medical staff and jail staff, Borys' complaint reiterated claims that are common in other recent cases against the jail: CCJ needs more staff, better training for their staff, and better infrastructure (computer programs, data-collection software, etc.). In the quest for disability rights and ensuring that disabled people at CCJ receive their federally protected right to reasonable accommodation, these claims support carceral ableism.

Carceral Ableism

Liat Ben-Moshe defines carceral ableism as "the praxis and belief that people with disabilities need special or extra protections, in ways that often expand and legitimate their further marginalization and incarceration" which often results in increasing resources for carceral expansion overall (Ben-Moshe, 2020, p. 17). The more disability-related settlements Cook County makes on behalf of its jail, the more enticing it becomes for politicians and County/Jail officials to request budget increases for the

Jail. These budget increases are justified by the alleged need to, for example, hire more guards (so accommodation requests do not slip through the cracks) and update the internal Jail computer systems/software (so medical needs and accommodations can be effectively communicated between medical staff and jail staff).

Famed activist, scholar, and abolitionist, Angela Y. Davis, has said that the most immediate question is how to prevent the further expansion of prison populations (Davis, 2003). So, although there are specific issues that people who are incarcerated in women's prisons experience (Drapetomania Collective, 2021), efforts to address these issues that further expand the carceral state can never end the violence that incarceration engenders. Similarly, activist and legal scholar, Dean Spade, explains that reforms that attempt to make incarceration *better* for trans, nonbinary, and intersex people ultimately become new mechanisms for enforcing racialized gender and sexuality norms to the detriment of the most criminalized populations; reducing or eliminating incarceration is the only way to address the horrifying conditions that trans, gender non-conforming, and queer incarcerated people experience (Spade, 2012). Abolition feminism, which has roots in Black feminisms and queer politics, emphasizes that state violence *is* sexual and gender-based violence and vice versa (Davis, Dent, Meiners, & Richie, 2022). Any grievance procedures put in place by a jail or prison system can only result in the further expansion of the facility's scope of surveillance and control; they can only ever be in the service of the institution itself.

A commitment to carceral abolition means a commitment to reducing the tools that institutions have to enact violence and avoid accountability. In the context of campaigns to defund the police, Miriam Kaba, who is an organizer, educator, and the

founder of Project NIA insists that any proposed reform that would allocate more money, advocate for more policing, or is primarily technology-focused should always be opposed (Kaba, 2021). Increasing the Jail’s budget, hiring more guards, and updating the internal computer systems *might* allow doctors to more effectively communicate medication needs and accommodation directives, but it would *definitely* increase the tools that CCJ has for enacting violence and its technologies of/for captivity. Although the County has settled numerous complaints regarding civil rights violations occurring at CCJ, other than financial payouts to a small portion of plaintiffs, the County, Sheriff, and Jail avoid accountability for nearly all of the harm that occurs in or because of CCJ. Similarly, increasing the Jail’s budget and capacity to surveil the people in its custody does nothing to address the extreme bureaucratic violence than many incarcerated people – especially those with disabilities – experience when trying to request/affirm the duty of care the Jail allegedly owes them.

Dylan Rodríguez argues, “All available empirical and archival accounts affirm that the institutional capacity, racialized asymmetry, geographic scale, multigenerational impact, and sheer longevity of U.S. incarcerating technologies stand alone in recorded human history, particularly in the realm of jails and prisons” (Rodríguez, 2019, p. 1584). What then, makes for a feasible, non-carceral measure that could clarify and expedite the process by which doctor’s orders get effectively communicated to Jail staff? While there are immediate harm reductions measures that might be useful (e.g., improving the Jail’s internal communication software), they are not capable ensuring the safety and well-being of people in the Jail because safety and well-being are impossible. Decarceration is the only way to resist/prevent increasing the Jail’s ability to intensify its violent and

disabling captivity of [mostly] poor Black men. In the next chapter, I discuss some key insights that feminist abolition (which is inherently intersectional and anti-racist) and Disability Justice (which foregrounds an anticolonial praxis) offer to these questions.

CHAPTER SIX

CROSS-CHAPTER ANALYSIS AND CONCLUSIONS

Introduction

In 1991, Mari J. Matsuda charged feminist researchers to “ask the other question” in an effort to identify the obvious and non-obvious relationships of domination and better understand the interconnectedness of all forms of oppression. For Matsuda, when a situation seems racist, she asks, “Where is the patriarchy in this?” or when a situation seems homophobic, she asks, “Where are the class interests in this?” (1189). In chapters three, four, and five, I identified obvious and non-obvious forms of oppression that I believe contributed to what happened in each of the three situations and why so many responsible parties avoided legal (and in many cases, social) culpability. I provided a specific analysis of settler colonialism, paternalism, and ableism in chapter three, anti-Blackness, ableism, and sanism in chapter four, and incarceration, bureaucratic violence, and ableism in chapter five. In this chapter, however, I offer an analysis of dynamics of power and control in these situations across and alongside each other and ask the other question and apply theories to situations where they might seem less applicable or less relevant. For example, in the case of Michael Hickson, a Black disabled man in Texas, where are the logics of settler colonialism and paternalism and what dynamics of power and control are reminiscent of the settler colonial strategy of using scientific/medical so-called authority to justice harm, removal, dispossession, and death?

To ask these other questions, I used a bricolage approach and performed three passes of analysis for each of the three situations, each pass analyzing the information from a different perspective: feminist and critical legal perspective, decolonial

perspective, and a Disability Justice perspective. The process of having three phases of analysis was especially useful because it ensured that each situation was analyzed from all three critical perspectives, even when those perspectives might not seem *as* applicable for a given situation. I engage with intersectional feminist theory as a key framing concept for this research because of its ability to identify and reflect on the interlocking relationships of power and patterns of institutional harm. In 1989, Kimberlé Crenshaw wrote about the U.S. legal system's inability to effectively address the "the combined effects of practices which discriminate on the basis of race, and on the basis of sex" (149). Intersectionality informs my meaning-making process, both across and between the three focal situations, because in each situation, the legal and extralegal proceedings are incapable of effectively addressing *all* of the contributing factors.

Following Matsuda's feminist methodological practice of asking the other question, I returned to the question "How did this happen" and considered three specific and overlapping systems of power: settler colonialism, patriarchy, and ableism. During the first pass of analysis I asked, "Where is the settler colonialism in this?" and identified how settler colonial dynamics of removal, erasure, dispossession, and power and control affected the situations and their outcomes. During the second pass I asked, "Where is the patriarchy in this?" and identified how patriarchal patterns of enacting gendered authority/power being to justify unfreedom contributed to the situations and their outcomes. Finally, during the third pass, I asked, "Where is the ableism in this?" and identified how dynamics of disposability and medical authority affected the situations and their outcomes. Settler colonialism, patriarchy, and ableism are, as Kimberlé Crenshaw instructs, interrelated, co-occurring, and mutually informing of one another.

Although they each have specific targets for their violence and specific, tailored methods for enacting that violence, their pedagogical influences reach beyond these specific targets and provide instruction for how to enact harm and evade culpability in other situations.

Settler Colonialism

Several key aspects of settler colonialism are evident in each situation. As an ongoing, structural attempt to seize land and resources through the annihilation of Native and Indigenous peoples *and* a logic that informs broader cultural understandings of who does and does not deserve care or violence, settler colonialism informs all aspects of social and political life in the US. Dispossession, removal, and erasure are central to the settler colonial project in the US and are part and parcel to cultural imaginations of who exists in the future and the institutional mechanisms put in place to create the conditions for that imagination. The paternal ways that institutions attempt to dispossess, debilitate, remove, and erase people is reminiscent of and directly informed by the US government's violent and ongoing occupation of Native lands.

In the Arizona Medical Board's discussion of whether or not they should issue Dr. Thanh Nguyen an advisory letter for his role in what happened to his patient, the Chair of the Board, Dr. Farmer, offered the comment that all Board members share "the greatest sympathy for the family, staff, the other people who were affected by a truly horrific act." This comment is important for two reasons: 1) Farmer only expresses the group's sympathy for the family, staff, and other people, but not for the woman whose experience of violence and neglect was the focus of the meeting and 2) he frames what happened as *a truly horrific act* rather than a *series* of horrific acts. The settler colonial impulse to

remove and erase the woman from the conversation, a conversation that would not have been possible without her presence, informs and is reflected by the Board offering sympathy to everyone except her. Framing what happened as a singular, isolated incident, rather than a series of interrelated events, is reminiscent of how settler colonialism is often misunderstood as an event, not an ongoing structure. If the Board frames the rape as having been the only horrific act to occur, they actually sanction the gross medical negligence that allowed that rape to go undetected and its subsequent pregnancy to go unnoticed/undiagnosed. A key aspect of this situation, which I believe is the reason it got so much national and international media attention, is because her pregnancy went unnoticed by doctors and staff at Hacienda and yet, according to the Chair of the Board, the only horrific act that occurred was when Nathan Sutherland raped the woman.

The AMB, just like the Arizona judge who sentenced Nathan Sutherland to ten years in prison and a lifelong status as a sex offender, recognized the rape of this San Carlos Apache disabled woman to be a criminal act, an act that is, at least on some level, not permissible. In the settler colonial, patriarchal, and ableist context of the current United States, where instances of rape and sexual violence often go uncriminalized, it is important to mark that a person was held legally culpable and criminally responsible for raping this woman. There is a rich tradition in feminist activism and feminist scholarship of expanding what is considered to be violent/violence. I continue this tradition by identifying and naming multiple additional violent acts that occurred. I argue that the months (or more) of gross medical negligence perpetrated by Drs. Gear Jr. and Nguyen as well as other Hacienda staff who worked closely with the woman – especially those who violated her Individualized Service Plan and allowed her to continually be alone with a

male employee – is violent. I also consider the AMB’s failure to directly acknowledge this woman’s presence and include her in their sympathy and their justification of why the majority of members did not vote to issue an advisory letter to Dr. Nguyen are also violent acts.

The Board’s Vice-Chair, Dr. Gillard, stated “this is a very serious situation but also very rare,” which not only goes against widely known and accepted statistics about how the people most likely to harm disabled people are their caregivers (Disability Justice, n.d.) but also suggests that a degree of leniency is in order. If, as Dr. Gillard suggests, this situation is very rare, then Dr. Nguyen should not be held *as* liable or responsible. This reflects similar colonial logics to how the United State government acts as the self-appointed sole arbiter of what acts of settler colonial violence are and are not admissible. Dr. Gillard and the wider AMB served the arbiters, whose decisions have the power to challenge or sanction the in/actions of licensed medical doctors in the State of Arizona. Such policies ignore or reject decades of empirical and anecdotal evidence on the different types of violence disabled people, especially those who have intellectual and developmental disabilities, experience from people tasked with providing “care.”

In contrast to the ways that this San Carlos Apache disabled woman and the multiple dimensions of violence she experienced were erased from the Board’s discussion, Michael Hickson was hyper-present and the violence he experienced was justified. Michael Hickson’s name, background, and specific medical diagnoses were brought to the forefront. His abilities, disabilities, daily care needs, and relationships with his family had direct influence over his experience at St. David’s Medical Center and how his experience was framed by medical providers. In contemporary mass media

coverage of police killing or attempting to kill Black people, all sorts of unrelated details are shared in an attempt to mar the victim's character and identify reasons why they were somehow *more* deserving of the violence. In the media coverage of St. David's killing of Michael Hickson, details about his diagnoses, family life, communication abilities, and projected care needs were discussed widely by doctors and news reporters alike.

Michael Hickson was not removed or erased from these discussions in the way the AMB erased the San Carlos Apache disabled woman, but he (and his family) was removed from the process of changing his code status to Do Not Resuscitate. The U.S. government's practices of land theft, material disinvestment, and broken treaties set the parameters for the acceptance of dispossession and depravity more broadly. While I do not mean to appropriate or misuse an analysis of settler colonialism, or imply that the erasure and removal of Native and Indigenous peoples is in any way "the same" as how St. David's and Family Eldercare removed Hickson and his family from the decision-making process, I do think the eager and capable cross-institutional erasure of people's decision-making abilities is informed by implicit settler colonial strategies that are fundamental to and emerge out of all aspects of life in the U.S. settler state.

The chronically unfulfilled duty of care in the Cook County Jail reflects the sustained and concerted disregard for human life in a carceral state. Jails and prisons in the US are known for being particularly committed to cruelty and erasure. Desires to eliminate, punish, and profit as well as the practices of forced removal, hyper-surveillance, and extreme isolation (geographic, social, political) are central to how the U.S. approaches penal incarceration and settler colonialism. Any challenge to the economic and political relationships that sustain contemporary forms of incarceration is

fundamentally a challenge to the economic and political relationships that fuel and are fueled by settler colonialism.

Patriarchy

Patriarchy is a system of supremacy in which gendered understandings of reason and capability are interpersonally and institutionally enforced, and it informs all aspects of social and political life in the US. These gendered notions of domination, capability, and control are central to the patriarchal structures in the US and are part and parcel to cultural imaginations of who is credible, who should have authority, and who is most valuable. Several key aspects of patriarchy are evident in each of the three situations.

Jails and prisons are gendered places, not only because the majority of people who are incarcerated and employed in these places are men or because of the culture of violent masculinity that reigns supreme, but also because they are about power and control. Racist, sexist, and ableist notions of who is and can be violent affect who is incarcerated in these places and these same notions affect how incarcerated people are treated. Patriarchy and ableism, for example, combine for a specific understanding of who deserves freedom, care, and dignity. When the Cook County Jail withheld Michael Joseph Borys' anti-seizure medication and denied his disability accommodation, however accidental that denial might have been, they enacted key features of patriarchal control: power and control. The County's inability to oblige their duty of care to Borys and all other people this jail incarcerates is, in part, affected by gendered, racialized, carceral, and ableist notions of who *deserves* to be protected and cared for. Although Borys' whiteness might have protected him from racialized violence from guards and jail administrators, he did not spend enough time at CCJ to experience that possible

protection. Instead, as a man who had diagnosed medical issues and was incarcerated, he was less deserving of protection and care.

For Michael Hickson, racist, sexist, and ableist conceptions of what *kind* of man can be valuable, if only to his family, and therefore deserving of care, contributed to the dehumanization and violence he experienced at St. David's. Convuluted and oppressive ideas about what kind of life is a man supposed to lead and what kind of man can lead that life affected his experience. Patriarchal and paternal decisions about who should get to make decisions for others played a key role in the ease with which doctors at St. David's and case managers at Family ElderCare made quick and deadly decisions on his behalf. Finally, the gendered conditions under which people decide whose experiential knowledge should be taken seriously is a direct outcome of patriarchal influence. Although Melissa Hickson had direct and demonstrated knowledge about her husband's medical history, care needs, and communication styles, this knowledge was swiftly overrun and dismissed by medical providers at the hospital. The dynamics of institutional and interpersonal power and control that St. David's wielded against both Michael and Melissa Hickson are reflections of the patriarchal, settler colonial, anti-Black, and ableist contexts of the hospital where this occurred and broader social and political life in the US.

The masculinization of medical authority and feminization of disability is also evident in all three situations, albeit in different ways. At Hacienda HealthCare, the woman's total dependency on others and the way authority figures framed her as helpless contributed to the extraordinary media attention the situation received. The disproportionately high rates of disabled people who experience caregiver violence and

Native women who experience rape are well known and well documented (Disability Justice, n.d.; Indian Law Resource Center, n.d.). The masculine dynamics of power and control that are at the core of medical authority affect how doctors treated a Black disabled hospital patient like Michael Hickson, how doctors sanctioned the gross medical neglect of a Native disabled patient like the San Carlos Apache woman at Hacienda, and even how Cook County validated Borys' complaint by agreeing to a high settlement amount *only because* a medical doctor had deemed Borys worth of medication and accommodation.

These dynamics of power and control in medical authority inform and are informed by broader, contested understandings of who can know and who can be known about. Michael Joseph Borys was understood as having been deserving to have his medications provided to him in a timely manner and his bed assignment accommodated *because* a medical provider sanctioned it. Michael Hickson was understood as not deserving of life-sustaining treatment or end-of-life compassion from hospital staff *because* medical providers sanctioned it. The San Carlos Apache woman was understood as only having been victim of one "horrible act" and therefore deserving the months of negligence that followed that act *because* medical professionals on the AMB sanctioned the actions and inactions of both of her primary care providers. The ways medical authority can render people to be considered more or less deserving of care, dignity, access, and life reflects two key features of patriarchal power: physical and epistemic domination and control over others.

Ableism

Several key aspects of ableism are evident in each of the three situations. As an oppressive system of individual and group valuation, ableism is connected to and informs all aspects of social and political life in the U.S. The paternal ways that institutions attempt to devalue and delegitimize people based on their deviation—real or imagined—from medicalized ideas of normal/sane is reminiscent of and directly informed by a larger eugenic, white supremacist, settler colonial, capitalist, and patriarchal project. Medical and social constructions of disability, race, and gender are mutually informing and contribute to what characteristics of a body/mind are valuable in a given space/time. The medical and scientific authority that overdetermines the mandatory features of what constitutes a life worth living and who can have such a life reflects the relational features of settler colonialism, anti-Black racism, and patriarchy: one group can only be *more* worthy or capable than another group(s) because that other group(s) has been designated as *less* worthy or capable. This relationality also shapes the boundaries for if and how people are included or excluded from a given group.

In the recorded conversation between Melissa Hickson and Dr. Vo, he indicates that when compared to other patients, Michael Hickson's inability to walk and talk made his projected potential for a full recovery less promising. In this admission of differential treatment, Dr. Vo exhibits the eugenic decisions medical professionals are able to enact on the basis of ableism as long as they disguise this bias as being a result of their medical expertise, not individual bias. The individual people at Hacienda who were supposed to be medically and legally responsible for this woman's well-being evaded responsibility, even though the State of Arizona awarded the San Carlos Apache disabled woman's

family a \$15 million settlement for the state's gross negligence of monitoring Hacienda's operations as they fell below the expected standard of care. Cook County agreed to a large settlement for what happened to Michael Joseph Borys, but the specific circumstances that allowed jail staff working the evening shift on October 12, 2014 to not carry out Borys' medical orders and thus violate the duty of care and perpetrate disability discrimination were never addressed. Unlike the sentiments expressed in Dr. Vo's comments about how Michael Hickson was *less* deserving of hospital resources because of his disability, Cook County's settlement with the Borys family signals that Borys *was* deserving of a certain standard of care *because* of his disability status. The explicit ways that institutions deny or only partially acknowledge the harm they cause does not lessen their capacity to continue causing harm.

Bureaucratic Violence

The pedagogical and procedural influences of settler colonialism, patriarchy, and ableism are evident in each of the three situations. Although the targets, methods, and justifications shift, they all result in institutions being able to cause harm and violence, while avoiding meaningful responsibility or transformation. I found the overwhelming effects of bureaucratic violence to be the most salient connection between all three situations.

The paternal dynamics of medical[ized] facilities, pervading anti-disability sentiments and bureaucratic violence make attempts for accountability, let alone justice, difficult to impossible. A distinguishing feature of bureaucratic violence is that despite how bureaucratic processes can and do carry out harm against a specific group of people, it seems non-violent on the surface (Norberg, 2021). In a recent panel discussion about

decolonizing the psychiatric institution, Liat Ben-Moshe explained that Disability Studies, Prison Abolition Studies, and Critical Indigenous Studies all share a critique of using scientific/medical so-called “expertise” to justify the incarceration, confinement, repression, and unfreedom of both individual people and populations of people (2022). In each of the three situations analyzed in this dissertation, the places of confinement rely on convoluted bureaucratic processes and underlying biases to evade responsibility and avoid having to make changes that might prevent or limit the harm they are able to cause in the future. The paternal structure of these institutions helps enable harm and creates pathways for that harm to be justified, but the faulty documentation processes are what make it difficult (and in many cases, impossible) for people to hold these institutions accountable for their actions and obligated to make major changes to prevent future harm. These documentation processes come in the forms of falsified medical charting in a Phoenix nursing home and disjointed investigations between different agencies/organizations, unethically simple paperwork procedure to change a patient’s code status in a Texas hospital, and the alleged inability to effectively convey a doctor’s orders in a Chicago Jail.

Dr. Thanh Nguyen repeatedly copied and pasted notes on his patients’ medical chart, which makes it difficult to know what examinations actually occurred, how thorough or brief those examinations were, and what – if any – observations were made. If Nguyen had fulfilled the required examinations and properly recorded his notes regarding those examinations, he might have made important observations and identified his patient’s pregnancy sooner. Since he falsified these records, what *actually* happened in his interactions with the woman remains unknown and the larger, institution-wide

circumstances that allowed for this situation to occur remain largely unaffected and unchanged.

In contrast, the detailed notes in Michael Hickson's medical chart are helping fuel Melissa Hickson's lawsuit because the doctors' notes do not align with their decision to abruptly change his care, pursue a code change with Family ElderCare, and end his life. Dr. Vo's recorded comments indicate that limited resources, care rationing, and his personal ableist values affected the decision to end Hickson's life. Had Drs. Vo and Cantu kept vague or brief notes like Dr. Nguyen did, it would be harder for Melissa Hickson and her attorneys to allege deliberate wrongdoing. Another bureaucratic process that contributed to the outcome of this situation is the ease and speed at which the doctors were able to get a paid third-party guardian (Family ElderCare) – who had no recent interactions with Michael Hickson – to authorize the hospital to make such a drastic and permanent change to his code status. These two entities used their institutional power and medical/legal authority to carry out the execution of a Black disabled man, and the process by which they carried out his execution is technically correct and by-the-book. This is a shining and devastating example of how bureaucratic violence enables violence and helps institutions evade responsibility for the harm they cause. If not for the doctors' detailed medical notes and Dr. Vo's recorded comments, there would be no grounds to contest what happened.

Michael Joseph Borys' complaint against Cook County and the Sheriff rested in large part on the fact that the Jail failed to fulfill the doctor's orders and provide him with his disability accommodation. The Jail cited its faulty internal communication process as causing the disconnect between the doctor and the guards. This procedural and

communication error is a bit different from the other two situations but is similar in that it still ended in harm. I would argue that his entire case against the County and Sheriff rested on the fact that the doctor *did* validate his medication and accommodation needs but the Jail failed to follow through with these orders. Had the doctor been less diligent with Borys' intake examination or failed to correctly identify his medication and accommodation needs in a timely manner, the Jail would have been much less culpable of violating their duty of care and therefore, less likely to agree to any settlement, let alone a settlement of nearly \$5 million.

Settler colonialism, patriarchy, and ableism inform the paternal structures of these carceral institutions, and the intense circumstances of unfreedom in these institutions share parallels with lack of oversight and possibility for accountability in other carceral locales. These institutions of unfreedom and captivity rely on bureaucratic violence to evade culpability/responsibility, positioning calls for redress or reform as unnecessary and even, ineligible. In the next section, I consider what intersectional, abolitionist, and decolonial feminist perspectives offer to the question of "What can be done?"

What is to Be Done?

Ruth Wilson Gilmore extends Vladimir Lenin's expansive, generative, and abolitionist question: What is to be done? Earlier chapters offer a specific analysis of how institutions cause harm, justify the harm they cause, and evade responsibility for their continued role in enabling that harm. In this chapter, I rely on critical disability studies perspectives, abolition feminism perspectives, and Indigenous feminist perspectives on how to reduce state violence and maximize people's collective well-being without legitimizing the US settler state, expanding carceral power, or clinging to rights-based

approaches. The disability rights-era mantra “Nothing about us without us” is instructive for thinking about what can be done. What can be done that does not rely on vengeance, punishment, and captivity? What can be done that addresses the maddening, sickening, and disabling conditions of occupation and colonization and embraces a vision of justice that is against the US settler state, not beside it? What can be done that does not legitimize medical/scientific so-called expertise? What can be done to resist the eugenic values that pervade US society and specifically address the violence of settler colonialism, anti-Blackness, patriarchy, and ableism?

Reform?

The rhetoric of “reform” is typically endemic of or adjacent to reformism and in opposition to abolition. Dylan Rodríguez defines reformism as “the ideological and political position that fixates on reform as the primary if not exclusive engine of social change/justice” (2020, para. 9). Whereas abolitionism seeks to radically transform society by eradicating violent logics and practices – and the institutions that carry out this violence – reformism seeks to *preserve* things as they are, save for a few isolated modifications. Rodríguez acknowledges that in cases of extreme unfreedom and violence, there can be a need to call for immediate institutional adjustments in order to preserve or save lives (Rodríguez, 2020). Ruth Wilson Gilmore defines nonreformist reforms as, “changes that, at the end of the day, unravel rather than widen the net of social control through criminalization” (2007, p. 242), and Andre Gorz insists they modify relations of power (1964). Gilmore, Gorz, and others have used this term to frame efforts that seek to improve or defend the existence of oppressed people without expanding the power of those oppressive systems.

An example of a harm reduction effort is the legislation proposed by Texas state Representative Smithee (R-Amarillo) that mandates private guardians to consult with the person's family before making end-of-life decisions. This mandate would not address the convoluted and often ethically ambiguous process of removing/granting guardianship, but it would act as a measure of harm reduction that would affect the ease and speed at which doctors like those at St. David's can change someone's code status. At Hacienda, a non-reformist reform would be the implementation of a tribal liaison to the Arizona Medical Board for any/all instances where the patient is a tribally affiliated person. At the Cook County Jail, the overhaul of pretrial detention and eradication of money bond that has occurred in the years since Michael Joseph Borys' incident is an example of a non-reformist reform; although the Jail is still incarcerating people, it is incarcerating far *fewer* people in pretrial detention.

Abolition

Dan Berger, Miriam Kaba, and David Stein discuss the tensions that abolitionists navigate, particularly regarding situations where there are immediate concerns about safety and health that need to be addressed but in doing so, might inadvertently broaden the scope of an institution's power and control (2017). Transformative justice emphasizes the need to change the conditions of what allowed harm to occur in the first place. Disabled people, especially disabled people who experience ableism and sanism alongside other, intersecting systems of oppressive power, offer poignant guidance for the question of what is to be done. Used with and alongside each other, Disability Justice and Indigenous feminisms create a different imaginary where self-determination and sovereignty meet interdependence and care.

Speaking in the context of prisons and jails, Angela Y. Davis explains that a major goal of abolition is decarceration, and a key challenge for abolitionists is to navigate the balancing act of working to create more humane, habitable environments for people [in prison] without bolstering the prison system and our society's reliance on captivity and punishment (2003). In the context of the medical industrial complex and the places of captivity where medical and psychiatric authority reign supreme, one important element of abolition is the deep and continuous rejection of the so-called 'expertise' that bolsters such authority.

Rose Braz, the late member of Critical Resistance explains, "A prerequisite to seeking any social change is the naming of it...in other words, even though the goal we seek may be far away, unless we name it and fight for it today, it will never come" (Bennett, 2008). Whether calling for the overhaul of information and communication systems in a Chicago jail, supporting legislation that curbs the power of third-party guardians in Texas, or reconfiguring the makeup of a state medical board in Arizona, it is essential to work for actionable measures that can increase livability while still imagining otherwise and working toward long[er]-term efforts that condition the possibilities for something else.

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