

# **Negotiating the Capability Imperative: Enacting Disability Inclusion in Medical Education**

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## Abstract

Medical education is a critical site for disability inclusion. Despite increased attention to diversity, equity, and inclusion, disabled medical students report enduring marginalization that reveals deeply-rooted inequities in medical systems and education.

This thesis presents a grounded theory of disability inclusion at four U.S. medical schools. Following a constructivist grounded theory methodology, I iteratively conducted and analyzed 52 semi-structured interviews with 19 disabled medical students and 27 school officials. Relevant medical school policies and observations of physical spaces comprised additional data sources. Theories from the field of disability studies, primarily studies in ableism and crip theory, were engaged to interpret findings.

Student and school-official interactions with inclusion were informed by a flawed, dichotomous cultural logic of medical education, *the capability imperative*. Dominant conceptions of disability as individual inability contrasted with expectations of hyper-ability in medicine. Student and school-official accounts illuminated the capability imperative, which consists of three motifs: selfless superhuman physicians, the “real world” of medicine, and the malleable student. Together, these conditions demanded that students fit existing medical training environments. Competing, alternative conceptualizations of disability supported actions beyond rejection of disability or exclusion, however, the *legibility* of a student’s experience moderated understandings of disability and associated inclusive actions.

I theorize disability inclusion in medical education as a process of *negotiating the capability imperative*. Students and school officials negotiated barriers to access depending on perceived consequences to seeking or making change. They *upheld* or *worked* the capability imperative to meet, or enable students to meet, existing expectations. Some actions resisted the capability imperative, through attempts to *resignify capability*. These negotiations illustrated an ableist hegemony at work, requiring hyper-able performances but with opportunities for subversion. An accommodations-focused approach to inclusion that individualized disability and access supported this hegemony. As a result, disability inclusion in medical education remains incomplete and requires transformation.

In response, I reimagine educational structures that value disabled medical professionals. Fueled by a politics of crip futurity, this transformative vision is grounded by universal design, reconceptualizes notions of capability, and fosters disability epistemology in professional identity formation.

For Dad and Ronald, who always knew I could do this—even when I did not.

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# Reading Guide

## Key Acronyms

AAMC	Association of American Medical Colleges
ADA	Americans with Disabilities Act (1990)
ADAAA	Americans with Disabilities Act Amendments Act (2008)
ACGME	Accreditation Council for Graduate Medical Education, the accreditation body for GME sponsoring institutions and residency and fellowship programs.
AHEAD	Association on Higher Education and Disability
GME	Graduate medical education, the period of medical training beyond completion of the M.D. degree in the US, including residency and fellowship.
LCME	Liaison Committee on Medical Education, the accreditation body for UME in the US and Canada.
UD	Universal design
UME	Undergraduate medical education, the first period of medical training to achieve the M.D. degree in the US. Students generally enter UME after completing at least a bachelor's degree program.

## Notes on Terms and Style

### Language of disability

In this thesis, I intentionally move between person-first (e.g., person with a disability, student with autism) and identity-first language (e.g., disabled person, autistic student). This recognizes the contested matter of preferred language among persons with disabilities (Dunn & Andrews, 2015; Zola, 1993), including those who participated in this research. Moreover, because I do not subscribe to a bifurcated conceptualization of impairment and disability, I generally do not distinguish between the two in writing (Kafer, 2013; Shakespeare, 2013).

### Bodymind

I use the term bodymind (rather than “body and mind” or alternating between the two) in recognition of the imbrication of mind and body and in resistance to Cartesian dualism (Price, 2015). In the spirit of crip politics the use of bodymind aims to “bring mind more centrally into debates” (Price, 2015, p. 271) about ableism, disability, and inclusion.

### Use of singular “they” pronoun

When a participant's gender is not central to the matter under discussion, I use the singular “they” pronoun as a tool to anonymize participant quotes or references to a specific participant. Furthermore, the singular “they” is used as an inclusive non-gendered pronoun when referring to a generic person (APA, 2019).

### **Participant quotes**

Throughout this thesis, participant quotes are italicized and followed by a reference to the participant number and their role (i.e., student or school official).

### **Italicized terms**

A technical term or concept is italicized the first time it is used and generally followed by a definition or explanation. After this, the term is not italicized or in quotes, except in the Conclusion, where concepts developed in the thesis are italicized for emphasis.

# Chapter 1. Introduction

## Seven Career Recollections

*I am talking to a group of health science faculty about a prospective student who uses a wheelchair. The student exceeds the admission requirements, but the faculty are unsure whether the student will be able to perform necessary procedures in the clinic. We talk about the possibility of height-adjustable beds and exam tables. The faculty say some hospitals have them but the attending physician determines the height during procedures and they could not be asked to change their practice for a student.*

*A student comes to see me, she saw me speak at orientation and says it gave her courage to talk to someone about her disability. She was not sure accommodations would be available in medical school and she is still uncertain whether she will use them. She wants to try to do it without “extra help” to help her prepare for the future.*

*I realize I have spent over 10 hours working with a student to assemble their request for accommodations on the national licensing board exam. The student has spent even more time than that tracking down early school records, writing a personal statement, getting updated testing, and asking former employers for letters of support. After waiting over 60 days for a decision, the request is denied. We get to work on an appeal.*

*A student calls who has migraines and needs a place to take medication and lie down to recover during his clinical rotations. I talk to the faculty and they say no, this is not possible. Students cannot access beds and, by the way, how will he function in a future job? I call the person responsible for employee accommodations at the hospital. They tell me this is a common accommodation and describe how they manage it with clinical employees. I eventually work out the accommodation with the program.*

*A student struggles throughout medical school to keep up with course load expectations, teaching styles, and performance requirements. The student works intensively with our learning specialist, several supportive faculty members, and me. Together we identify accommodations, strategies, and other ways to support the student’s participation. The student ultimately excels and matches in a competitive residency.*

*I notice that many of the accessible bathroom stalls around campus have a curtain around them, much like the curtains that separate patient beds in hospitals. We ask someone in facilities about it and they tell us this design offered a way to create accessible stalls without fully renovating the bathrooms.*

*A program decides to ban laptops to address concerns that students are not paying attention during lectures. The students I work with who require laptops to take notes and magnify materials now need accommodations to use a laptop in class. Several students stop using their laptops because now they have to explain themselves to their peers if they do.*

## **The Problem of Inclusion**

I became captivated by the matter of disability inclusion in health science education in 2007, when I began my first role as a university disability services coordinator. Since that time, I have worked in various capacities to implement and advance disability inclusion in health science education. These snapshots represent enduring moments from my professional experiences. I offer them to illustrate some of the everyday injustices that permeated student experiences, the labor required to seek and ensure access, and the successes that sometimes followed.

As a practitioner, I was increasingly wary of my part in a system of biocertification (Samuels, 2014), requesting and evaluating medical documentation to “prove” disability status and unlock rights. In turn, there was a never-ending bureaucratic process to access those rights. Although I worked with colleagues to shift these practices, to make them less burdensome, we were always starting from behind in the work. We were putting out inaccessibility fires more often than we could keep them from flaring. Preventative work showed promise but was not always possible. Ultimately, levers of power were limited. I was working within a system, trying to continually improve the work and cultivate new perspectives among colleagues. I could not help feeling my efforts were insufficient and I was continuously reinventing the wheel.

After eight years in the field, my colleague convinced me that we should join forces with others in our professional community to formally share what we had learned with others, to advance practices in the area. The result was a book based on our collective professional knowledge and interpretations of the legal standards that underpinned our work (Meeks & Jain, 2016). Although proud of this work, I was cognizant that there was much we still did not know. Empirical study in the field, especially that was informed by student voices, was thin. What could we not see or know that might be necessary to advance inclusion practices?

Beyond our anecdotal experiences of success, did our practice improvements sufficiently shift student experiences? My professional journey was the impetus for this thesis.

Harding's (1991) feminist exploration of science highlighted the challenges inherent in bringing people and subjects into areas of thought that have been "defined against [the] other" (p. 20). Harding's (1991) exploration holds resonance for disabled people and medicine. Disabled people have had a long, complicated relationship with medicine that persists today (Clare, 2017; Mingus, 2015). At once reliant on medicine for life-sustaining treatment, access to necessary benefits, and enabling interventions, disabled people have also been simultaneously repelled by a "long history of medical abuse" (Kudlick, 2013, p. 543) and medicine's pursuit of "disabled people's erasure, both literally and figuratively" (p. 543). As Dolmage (2017) explained, eugenics and associated practices such as institutionalization were built by, promoted through, and ultimately sustained academia, in particular, academic medicine and medical education. Dolmage (2017) demonstrated that threads of these eugenic roots remain present today. One need only look to the COVID-19 pandemic to see quick movements to justify medical rationing practices that endangered and devalued disabled people's lives (Ne'eman, 2020; Shapiro, 2020; Singh, 2020; Wong, 2020). That medicine historically failed and continues to fail disabled people is well-established.

Studies have found that disabled people experience worse health outcomes than their non-disabled peers, and that this cannot be attributed solely to their impairments (National Council on Disability [NCD], 2009; World Health Organization [WHO], 2011). Some examples of systemic barriers include inaccessible medical facilities and diagnostic equipment, as well as healthcare professionals' limited understanding of disability and their responsibilities under the Americans with Disabilities Act (ADA; Agaronnik, Campbell, Ressalam, & Iezzoni, 2019a, 2019b; Agaronnik, Pendo, Campbell, Ressalam, & Iezzoni, 2019; Mudrick, Breslin, Liang, & Yee, 2012; Mudrick, Swager, & Breslin, 2019; NCD, 2009; WHO, 2011). Disabled people at the intersections of marginalization, due to their racialized, ethnic, or gendered social locations, experience heightened barriers to access and their health outcomes are further diminished (Disability Rights Education and Defense Fund, 2018; Yee et al., 2018). These well-established circumstances point to medicine's systemic inadequacies that inhibit the provision of adequate care for people with disabilities.

In addition to the need for structural, environmental, and educational reform in the realm of healthcare and disability, increasing the number of physicians with disabilities is one proposed mechanism to shift educational environments and health outcomes for disabled patients (Iezzoni, 2016; McKee, Smith, Barnett & Pearson, 2013; Meeks, Herzer, & Jain, 2018; Ouellette, 2013). Some argue that disabled people, through their positionalities or disability epistemologies, have the potential to positively inform their educational settings,

their work with the public, and influence their professional discipline (Fergus, Teale, Sivapragasam, Mesina & Stergiopoulos, 2018; Garland-Thomson, 2017; Iezzoni, 2016; Mogensen & Hu, 2019). This follows Allport's (1954) contact theory, which posits that intergroup contact of people at equal statuses working together towards a common goal can shift negative attitudes and stigmatization. Meeks, Poullos, and Swenor (2020) demonstrated this potential in their depiction of a program that offered opportunities for undergraduate premedical students and foreign medical graduates to shadow a physician with a disability. Returning to Harding (1991), however, larger questions are at stake behind the pursuit of equity, begged by the persistent problem of healthcare access for disabled people. What does it mean to bring disabled people into the field of medicine, a field defined against disability? How does that inclusion meaningfully happen? What about medicine must change in response, and how is this happening now?

Students with disabilities remain underrepresented in U.S. medical education. Studies of prevalence suggest that representation has increased over time, with the most recent figure showing that 4.6% U.S. of medical students disclosed a disability to their school (Meeks, Case, Herzer, Plegue, & Swenor, 2019). The vast majority of these students had non-apparent disabilities such as ADHD, psychological, learning, and chronic health disabilities (Meeks, Case, et al., 2019; Meeks & Herzer, 2016). Despite a noted increase shown in the 2019 study (Meeks, Case, et al., 2019), the number of students with physical and sensory disabilities remains relatively consistent with historical data (see, e.g., Eickmeyer, Do, Kirschner, & Curry, 2012) making up only 0.3% of all medical students. The overall figure of 4.6% demonstrates continued underrepresentation in that it remains short of disability prevalence in the general population, which is 14.4% among similar-aged peers (D. Taylor, 2018). Moreover, as Meeks, Case, and colleagues (2019) concluded, an increase in overall prevalence is promising but says little about students' qualitative experiences with their medical schools.

Recent advances in the legal realm also show promise for inclusion in U.S. medical education. Historically, health professions programs were able to use the courts' deference towards academic medicine to limit access for disabled students (Francis & Silvers, 2015; Ouellette, 2013). Students with disabilities and their advocates have challenged this traditional deference using the renewed Americans with Disabilities Act Amendments Act (ADAAA, 2008). These efforts have broadened the standard for what constitutes reasonable accommodations (see, for example, *Argenyi v. Creighton University*, 2013; *Dean v. University at Buffalo School of Medical and Biomedical Sciences*, 2015; *Featherstone v. Pacific Northwest University of Health Sciences*, 2014; *Palmer College of Chiropractic v. Davenport Civil Rights Commission*, 2014). At the same time, medical schools still hold the ability to set standards that need not be altered for the purpose of inclusion (*McCulley v. University of*

*Kansas School of Medicine*, 2015). Along with the increase in numbers of students requesting accommodations, advances in legislation and legal precedent have sparked renewed efforts to ensure equal access to the complex curriculum (Bagenstos, 2016; Meeks, Bisagno, Jain, & Herzer, 2015; Meeks & Jain, 2016, 2018; Meeks, Maraki, Singh, & Curry, 2020; Meeks, Montgomery, & Moorehead, 2017). For students with disabilities in medical education, then, progressive legislation has often provided the “stick” to drive disability access efforts. While these pressures have advanced change, systemic barriers remain, which may subvert gains if not appropriately addressed (Meeks & Jain, 2018).

Advances in disability access are congruent with the wider diversification movement in medicine, which contends that diversity and inclusion contributes to overall excellence and that the physician population ought to be representative of the general population (Cohen, 1997, 2004; Cohen, Gabriel, & Terrell, 2002; DeLisa & Lindenthal, 2012; DeLisa & Thomas, 2005; Nivet, 2011, 2015). This move towards diversity in the profession is supported by research that shows physician-patient concordance benefits health outcomes (Saha & Beach, 2020; Street, O’Malley, Cooper, & Haidet, 2008). Despite these gains and stated aims, however, research and first-person accounts demonstrate that medical students, who embody this diversity, nonetheless experience persistent marginalization during their training (Ackerman-Barger, Boatright, Gonzalez-Colaso, Orozco, & Latimore, 2020; Anonymous, 2019; Binder, Garcia, Johnson, Fuentes-Afflick, 2018; Bulk et al., 2017; Mansh et al., 2015; Meeks & Jain, 2018; Robertson, 2017; Shrewsbury, 2015). These findings suggest that more work is needed to meaningfully advance inclusive ideals in medical education. Exploration of how and why marginalization persists, including a deeper understanding of how inclusion efforts currently operate, the associated dynamics, benefits, and limitations at play, would aid this effort. This thesis delves into these concerns, focusing on disability inclusion as the site of interest. The central research question driving this study was:

*How is disability inclusion enacted at the participating medical schools?*

## **Structure of the Thesis**

This thesis offers a constructivist grounded theory (Charmaz, 2014) about how disability inclusion operated at four U.S. medical schools. The theory is built from the perspectives of students with disabilities and school officials (faculty and administrators) from those schools, reflecting their lived experiences in the process of inclusion. Data also included observations of physical spaces and analysis of policies. In the remainder of this introduction, I provide an overview of how this thesis and its major arguments unfold.

**Chapter 2** lays the initial theoretical foundations for the study with regard to disability and inclusion practices. The first part of the chapter discusses philosophical debates



concerning disability. This offers divergent theoretical framings of disability informed by realist and constructivist ontologies and epistemologies that will be used as theoretical tools to analyze data later in the thesis. I focus on the realist or individual medical model, the social and minority models, ableism and crip theory, and the political/relational model. For each, I note their major implications and discuss critiques that have been leveled against them. I locate my allegiance with the political/relational model (Kafer, 2013), a way of understanding disability informed by feminist and queer theories of disability. The second part of the chapter discusses the two main approaches to disability inclusion discussed in the literature of U.S. higher education: accommodations and universal design (UD). Because empirical study of inclusion in medical education is thin, I widen the gaze to higher education more generally, and then offer relevant findings from the medical education literature. I conclude that research into disability inclusion in medical education that centers the perspectives of students, takes a relational approach to disability, and incorporates perspectives of school officials, inclusion policies, and physical spaces is not yet available.

**Chapter 3** continues to lay the foundations of the study by describing the research methods upon which it is based. Part one locates the epistemology in social constructionism, the theoretical perspective in symbolic interactionism and disability studies, and the methodology in constructivist grounded theory. I describe the methods used, which included interviewing, unobtrusive observation of physical space, and document analysis. Part two locates the study and participants, describing how the four medical schools and 46 participants (19 students and 27 school officials) were recruited. I provide some background information concerning the schools and demographic details to highlight student and school-official participants' social locations. In part three of the chapter, I describe the iterative data analysis process used, in line with a constructivist grounded theory approach. I also discuss considerations and limitations of the study, including research ethics, saturation, representation, and Charmaz's (2014) criteria to evaluate constructivist grounded theory studies: credibility, originality, resonance, and usefulness. I close the chapter by exploring my reflexivity through the research process.

**Chapter 4** begins the presentation of substantive findings and arguments, focused on participants' ways of knowing disability that informed their interactions with inclusion processes. I describe four characterizations of disability evident in participant accounts: individual inability; contextual production; valuable; and a legal construct. Then, I develop the construct of legibility to further characterize ways of knowing disability and how this influenced connections to inclusive possibilities. I found that some experiences of disability—especially those that conform to disability stereotypes—were the most legible, while other experiences of disability were less so. Aspects of legibility influenced a student's legitimacy

as a disabled person and the ability to imagine whether and how they could be included in medicine. In the final section of the chapter, I characterize the ways students and school officials navigated inclusion in relation to their ways of knowing disability. I ultimately argue that participants' understandings of disability and, therefore, their interactions with inclusion, were overshadowed by a characterization of disability as individual inability. At the same time, alternative conceptions of disability opened the possibility for subversive action.

**Chapter 5** continues the presentation of findings, charting how participants knew medicine and how such epistemic assumptions regarding medicine influenced disability inclusion. Here it is argued that understandings of medicine were underpinned by what I refer to as the “capability imperative.” Building from McRuer (2006), I suggest this is a context-specific manifestation of ableism that demands hyper-able-bodiedness and mindedness. Understandably, this further challenged the pursuit of disability inclusion. The capability imperative is expounded through three motifs, including the superhuman physician, the “real world” of medicine, and the malleable student. These three motifs encapsulate the demands made of individual professionals within the medical field, and for students in training. The superhuman physician must be capable of being and doing all things, does not show weakness, and does not have personal needs. The “real world” of medicine constructed future phases of training and practice as a fixed and unmalleable space that trainees must be equipped to survive. This construction implied the need for malleable medical students. That is, medical education demanded students who could comply with a singular path of training and maintain their own wellness despite the demands placed upon them. I depict the ways that this rendered disabled students as misfits (Garland-Thomson, 2011), and how students attempted to fit the context and the challenges therein.

**Chapter 6** brings together the findings presented in Chapters 4 and 5 to construct a grounded theory of inclusion in medical education, through a process of *negotiating the capability imperative*. This chapter progresses in three parts. The first establishes that students with disabilities occupy a continually precarious status in medical education. The primary mode of inclusion—accommodations—presented a paradox that required students to risk being perceived as incapable in order to access uncertain inclusion. This prompted students and school officials to engage in a negotiation.

In part two of the chapter, I characterize the ways that students and school officials negotiated risk and resignified capability: through upholding the capability imperative, working the capability imperative, and resignifying capability. The first two categories of action tended to conform to existing notions of capability, thereby representing attempts to normalize. Resignifying capability represents overtly subversive and political acts to reform collective notions of capability in medicine, as well as more covert attempts (crossing into

upholding or working the capability imperative) that found subversive potential within existing expectations.

In part three of this chapter, the theoretical implications of negotiating the capability imperative are discussed. The process is discussed in light of Campbell's (2001, 2009a) theory of ableism, McRuer's (2006) compulsory ablebodiedness, and Butler's (1988, 1990, 1991) explanation of heterosexual hegemony and performativity. I suggest that these theories help to understand the ways that participants performed and subverted hyper-abledness. Then I return to critiques of the primacy of accommodations in disability inclusion in U.S. higher education, initially discussed in Chapter 2. I suggest that the theory of negotiating the capability imperative lends support to critiques of the individualizing effects of accommodations as a means of inclusion, which tends to uphold systems of ableism and limits inclusive possibilities. Finally, I argue that disability inclusion remains incomplete in medical education, tending towards inclusionism (Mitchell & Snyder, 2015), and suggest that mechanisms for inclusion require reconsideration.

**Chapter 7** employs a politics of crip futurity (Kafer, 2013) to imagine transformative possibilities for medical education, designing from a disability perspective. This chapter represents a crippling project, closely located with theories of UD. The transformation focuses on two areas: reconceiving capability and fostering disability epistemology in professional identity formation. I reconceive of capability related to productivity, time, pluripotency, and independence. Disability epistemology is imagined to have a prominent place in curriculum and pedagogy as well as in community development and mentoring. This transformative vision aims to dismantle the capability imperative and build a more capacious understanding of capability through structural change.

**Chapter 8** provides concluding remarks and brings the thesis to a close. I reflect on my personal evolution through the research process, summarize the key arguments made throughout, consider the contributions to knowledge made by the study, and explore future research directions.

## **Chapter 2. Theorizing Disability and Inclusion in Higher and Medical Education**

### **Introduction**

To explore disability inclusion in medical education, one must understand the larger debate about the nature of disability. This is a major topic of contestation in disability rights movements and the related academic field of disability studies that expose various ontological positionings of disability and the suppositions and social arrangements that follow. This body of work offers rich theoretical tools to deconstruct experiences of disability, policies, physical space, and attempts at inclusion. These understandings provide a foundation from which to interpret disability and inclusion experiences and identify alternatives.

Within U.S. higher education, approaches to disability inclusion are firmly guided by disability law, alongside subsequent regulatory guidance and case law (Grossman, 2014; Laird-Metke & Moorehead, 2016). Scholars of disability inclusion in higher education have examined the law, existing practices, and their effects to identify and critique mechanisms for inclusion and their efficacy. The primary mechanisms for inclusion in higher education are accommodation and UD, which reflect divergent theories of disability (Dolmage, 2017). With the purpose to prepare for a specific career and its traditionally exclusive nature, medical education challenges inclusive possibilities (Boursicot & Roberts, 2009; Razack, Hodges, Steinert, & Maguire, 2014). At the same time, research and scholarly writing illustrate a history of disabled peoples' success in medicine that cannot be ignored. Further examination of the research reveals a relatively small amount of empirical work and that which does exist is narrowly informed by disability theory.

In response, this chapter outlines the theorizations of disability and its intersections with higher education as it relates to medicine and is divided into two parts. The first is focused on philosophical (i.e., ontological and epistemological) debates concerning disability. The second part explores the practice of inclusion in higher and medical education with attention to the two main mechanisms for inclusion: accommodations and UD.

### **Part I. Theorizing Disability**

The ontological positioning of disability is a fundamental matter that underpins this research. The debate over the construct of disability has been the focus of the disability rights movement and the field of disability studies (Goodley, 2017; Shakespeare, 2013). The ontological positioning of disability informs the epistemic tools used to examine disability experiences, how disability is theorized, and the possible actions and social arrangements—the politics—that follow from the research. At the same time, the ontological positioning of

disability adopted, implicitly or explicitly, within a social space informs how disability is framed, understood, and treated.

Broadly speaking, research in the field of disability studies hinges upon questioning a realist understanding of disability. Within the field, however, positions differ in the degree to which “realness” is questioned. To explicate the spectrum of positions about disability, I group these into two positions: the *realist* and the *constructivist*. Within each position, I outline the central argument, the promises of the position, and the limitations. In the constructivist position, I describe two key variants of thought in disability studies:

1. the social and minority models of disability, and
2. ableism and crip theory.

These are not the only schools of thought within disability studies (Goodley, 2017; Oliver, 1996; Shakespeare, 2013; Withers, 2012). Indeed, disability studies can be understood as a spectrum of thought under a broadly-conceived constructivist umbrella. However, these constructivist positions represent the theoretical strands most relevant to this thesis. Comparison of these positions on the constructivist spectrum also allow for clearer differentiation. Then, I locate my position—and the rationale for it—which is broadly consistent with Kafer’s (2013) *political/relational model*. This position is heavily informed by several interpretations of constructivist approaches, which I outline to explicate and justify this position.

### **Realist position**

Most disabled activists and academics in disability studies work in opposition to a pure realist notion of disability (Linton, 1998). A realist account assumes that disability is an objective fact. A diagnosis and the experiences that follow can be known through positivist framings that place norms around measurement and evaluation criteria that are supposedly objective and free of bias. According to this logic, there is no meaningful distinction between a diagnosis and disability (Oliver, 1996). The extension of this “neutral” framing thereby translates these conclusions as if something is inherently wrong, defective and pathological, within the person and the goal is to cure, overcome, or eliminate it (Campbell, 2009a). The experience of disability is, therefore, understood as a personal tragedy that results in shame and suffering (Oliver, 1996). This sets up an essential nature to disability: it is a fact of the body with negative outcomes. In other words, “individual conceptualizations of disability. . . require impairment to be treated as if it is the cause of people’s lack of participation in education, employment, leisure, and love” (Titchkosky, 2011, p. 5). Within this realist position sits conceptualizations referred to as the medical, moral, individual, tragedy, and eugenics models of disability (Goodley, 2017; Linton, 1998; Oliver, 1996; Withers, 2012).

The solutions and responsibilities that follow from a pure realist approach are largely individual. Within this frame, individuals should seek medical care and rehabilitation to aid in cure and elimination of disability (Campbell, 2009a). This sets up what Kafer (2013) refers to as the *curative imaginary* “an understanding of disability that not only *expects* and *assumes* [medical] intervention but also cannot imagine or comprehend anything other than intervention” (p. 27). If the impact of the disability cannot be eliminated through medical care or rehabilitation, the individual must adjust to their condition as a person with a disability through treatment and individual will (Goodley, 2017). Because society is not directly implicated in individual problems, there is no fundamental duty for a societal response (Hahn, 1988).

Thus, any positive action towards disability is benevolent, supporting a charity-oriented approach (Fleischer & Zames, 2011). Furthermore, because disability is undesirable, it follows that sequestering disabled people from public life is reasonable (Schweik, 2009). This allows for social exclusion of people with disabilities, with inclusion only to the degree society or private entities determine are practical in acts of beneficence. As the problem is within the person, eliminating a fetus, euthanasia, or sterilization may be deemed reasonable to rid a person (or possibility of a person) of a life with the “unfortunate” experience of disability (Kafer, 2013; Longmore, 2009; Ouellette, 2015; Saxton, 2013).

The promise of the realist position is that innovations in medicine and technology will be able to name and resolve the problem—to free a person from disability. A diagnostic label affords a person treatment, access to rehabilitation, and other life-saving and sustaining services (Clare, 2017; Goodley, 2017; Graham & Tancredi, 2019; Linton, 1998; Shakespeare, 2013; Wendell, 1996, 2013). Viewing a diagnosis or disability as a devastating problem fuels philanthropy, fundraising, medical research, and technological developments that promise to improve disabled peoples’ lives (Clare, 2017; Fleischer & Zames, 2011; Mitchell & Snyder, 2015; Withers, 2012). Furthermore, a realist position validates negative experiences of disability. For example, a person may experience pain, suffering, depression, or physical restriction as negative aspects of their embodiment that they may not wish to experience (Shakespeare, 2013; Wendell, 1996).

To acknowledge limitations to the realist position is perhaps an understatement, given the atrocities that have flowed from realist and supposedly objective positions, such as eugenics, that continue to influence modern understandings of disability (Davis, 1995; Pfeiffer, 1994; Snyder & Mitchell, 2002). The realist position presumes the existence of a body that is normal and natural, which disability represents deviation from. This presumption denies that conceptions of normal have changed over time and place, often fabricated through dubious processes (Davis, 1995). These changes suggest not a shift in “reality” but rather that

ideas of normality and deviance are themselves constructed phenomena. Under the assumptions embedded in the realist position, however diagnosis, treatment, and lived experience are not socially mediated. An experience, therefore, is not “real” until it can be medically labeled. This denies peoples’ lived experiences until classified through medical research and certified by a medical professional (Wendell, 1996, 2013). This faith in a supposed scientific objectivity, however, obscures the role of social inequities, barriers, and bias in access to care, medical professional conduct, labeling, research, treatment, and outcomes (Annamma, Connor, & Ferri, 2013; Baynton, 2001; Carel & Kidd, 2017; FitzGerald & Hurst, 2017; Hairston, Gibbs, Wong, & Jordon, 2018; Longmore, 2009). By deputizing medical and rehabilitation professionals to identify what conditions are real and to determine treatment, disabled people are excluded from choice, control, and leadership of their own lives (Linton, 1998; Oliver, 1996).

This positioning, furthermore, ignores the role that social arrangements and practices such as architecture, pedagogy, and economic systems play to further constrain and oppress disabled people from access to social life (Linton, 1998; Oliver, 1996). With charity rather than widespread social change as a “solution,” disability becomes a business. Disabled people become a product used to generate income and, in order to demonstrate the value of charity, they must promote narratives of “overcoming” disability (Withers, 2012). Withers (2012) argued this ultimately benefits non-disabled people through the feel-good avoidance of disability generated by giving but ultimately limits support for disabled people’s everyday lives. Furthermore, because disability is treated as inherently negative in the realist position, there is no room for a positive or neutral interpretation of disability.

Despite the evolution in treatment of people with disabilities over time, as evidenced by the progress of disability rights legislation worldwide, the realist formulation of disability remains the most dominant, taken-for-granted position in society. Disability rights activists and disability studies scholars have critiqued these taken-for-granted, deficit-oriented formulations of disability. Instead they argue that disability is “powerfully shaped by social forces” (Shakespeare, 2013, p. 12) and seek to shift “disabling socio-political and cultural practices” (Goodley, 2004, p. 123).

### **Constructivist positions**

Within constructivist positions, the location and cause of disability shifts. Rather than a fact of the body, disability is constructed through social, political, and cultural practices. I begin with a discussion of the social model of disability prominent in the UK and its American counterpart, the minority model (Hahn, 1985a, 1985b; Longmore, 2009; Oliver, 1996; UPIAS, 1975). Then I move to a differing constructivist orientation found in studies in ableism

(Campbell, 2001, 2009a, 2017, 2019) and associated ideas from crip theory including compulsory able-bodiedness and able-mindedness (McRuer, 2006; Price, 2015; Thorneycroft, 2020; Thorneycroft & Asquith, 2019).

### *Social and minority group models*

In the social model, disability is conceived of as oppression created by social barriers. This position was initially formulated by activists in the UK, the Union of the Physically Impaired Against Segregation (UPIAS, 1975), and further developed by disabled scholars (Oliver, 1996). This variant is also referred to as the *materialist* or *strong social model* (Shakespeare, 2013). In this formulation, people have impairments (the embodied experience) but society disables them through discriminatory practices that create physical inaccessibility, social isolation, economic dependence, and removal of choice and control (Oliver, 1996). Thus, impairments themselves are not theorized as socially constructed and are treated as neutral. Instead, the focus is on how disability is constructed by societal arrangements and attitudes.

Closely related to the social model is the minority model of disability (Hahn, 1985a, 1985b; Longmore, 2009). This conception of disability arose in the US in the 1970s and 1980s and drew inspiration from other civil rights movements (Hahn, 1985a). In this framework, disabled people are an oppressed minority group entitled to legal protection. The minority model differs from the U.K. social model through a less firm divide between impairment and disability, instead conceiving of disability as more of a relational construct, one that sits between a stigmatized body and social arrangements (Longmore, 2009). Longmore (2009) asserted the connection between the two models, “both paradigms shift the focus from individuals and pathologies to institutions and ideologies” (p. 2). Research following from this understanding “critically analyzes the ideas about disability that have shaped societal organization and public policies, cultural values and architectural design, individual behavior and interpersonal encounters, professional training, and delivery of services” (Longmore, 2009, p. 2). Both the social and minority models have been influential in disability rights movements across the world (Charlton, 1998; Driedger, 1989), subsequent public policy developments (Scotch, 2000, 2001), and academic work in disability studies (Linton, 1998; Oliver 1996).

The promise of the social and minority models is a non-disabling society. The models operate as political tools that foster collective organizing (Goodley, 2017; Linton, 1998; Oliver, 1996). The move away from individuals as inherently problematic to a problematization of societal arrangements holds the potential for disabled peoples’ liberation (Shakespeare, 2013). If disability is created by society, the response must be societal. The proposed resolution to the social problem of disability, then, is to remove the societal barriers



that create disability (Oliver, 1996; Shakespeare, 2013). This necessitates policy development to fuel architectural changes, the provision of accommodations (adjustments to policy and practice), and the recognition of rights to allow disabled people equivalent access to social and economic activities (Scotch, 2000). Under these models, key sites of change include education, employment, independent living in the community, and access to public services such as businesses, transportation, and telecommunications (Donoghue, 2003; Goodley, 2017; Oliver, 1996). Furthermore, leadership by disabled people is necessary to remediate social oppression, calling for coalition around a collective identity (Garland-Thomson, 1997; Linton, 1998; Oliver, 1996).

Although the social and minority models of disability have been life-changing for many disabled people, they too have limitations. In the U.K. social model, the insistence on a firm divide between disability and impairment has generated significant critique from feminist, poststructuralist, and critical realist scholars, as well as those with chronic illnesses (Crow, 1996; Garland-Thomson, 1997; Hughes & Paterson, 1997; Kafer, 2013; Morris, 1991; Shakespeare, 2013; Wendell, 1996, 2013). These arguments suggest that separation of the embodied experience (e.g., pain, depression) from disability has led to their omission from the political sphere. This separation fails to recognize that the body itself is social, experienced and interpreted through discourse (Crow, 1996; Hughes & Paterson, 1997; Kafer, 2013; Morris, 1991; Wendell, 1996, 2013). Furthermore, some contend that the framing and resolutions offered under the social model are most beneficial for those with physical impairments, or the “healthy disabled” (Wendell, 2013, p. 162), whose status is fairly static and, therefore, their accommodation requirements are more straightforward. In contrast, those with chronic illness and mental disabilities<sup>1</sup> may experience a more dynamic interplay between their impairment and society, necessitating more flexible and shifting solutions. Although some have moved beyond the social model, due to its perceived dogmatism and the tiresome debates it spawns (Shakespeare, 2013; Thorneycroft, 2020), others have argued for an anti-foundationalist shift to the social model that makes space for the breadth of disability experiences. This would allow for the model to hold a more nuanced, but united, politic (Goodley, 2004). A more capacious social model, for example, would recognize that “disabled people experience impairment, as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction” (Hughes & Paterson, 1997, p. 337).

The social model, the minority model, disability rights movements, and indeed the field of disability studies are limited by their inattention to intersectionality. *Intersectionality*

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<sup>1</sup> *Mental disabilities* is an inclusive term for psychiatric, cognitive, and intellectual disabilities promoted by Lewiecki-Wilson (2003) and Price (2011).

(Crenshaw, 1991) theorizes that lived experiences at the intersection of two or more marginalized positions<sup>2</sup> “cannot be captured wholly by looking at the . . . dimensions of those experiences separately” (p. 1244), thus highlighting “the need to account for multiple grounds of identity when considering how the social world is constructed” (p. 1245). Taking this concept into the realm of disability, intersectionality demands that to fully understand and seek justice for all disabled people, it is insufficient to look at disability in isolation.

The critiques of disability movements and scholarship on these grounds have targeted oversimplified comparisons between experiences of disability and those of other marginalized groups, inattention to the ways disability experiences differ in bodyminds that are gendered, racialized, and/or queer, and work that does not recognize how constructions of disability are inextricably entangled with other systems of oppression (Annamma et al., 2013; Baynton, 2001; Bell, 2017; Clare, 1999; Erevelles & Minear, 2010; Garland-Thomson, 1997; Hirschmann, 2013; Kafer, 2013; McRuer, 2006; Miles, Nishida, & Forber-Pratt, 2017; Morris, 1991; Samuels, 2003; Stuart, 1992; Vernon, 1999; Withers, 2012). These concerns, for example, inspired Bell’s (2017) piece, “Is Disability Studies Actually White Disability Studies?” These critiques have prompted work that brings together disability studies with feminist, critical race, and/or queer theories to form new theoretical and political tools that better account for co-constitutive social forces and encourage cross-movement organizing (Annamma et al., 2013; Bailey & Mobley, 2019; Kafer, 2013; McRuer, 2006; Sins Invalid, 2019; Wendell, 1989; Withers, 2012). These theoretical advances, informed by intersectionality, call for consideration of disability experiences in their heterogeneity, with broader attention to multiple axes of difference and the colluding forces of sexism, racism, cis-heteronormativity and nationalism rather than a singular focus on disability.

A final critique of the minority model and other civil rights approaches to disability is that they focus on the elimination of discrimination and rely on liberal, market-based solutions to inequities and, therefore, insufficiently challenge normativity (Dossa, 2009; Mitchell & Snyder, 2015; Shakespeare, 2013; Withers, 2012). As Withers (2012) explained, rights-oriented models focus “on getting disabled people access to society and changing it only as much as is necessary to establish their desired rights. . . [not] to fundamentally restructure society” (p. 82). This narrow focus ensures that normative structures remain centered and realist conceptions of disability are not dismantled (Donoghue, 2003). I will return to this critique and respond to it in Chapters 6 and 7.

Furthermore, Mitchell and Snyder (2015) demonstrated that rights-based discourses have been co-opted in neoliberal societies to limit the effects of inclusion and promote

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<sup>2</sup> Crenshaw (1991) addressed the experiences of Black women.

normalization. I will return to these arguments when I discuss accommodations and UD for higher-education inclusion later in this chapter. As an alternative, Shakespeare (2013) argued for redistribution alongside the recognition afforded through a rights approach, citing the feminist ethic of care (Tronto, 1993) and the capability approach<sup>3</sup> (Sen, 1992; Nussbaum, 2006), as ways to move beyond the creation of a “level playing field” to access existing environments. I find, however, that Shakespeare’s (2013) turn to pragmatic solutions falls into the same trap as rights-based approaches, in that they do not go far enough to reimagine normative conditions.

### *Ableism and crip theory*

Critical studies in ableism and crip theory describe the social order that realist discourses of disability instantiate and seek to disrupt the hegemony of these normative conditions.

Goodley, Lawthom, Liddiard, and Runswick-Cole (2019) explained that critical studies in ableism attend “to the desires and ambitions of disability politics” (p. 985) through “unpack[ing] the dominant cultural imaginaries and socio-political conditions that uphold ability as the central marker of successful human accomplishment and progression” (p. 985). That is, studies in ableism take the production of ability and disability as connected sites of interest. Campbell (2009a) suggested that studies in ableism invert the traditional disability studies approach in order to concentrate on “what the study of disability tells us about the production, operation and maintenance of ableism” (p. 4). This approach brings to the fore what Garland-Thomson (1997) called the *normate* position, “the figure outlined by the array of deviant others whose marked bodies shore up the normate’s boundaries” (p. 8), a position that is otherwise neutralized, naturalized, and obscured—similar to, and certainly caught up with, whiteness. Campbell (2001) defined ableism as

A network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical and therefore essential and fully human. (p. 44)

Campbell (2009a) argued that this creates a system of ableism with two core elements, “the notion of the normative . . . and the enforcement of a constitutional divide” (Campbell, 2009a, p. 6). Through these elements, a certain idea of what is considered normal embodiment is upheld and separated from that which is considered abnormal. Through ableism, then, some ways of being are systemically entitled while others are excluded (Campbell, 2017). This is achieved through the “differentiation, ranking, negation, notification and prioritization of sentient life” (Campbell, 2017, p. 288). Through these dividing practices of ableism, those

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<sup>3</sup> Although I engage with capability in this thesis, I do not use the capability approach (Nussbaum, 2006; Sen, 1992) as a tool of analysis beyond this reference. The capability approach may have resonance in future projects to explore the capability imperative, but that is not the focus of this thesis.

who do not fit the standard are marked out as different, justifying discrimination against them. Under ableism, disability becomes a *negative ontology*, “a diminished state of being” (Campbell, 2001, p.44) that is central to marking out difference. Concepts of disability and abledness are, therefore, inextricable and co-constitutive—continuously producing and reliant on each other (Goodley, 2014). This system of ableism produces a social order that privileges certain ways of being as normative and, therefore, desirable in comparison.

Campbell’s theory of ableism is closely aligned with McRuer’s (2006) formulation of *compulsory able-bodiedness*<sup>4</sup> in crip theory. Compulsory able-bodiedness further theorizes how ableism maintains its dominance. Building from Butler’s (1991) discussion of performativity, McRuer (2006) explained that the “abled” corporeal standard upheld in the system of ableism is an impossible one, but individuals are nonetheless compelled to approximate it. In other words, the social enforcement of unreachable bodymind standards compels the individual to try to live up to them. These continuous attempts further entrench the standard, leading to its hegemony. In this process, however, there is also the opportunity to disrupt, or *crip* abled standards through “twist[ing] and flaunt[ing]” (Thorneycroft, 2020, p. 96) the norm.

The promise of theories of ableism and crip theory are to expose the false binary of disability and ability, and to blur the binary to open up new possible arrangements. Hutcheon and Wolbring (2012) explained two ways of understanding ableism, “as a *hegemony* which promotes ability preference and as an *analytical tool* used to understand these preferences and their impact” (p. 40, original emphasis). Through deconstruction of the underlying assumptions in everyday life that uphold ableism, systems of entitlement and oppression are revealed. Ableism and crip theory make way for an understanding of disability as subjectivity rather than identity, to see the “ways in which bodies and lives are constituted, regulated, governed, and violated” (Thorneycroft & Asquith, 2019, p. 4).

Furthermore, this subjectivity is contingent, fluid, leaky, slippery, and shifting (Butler, 1993; Shildrick, 1997; Thorneycroft & Asquith, 2019). Disability lacks a clear boundary, it is unfixed. While this formulation demonstrates that people may be subjected to the status of “disabled” through ableism, there is also room for productive possibility. Goodley and Runswick-Cole (2016) explained that “when we start to interrogate ableism and ability, then disability emerges not just as the Other side of the oppressive coin, but also as a resistant

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<sup>4</sup> The alliance between crip theory and mad studies proposed by Thorneycroft (2020), as well as Price’s (2015) support for the concept of *bodymind*, which emphasizes the connectedness between body and mind and builds attention to able-mindedness in concert with able-bodiedness, together suggest that compulsory able-bodiedness could be reformulated as *compulsory able-bodymindedness* or *compulsory able-bodiedness and mindedness* to signal the connected concerns between mental and physical disabilities held up by ableism.

alternative” (p. 4). Failures to achieve abled normalization bring about the possibility of *cripping* the norm, exposing the falsity of the abled ideal and opening new possible ways of being in the world (McRuer, 2006; Mitchell & Snyder, 2015; Sandhal, 2003; Thorneycroft, 2020). Goodley and Runswick-Cole (2016) suggested that troubling normalcy by thinking from the margins provides an opening to move towards the *dishuman*, wherein “thinking about the human . . . always involve[s] thinking about disability” (p. 13). This creates a broadened view of humanity, with space for many ways of being and doing “human.” This can be facilitated by thinking beyond the autonomous human subject to notions of *assemblage*, that consider new ways of being human in relation to human and non-human others (Goodley, 2014, 2017; Goodley & Runswick-Cole, 2016).

Like other ways of thinking about disability, there are limits to ableism and crip theory. Most critiques have questioned the utility of these approaches to address the political, ethical, and material concerns of disabled people. First, Vehmas and Watson (2014, 2016) suggested that analysis of ableism alone, without clear conclusions about what is right or wrong, ultimately does not move towards remedying conditions. Analyses using ableism may not provide tangible solutions. Destabilizing the taken-for-granted, however, may be a first step towards the consideration of alternatives.

A second critique is that the reliance on deconstruction in these theories obscures the tangible effects of impairment on disabled peoples’ everyday lives (Shakespeare, 2013; Vehmas & Watson, 2014). This critique relies on the presupposition that not everything is socially constructed or discursive, and thus deconstructive analyses ignore the need for medical treatments or social arrangements to address biological matters (Shakespeare, 2013; Vehmas & Watson, 2014).

Another concern is that categorization is necessary to fairly reconcile differing needs (Shakespeare, 2013; Vehmas & Watson, 2014). Thus, the goal of blurring boundaries may not be useful, even harmful. This critique, however, assumes that existing systems that rely on differentiation are necessary, but only in need of improvement. This concern fixes social relations in place without imagining how they might be otherwise (Kafer, 2013).

Vehmas and Watson (2014) also questioned the critique of “normal” inherent in ableism and crip theories, noting that if everything normative is considered oppressive, this disallows the pursuit of “normal” goals such as work, education, and health promotion. Goodley and Runswick-Cole (2016) responded to this critique, explaining that studies in ableism:

need not inevitably lead us down a path where we ignore the importance of the normative, perhaps even ableist ideals, but, and this is the crucial point here, the presence of disability always disrupts, shakes up, and interrogates the normative position. (p. 4)

This quote points out that reconsideration of the underlying values tied to the things considered normal and desirable is central to thinking with ableism. What follows under a crip ethos is the development, pursuit, and recognition of alternative forms of normative desires, not necessarily a call to reject them altogether.

Another noted limitation to these approaches is the possible political consequences of dissolving the category of disability, resulting in “no disabled people left to either fight for the right to be, or to be a citizen” (Vehmas & Watson, 2014, p. 646). Indeed, Campbell (2019) stated that pursuing “the endless question of who is deemed ‘disabled’ and ‘abled’ becomes redundant” (p. 145), referring to this as “conflicted proliferating thinking” (p. 145) that upholds a false binary. The critique of dissolution suggests that categories are necessary to declare and demarcate difference in order to fight for necessary supports and equity. Garland-Thomson (1997) similarly contended that constructivist approaches “[threaten] to obscure the material and historical effects of differences and to erase the very social categories we analyze and claim as significant” (p. 22). Making similar claims, Garland-Thomson (1997) and Linton (1998) asserted that disability ought to be claimed, recognized, and accommodated, not fully dispensed with given the real, entrenched discrimination that disabled people experience, entwined with popular responses of pity and good will rather than rights and justice. This suggests the need for *strategic essentialism* (Butler, 1993; Garland-Thomson, 1997; Spivak, 1990; Thorneycroft, 2020), “the tactic of essentializing identity in order to mobilize change and/or recognition” (Thorneycroft, 2020, p. 105). The risk of this strategy is that it reifies, simplifies, and homogenizes constructed categories. McRuer (2006), Goodley (2017), and Thorneycroft (2020), however, contended that strategic essentialism may be employed within crip theory as a starting place, not an endpoint. The first tenet of crip theory is “claiming disability *and* a disability identity politics while nonetheless nurturing a necessary contestatory relationship to that identity politics” (McRuer, 2006, p. 71). Thus, crip theory arguably represents an intervention on disability and identity politics rather than a dissolution of it. The goal of ableism and crip theories, then, is to “disorientate normativity” (Goodley, 2017, p. 197) through disability.

A final critique brings about the question of whether normativity can ever actually be disrupted, no matter the ontological underpinnings of the understanding of disability. Goodley, Lawthom, Liddiard, and Runswick-Cole (2017) suggested that “normative practices—especially of neo-liberal advanced capitalist societies—are incredibly good at maintaining their modes of production, their character and their everyday practices” (p. 494). Crippling may present an opening, but institutions and societies may never shift in response, or their shifting may subsume and water down radical possibility for their own purposes. Others have made similar arguments (Mitchell, 2016; Mitchell & Snyder, 2015), noting that neoliberal

institutions have found ways to co-opt the political aims of disability rights and inclusion movements to benefit capitalism and solidify ablenationalism, resulting only in “anemic inclusionism” (Mitchell, 2016, p. 19). These arguments question whether political action or academic critique can ever fundamentally shift entrenched and powerful structures, or if the only response is to find ways to resist and to document injustice.

### **The political/relational model**

The varied ontological positionings of disability, presented thus far, establish this matter as contested ground and offer a palette from which to interpret findings. In line with the constructivist grounded theory methods used in this thesis (to be discussed in detail in Chapter 3), I must locate my own positioning in the ontological debate regarding disability. My understanding of disability is itself shifting and contested, based on my evolving learning and life experiences. When I began this study, my thinking aligned most closely with the minority model of disability. Through the process of this research project and in search of analytical tools to make sense of data my allegiance shifted.

The positioning that best resonates with my current understanding of disability is Kafer’s (2013) *political/relational model*. This model builds on the social and minority models and reforms them through feminist and queer critiques of identity within a context of ableism. In line with the social and minority models, and theories of ableism, the political/relational model posits that:

The problem of disability is located in inaccessible buildings, discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies. The problem of disability is solved not through medical intervention or surgical normalization but through social change and political transformation. (Kafer, 2013, p. 6)

Unlike the U.K. social model, the political/relational model does not distinguish between impairment and disability, with the understanding that both are bound up in “social meanings and understandings” (Kafer, 2013, p. 7). The political/relational model brings back into theorization and activism aspects of disabled people’s lived experience, such as pain, fatigue, and the pursuit of medical intervention, which have been excluded by the social model. Reflecting the principle that disability is always political, medical interventions are, however, subject to critique. This recognizes that “medical representations, diagnoses, and treatments of bodily variation are imbued with ideological bias about what constitutes normalcy and deviance” (Kafer, 2013, p. 6). In doing so, the model holds ambiguity, allowing for the possibility that people perceive their lived experience of disability and diagnosis as negative, while always recognizing that social contexts shape these understandings.

As suggested by the name, the political/relational model understands disability as both relational and political. To view disability as a relational construct allows for broader

theorization of the notion of disability and the impacts of ableism. Kafer (2013) suggested that this allows, for example, examination of how ableism affects all people—not just those with impairments—and how “disability is experienced in and through relationships; it does not occur in isolation” (p. 8). To insist that disability is always political emphasizes its enmeshment with power relations. This positioning allows disability to be collectively reimagined, critiqued, contested, and transformed (Kafer, 2013, p. 8). Thus, aligning with ableism, crip, and feminist poststructuralist theories (Campbell, 2001, 2009a, 2017, 2019; Garland-Thomson, 1997; McRuer, 2006; Shildrick, 1997; Thorneycroft, 2020), the political/relational model insists that disabled and non-disabled are not “discrete, self-evident categories” (Kafer, 2013, p. 10). Rather, they are socially, politically, and relationally formed. With this understanding, the political/relational model incorporates broad experiences into the category of disability and is accountable to intersectional experiences.

The matter of whether to collectively organize under the banner of disability is also addressed within the political/relational model. Rather than rejecting disability identity, the model expands the politics of and identification with disability through a crip ethos. This aligns with the principle of strategic essentialism discussed previously. The model stabilizes the disability category for the purposes of political organizing, while simultaneously questioning it. Given that disability is unstable and defies definition, Kafer (2013) explained that identification with disability is best delineated through “collective affinities” (Scott, 1989), by which Kafer means those who “have been labeled as disabled or sick and have faced discrimination as a result” (Kafer, 2013, p. 11). By continually questioning the category of disabled, this political stance simultaneously seeks to improve conditions for those constructed as disabled while seeking to dissolve the abled/disabled binary. Kafer (2013) argued that attention to structural inequality and patterns of exclusion and discrimination resists the potential for dilution of disability politics, noting that “deconstructing the binary between disabled and able-bodied/able-minded requires *more* attention to how different bodies/minds are treated differently, not less” (p. 14, original emphasis). This positioning suggests that social exclusion that results from and instantiates the false binary ought to be the focus of analysis, with the goal of social interactions and systems that reimagine difference as essential aspects of our collective future.

An important theoretical or epistemological construct that follows from the political/relational model is Kafer’s (2013) *politics of crip futurity*. To think from this angle demands the realization that disabled peoples’ lived presents and possible futures are political productions. This concept builds from crip theory and theories of ableism in that it identifies that ableism tends to lock normative conditions into a naturalized, taken-for-granted state and that resistance is also the possible. Thinking with a politics of crip futurity calls for revelation



of the ways that disabled people's presents and futures are limited by a normative and often curative imaginary, and at the same time can and must be imagined differently.

Having established my own understanding of disability, alongside other models of disability and their underpinning politics and criticisms, I move to the next major area of literature relevant to this thesis. In the following section, I discuss disability inclusion in higher education with a focus on medical education.

## **Part II. Disability Inclusion in Medical Education**

Access to higher education is a longstanding issue of the disability rights movement, given its critical role in social advancement and access to skilled employment (Dolmage, 2017; Fleischer & Zames, 2011; Longmore, 2009; Scotch, 2001; Shapiro, 1994). Despite hard-fought U.S. legislation that has guaranteed equal access to postsecondary settings since 1973 (Rehabilitation Act, 1973; ADA, 1990, ADAAA, 2008), access to graduate and professional education has lagged. As discussed in the Introduction, the number of disabled students in U.S. medical education appears to have increased over time, however, this is difficult to definitively establish due to inconsistent definitions of disability and methods used in studies of prevalence (Association of American Medical Colleges [AAMC], 2019, 2020; Eickmeyer et al., 2012; Meeks, Case, et al., 2019; Meeks & Herzer, 2016; Moore-West & Heath, 1982; Moutsiakis & Polisoto, 2010; Sack et al., 2008; Wu, Tsang, & Wainapel, 1996). The most recent study found that only 4.6% of medical students reported a disability to their schools, with the largest percentage of these students having less-apparent disabilities (Meeks, Case, et al., 2019). Compared to a disability prevalence rate of 14.4% among similar-aged peers in the general population (D. Taylor, 2018), the 2019 figure of 4.6% represents continued overall underrepresentation of students with disabilities in medical education. Despite underrepresentation, disabled people have a strong history of success in the medical profession, extending long before legislative protections against discrimination (Hartman & Asbell, 1978; Keeney & Keeney, 1950; Lewis, 1983; Wainapel, 1987a; Zazove, 1993). Coinciding with this historical narrative is evidence that students with disabilities encounter marginalization and insufficient access to medical school that extends into later stages of training and employment (Anonymous, 2019; Brown, 1998; Bulk et al., 2017; Easterbrook et al., 2015, 2019; Meeks & Jain, 2018; Neal-Boylan et al., 2012; Newlands, Shrewsbury, & Robson, 2015; Schwarz & Zetkolic, 2019; Shrewsbury, 2018; Steinberg, Iezzoni, Conill, & Stineman, 2002; Stergiopoulos, Fernando, & Martimianakis, 2018). Access to medical education remains a challenging subject, with perceived tensions between program standards, professional structures, and legal requirements for non-discrimination (Althuler, 2009; Argenyi, 2016; Boursicot & Roberts, 2009; Hafferty & Gibson, 2001; Melnick, 2011).

Thus far, disability inclusion in medical education has been under-researched. Much discussion of inclusion has come from commentaries and first-person accounts. There have been very few qualitative studies that seek to understand student experiences and institutional inclusion efforts in depth, and the studies that do exist were all published from 2015 onwards (Bulk et al., 2017;<sup>5</sup> Easterbrook et al., 2015, 2019; Kim, 2015; Meeks & Jain, 2018; Newlands, et al., 2015; Shrewsbury, 2018; Stergiopoulos et al., 2018; Tso, 2017). Given the limited scope of research in this area, it is necessary to widen the lens to the literature of disability inclusion in higher education. This broadened scope reveals two main approaches to disability inclusion in higher education: accommodations and UD. In the following sections I discuss each approach, their underlying assumptions regarding disability, their implications in higher education generally and, more specifically, in the context of medical education.

### **Accommodations in higher education**

In line with legal parameters, accommodations are the most prevalent approach to disability inclusion used in U.S. higher education (Guzman & Balcazar, 2010; Kimball, Wells, Ostiguy, Manly, & Lauterback, 2016). The ADA and Section 504 of the Rehabilitation Act of 1973 mandate the provision of accommodations, adjustments to policy and practice, and auxiliary aids to qualified students with disabilities to facilitate equitable access to the educational environment (ADA, 1990; DOE Nondiscrimination, 1980). Accommodations are required so long as they are “reasonable,” meaning they do not fundamentally alter the educational program, impose an undue financial or administrative burden on the educational institution, or pose a risk to health and safety of others (ADA, 1990). Within this approach, students declare their disabilities to a designated school official, provide medical documentation or other evidence to confirm their disability, and request accommodations (Association on Higher Education and Disability [AHEAD], 2012; Laird-Metke & Moorehead, 2016; Laird-Metke, Serrantino, & Culley, 2016). The institution then determines the student’s eligibility for accommodations, through an assessment of the student’s disability status, an exploration of the barriers they encounter, and the requirements of their program (Laird-Metke & Moorehead, 2016; Laird-Metke, Serrantino, & Culley, 2016; Ofiesh, Hughes, & Scott, 2004). The law requires that this process is interactive and informed, in that it involves the student, a school official knowledgeable in disability, and consultation with faculty members knowledgeable about the academic program (OCR Letter to El Camino College, 2014; OCR Letter to Kellogg

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<sup>5</sup> Papers by Bulk et al. (2017) and Easterbrook et al. (2015, 2019) are derived from the same study, which examined experiences of students and school officials across health and human service disciplines (medicine, nursing, occupational therapy, physical therapy, social work, and teaching) at three Canadian universities. Although few of their participants came from medical education (one student, two stakeholders), their findings resonated strongly with medical-education specific studies, thus, they are included here.

Community College, 2015; OCR Letter to Robert B. Miller College, 2010). Although an individualized approach to access through accommodations is legally mandated and suggests customization to the student—not to mention its alignment with social and minority-model solutions—research has problematized its effectiveness, implications, and intersectional inequities.

Research into the efficacy of accommodations reveals mixed findings. While some research suggests that accommodations support academic performance and participation (Bolt, Decker, Lloyd, & Morlock, 2011; Kim & Lee, 2016; Ofiesh, 2007; Schreuer & Sachs, 2014), other studies suggest some accommodations (e.g., extended time and private room for testing) have mixed, minimal, or even detrimental effects on academic performance and assessment validity (Gregg, 2012; Gregg & Nelson, 2012; Royer & Randall, 2012; Weis & Beauchemin, 2020). Research in this area is limited, in that the number of empirical studies is small, focused primarily on students with learning disabilities and ADHD, applied to standardized exams only, and with varied methods, making them difficult to compare and not reflective of most university environments (Gregg, 2012; Kimball et al., 2016; Ofiesh, 2007; Royer & Randall, 2012). In addition, accommodation decision-making, use, and perceived effectiveness has been shown to be multifactorial and contextual, suggesting that the value of accommodations may be difficult to isolate through quantitative analysis. Studies have identified a wide variety of factors that influence perceived effectiveness and use of accommodations. By no means an exhaustive list, scholars have found that disability professionals' experience and training, student experience of and attitudes towards using accommodations, faculty and peer attitudes, and quality of services (e.g., notetaking) all effect accommodations effectiveness and use (Barnard-Brak, Davis, Tate, & Sulak, 2009; Bolt et al., 2011; Hartman-Hall & Haaga, 2002; Kurth & Mellard, 2006; Lyman et al., 2016; Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010; Olney & Brockelman, 2003; Schreuer & Sachs, 2014). Given the many factors in play, assessing accommodation efficacy is difficult. Moreover, the mixed evidence base that follows sit in tension with the legal imperative to provide accommodations to facilitate access.

The performative effects of an accommodation approach to inclusion are worth exploration. In its focus on individual adjustments, an accommodation approach implies that the disabled person is the source of access concerns rather than the inaccessible system (Burgstahler & Cory, 2008; Dolmage, 2017; Guzman & Balcazar, 2010; Higbee, 2003; Kimball et al., 2016; Kroeger, 2010; Kurth & Mellard, 2006; Liasidou, 2014). This reflects a deficit orientation to disability that aligns with realist or medical models. The language of accommodations follows this understanding, including the term itself and the associated requirements that they be reasonable and not burdensome. These linguistic phrasings promote

discourses of containment, gatekeeping, charity, and expert authority, rather than socially-just inclusion (Gabel & Miskovic, 2014; Krebs, 2019; Lester, Dostal, & Gabriel, 2013; Shrewsbury, Mogensen, & Hu, 2018). As Burgstahler and Cory (2008) explained, these discourses construe accommodations as potentially unfair and students as likely to fake disability to get ahead. Furthermore, the mechanisms of accommodation tend to create a separate-but-equal approach that amounts to exclusion (Higbee, 2003). That is, accommodations constitute retrofits to the existing environment that often separate disabled students from their peers (Dolmage, 2017). Amid these implications, students carry the responsibility for ensuring their inclusion. This requires that they understand their experience as disability, actively seek accommodations, and manage their implementation (Gabel & Miskovic, 2014). By interrogating the accommodation approach, philosophical clashes emerge between its intent and its implications.

The use of accommodations to achieve equity has intersectional consequences. Under this model, a requirement for medical documentation to substantiate disability privileges those with socioeconomic resources to secure it, and disadvantages those who experience biomedical oppression, for example, racialized and LGBTQI+ peoples (Annamma et al., 2013; Burgstahler & Cory, 2008; Gabel & Miskovic, 2014; Krebs, 2019). Those in already-privileged social positions may have an easier time accessing accommodation-oriented systems, given their ready access to medical documentation, thereby heightening marginalization in educational settings. Notably, the Association on Higher Education and Disability (AHEAD, 2012)<sup>6</sup> recommends a flexible approach to disability documentation that treats student self-report, observation and interaction, and third-party documentation as all valid sources of information. This type of approach may lessen intersectional inequities to secure formal, third-party documentation of disability. Nonetheless, each educational institution treats third-party documentation differently and not all follow AHEAD's guidance. Taken together, these critiques of the accommodation approach raise questions about its suitability to achieve educational inclusion.

### **Accommodations in medical education**

Much of the research, commentary, and practice-informed writing in the scholarly literature about disability inclusion in medical education focuses on accommodations. This work covers two key themes: (a) the degree to which technical standards and other policies ought to permit accommodations, and (b) determination and implementation of accommodations and surrounding policies.

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<sup>6</sup> AHEAD is the “leading professional membership association for individuals committed to equity for persons with disabilities” (AHEAD, n.d., n.p.).

### *Accommodations, technical standards, and medical education*

Technical standards are the non-academic requirements for admission, continuation, and graduation in an educational program. The concept originates from regulatory language for Section 504 of the Rehabilitation Act of 1973, which defines a qualified person, one protected from disability-based discrimination, as one “who meets the academic and technical standards requisite to admission or participation in the . . . education program or activity” (HHS Nondiscrimination, 1977). The Liaison Committee on Medical Education (LCME, 2019) accreditation standards necessitate that undergraduate medical programs develop and publish technical standards in accordance with legal requirements. The AAMC (1979) provided guidelines for technical standards, which identified five categories of ability necessary for medical graduates: (a) observation; (b) communication; (c) motor; (d) conceptual, integrative, and quantitative; and (e) behavioral and social. Subsequent guidance has not updated the principles of the 1979 document, which situate medicine as a broad undifferentiated degree, and it remains the primary referent for schools (AAMC, 1993; Kezar et al., 2018; Medical School Objectives Writing Group, 1998; Watson & Hutchens, 2005). With no nationally-required technical standards, however, each school defines and interprets them independently, leading to inconsistency (Argenyi, 2016; McKee et al., 2016; Zazove et al., 2016). In their national study of technical standards, furthermore, Zazove et al. (2016) found that many schools’ standards were vague, outdated, difficult to find, and did not comply with ADA requirements to consider accommodations.

Scholarly discussion about technical standards is dominated by two distinct positions concerning what is essential to medical training. The first position advocates constraint, suggesting that restrictive standards are necessary to protect the medical profession and should not be substantively modified through accommodation. The second position advocates a more progressive interpretation of technical standards and, therefore, an expanded range of permissible accommodations.

Although work directly advocating constraint in technical standards and accommodations is less common in the literature, it can easily be understood as an absent presence. Even when not directly articulated or advocated for, this perspective is relayed through study findings (Eickmeyer et al., 2012; VanMatre, Nampiaparampil, Curry, & Kirschner, 2004), policy analysis (Argenyi, 2016; McKee et al., 2016; Shrewsbury et al., 2018), the framing of papers and reports (Babbitt & Lee, 2016; Watson & Hutcheon, 2005), and the need for persistent arguments against constraint positions. Two commentaries directly uphold the constraint position, but each concedes that some disabled students are successful and add value to the profession (Hafferty & Gibson, 2001; Melnick, 2011). Both arguments position disability inclusion in conflict with the profession’s ethical responsibilities for patient

wellbeing (Hafferty & Gibson, 2001; Melnick, 2011). In both pieces, they suggest the profession must determine what is essential to medical practice at all levels in order to more clearly define what is a fundamental alteration and, in turn, what accommodations are permissible (Hafferty & Gibson, 2001; Melnick, 2011). Melnick (2011) takes this position further to advocate for an “evidence-based approach to accommodations” (p. 676), which, in his view, requires research to ensure accommodations do not provide unfair advantage to the student or risk patient safety. While these authors are not necessarily in disagreement with those advocating for more progressive policy and practice in their argument for re-evaluation of the essential requirements of a physician, they differ in their assumption that disability presents a risk to the profession.

Some legal analyses implicitly support the constraint position. Babbit and Lee (2016) and Watson and Hutcheon (2005), for example, do not directly advocate constraint, but advance this position through their promotion of strict compliance-oriented practices. These analyses base practice recommendations only on case law but lack any attention to the utility of compliance. Thus, the authors attend to the extent of practice required based on interpretations of the law taken from the cases that have appeared in the courts, but not a larger goal of inclusion. Effectively, disabled students’ lived experiences, histories of exclusion, and their potential as valuable clinicians are erased from the discussion. As Shrewsbury et al. (2018) found in their examination of medical education policies in the UK and Australia, these seemingly neutral legal analyses frame students with disabilities only as a problem to be managed and contained, a potential threat to the profession. This illustrates how a rights-based approach can be constrained in practice through narrow attention to compliance that does not disrupt realist conceptions of disability.

The limited direct support for restrictive technical standards and accommodation practices in the literature may, paradoxically, reflect its dominance in the field. Critiques are necessary to challenge the dominant position, while defense of the status quo is not necessary because it is not perceived as under threat. Critiques of restrictive practices have remained consistent over time. This suggests that the constraint position is entrenched in medical education, thus animating a need for continued opposition.

Critiques of restrictive technical standards center on their tendency to adhere to the AAMC’s 1979 guidance principle of an *undifferentiated graduate* and their essentialization of the means to achieve essential tasks rather than the ends. Scholars have argued that restrictive technical standards exclude students with physical and sensory disabilities, and do not align with modern medical education and practice (Argenyi, 2016; Bagenstos, 2016; DeLisa & Thomas, 2005; Eickmeyer et al., 2012; Hartman & Hartman, 1981; Kezar et al., 2019; McKee et al., 2016; Meeks & Jain, 2018; Meier, 1993; Ouellette, 2013; Reichgott, 1996, 1998;

Schwartz, 2009; VanMatre et al., 2004; Wainapel, 2015; Zazove et al., 2016). The undifferentiated graduate principle, as currently applied, suggests that in undergraduate medical education, all students must prepare to enter all medical specializations upon graduation. This necessitates that students perform clinical tasks and learn conceptual content across all areas of medicine. The concept can be traced as far back as a 1950 report that stated:

Medical education aims to give the student a comprehensive concept of man [*sic*] and his [*sic*] diseases and to inculcate those habits of mind which will enable him [*sic*] to enter without handicap any one of the fields of medical practice and research, be it medicine, surgery, psychiatry or public health. It is the undergraduate phase which aims to give the student general competence. (DeBakey et al., 1950, p. 524)

The way that medical education currently functions, especially given its end goal of specialization, brings the undifferentiated graduate principle into question (Hartman & Hartman, 1981; Reichgott, 1996, 1998; VanMatre et al., 2004). Furthermore, later in the 1950 report it states, “The student must be given sufficient understanding of the breadth of medicine for him [*sic*] to know his [*sic*] limitations” (DeBakey et al., 1950, p. 525). Hartman and Hartman (1981) contended that this additional statement allows for reinterpretation of the undifferentiated principle with scope for students to master broad content without a need to perform all clinical tasks, self-regulate their practice based on strong clinical knowledge, and select a specialization that best matches their abilities.

To add to the critiques of technical standards, several studies of medical professionals, educators, and trainees found substantial disagreement about which standards are essential to medical practice (Eickmeyer et al., 2012; VanMatre et al., 2004). This suggests that technical standards are not actually “standard,” based on an authoring group’s framing of the physician role rather than widespread professional agreement. Until recently, courts have deferred almost absolutely to schools’ professional assessments of fundamental alteration and development of technical standards (Babbit & Lee, 2016; Bagenstos, 2016; Ouellette, 2013), which Ouellette (2013) argued has allowed schools to maintain ableist technical standards. These critiques and findings suggest that technical standards may arbitrarily restrict the scope of possible accommodations for students with disabilities and contribute to their underrepresentation in medicine.

To break the impasse between those advocating constraint and those advocating expansion, there have been calls for renewed, deep, and ongoing exploration of what is essential to physician practice (Argenyi, 2016; DeLisa & Thomas, 2005; Hafferty & Gibson, 2001; Melnick, 2011; Schwarz & Zetkolic, 2019). Following the “nothing about us, without us” (Charlton, 1998, title) adage, those advocating for progressive practices insist this exploration must substantively include people with disabilities, ethicists, disability specialists, and legal professionals to challenge implicit biases against disabled people in medicine

(Argenyi, 2016; Schwarz & Zetkulich, 2019). Such a joined-up, ongoing, national effort has not yet occurred. In the interim, students are subject to school-specific definition, interpretation, and implementation of what is fundamental to medical education.

### ***Determining and implementing accommodations in medical education***

The determination and implementation of accommodations in medical education is the second focus of literature in this area. The breadth of accommodations afforded to disabled medical students have expanded over time (Eickmeyer et al., 2012; Faigel, 1998; Meeks & Herzer, 2016; Meeks, Case, et al., 2019; Moreland, Latimore, Sen, Arato, & Zazove, 2013). This expansion follows evolving case law, which has enforced a wider duty to accommodate, and evolving disability-inclusion practice in health science education (Bagenstos, 2016; Meeks & Jain, 2016; Meeks, Jain, & Laird, in press; Meeks & Neal-Boylan, 2020). For example, the first Supreme Court case heard under Section 504 of the Rehabilitation Act of 1973, *Southeastern Community College v. Davis* (1979) found a nursing program permissibly denied admission to a deaf student because she would not be able to access information in a surgical setting where masks are worn. Two recent cases have shifted this earlier precedent. *Argenyi v. Creighton University* (2013) and *Featherstone v. Pacific Northwest University of Health Sciences* (2014) firmly established that schools must provide captioning and sign-language interpreting to deaf and hard-of-hearing students who require it in clinical settings. These cases exemplify the post-ADAAA (2008) shift towards expanded reasonable accommodation responsibilities for schools. The growing body of literature that aligns with this shift recommends and documents inclusion practices for disabled students in programs such as medical education. This work has focused on how to determine and implement accommodations, describes the types of accommodations that may be permissible, and ways to orient policy and practice to facilitate accommodation access (Blacklock, 2016, 2017; Haverstick, 2018; Laird-Metke, 2016; Littrell, 2018; Meeks et al., in press; Meeks & Jain, 2016; Meeks & Neal-Boylan, 2020; Meeks & Murray, 2019; Mehta & Clifford, 2017; Serrantino, 2016; Sullivan, 2018). This body of literature is based on practice experiences and framed by legal guidance rather than empirical findings. Collectively, this work posits that specialist disability support, clear accommodation policies, legal compliance, increased privacy, a welcoming tone, and greater use of accommodations will facilitate inclusion and reduce the stigmatizing potential of disability and use of accommodations in medical education.

Several studies speak to the topic of accommodations efficacy in medical education. Cook, Griffin, Hayden, Hinson, and Raven (2012) evaluated the use of a “student support card” to facilitate access to accommodations in clinical settings. While a survey of card



holders and subsequent interviews demonstrated the intervention was overall useful, students also limited their use of the card indicating accommodation requests as potentially stigmatizing (Cook et al, 2012). This raises questions about the overall efficacy of an accommodation approach to achieve inclusion.

Other studies utilized quantitative approaches to examine disabled-student performance. Teherani and Papadakis (2013) found that disabled students at one medical school performed less well on academic assessments and were less likely to graduate than their non-disabled peers, and that students with mental disabilities had lower clinical clerkship performance than non-disabled peers. Although participating students had registered with disability services, the study did not factor in whether they actually used accommodations and their associated experiences, making effectiveness difficult to interpret. Another study found that students who received extended time accommodations on the Medical School Admission Test (MCAT) had significantly lower pass rates on Step 1 of the U.S. Medical Licensing Exam (USMLE) and took longer to graduate (Searcy et al., 2015). The authors raised concerns about the validity of accommodated MCAT scores to predict USMLE performance (Searcy et al., 2015), implying that accommodated MCAT scores are to be treated as inaccurate, if not invalidated due to accommodations. This conclusion should be read with caution, however, as results did not consider whether students had similar access to USMLE accommodations (Meeks & Herzer, 2015).

As a rejoinder to the skepticism of Searcy et al. (2015), Meeks and Jain (2018) found that disabled medical students named access to accommodations and knowledgeable disability support services a facilitator in their training. Several case studies and first-person accounts, similarly, described specific accommodations as beneficial to student performance (Hartman & Hartman, 1981; Herzer, 2016; Jauregui, Strote, Addison, Robins, & Shandro, 2020; Meeks, Engelman, Booth, & Argenyi, 2018; Meeks, Laird-Metke, et al., 2015; Takakuwa, 1998). In addition to registering student perspectives, a large body of publications offer practical advice concerning accommodations. Much of this is premised upon the view that providing accommodations facilitates inclusion and student success (Blacklock, 2017; Littrell, 2018; Meeks & Jain, 2016; Meeks & Murray, 2019; Meeks & Neal-Boylan, 2020; Serrantino, 2016; Sullivan, 2018). Although this work suggests that accommodations can facilitate access to medical education, Meeks and Jain (2018) also found that access to appropriate accommodations, especially for clinical settings, remains a barrier for many medical students. Furthermore, cultural barriers in medical training, including the stigmatizing potential of disability and accommodations, persist (Meeks & Jain, 2018; Bulk et al., 2017; Cook et al., 2012; Easterbrook et al., 2015, 2019; Grant, Rix, & Shrewsbury, 2019; Miller, Ross, &

Cleland, 2009; Newlands et al., 2015; Stergiopoulos et al., 2018; Tso, 2018; Walker, Dearnley, Hargreaves, & Walker, 2013).

The literature exploring the use of accommodations to achieve disability inclusion more generally in postsecondary education, and specifically in medical education, suggest this strategy is widespread and, in the US, closely informed by legal requirements and precedent. In medical education, broader access to accommodations has been facilitated by legal developments and evolution in professional practice. At the same time, concerns about broadening accommodations remain, with disagreement about what is fundamental to medical education and practice. The performative effects of the accommodation approach, including its attachment to individualizing discourses of disability, intersectional inequities, and tendency toward containment raise further concerns, suggesting that it is still an approach that adheres to ableist principles.

### **Universal design**

An alternative approach to inclusion in higher education is UD. As originally conceived in the architectural field, UD is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaption or specialized design” (Center for Universal Design, 1997). The Center for Universal Design (1997) laid out seven principles of the construct:

1. Equitable use
2. Flexibility in use
3. Simple and intuitive
4. Perceptible information
5. Tolerance for error
6. Low physical effort
7. Size and space for approach and use

Building upon Garland-Thomson’s (1997) concept of the *normate*, Hamraie (2012) explained that UD is a response to the *normate template*, the “privileged and destigmatized body representing a universal or ideal type” (n.p.) used in mainstream design as “a template for the likely user of space” (n.p.), that “privileges a small group of individuals. . . giving [them] the appearance of normalcy or universality due to their fit in the environment” (n.p.). In contrast, UD begins with a wide array of difference in mind, which, in its blurring of a dis/abled binary reflects an anti-ableist approach consistent with theories in ableism and crip theory.

Scholars have extended the architectural design concept of UD into other areas, including education. Bowe (2000) defined UD in Education (UDE) as “the preparation of curricula, materials, and environments so that they can be used, appropriately and with ease,

by a wide variety of people” (p. 45). Additional frameworks that apply UD principles to postsecondary education contexts use the varied labels of UD for Learning (UDL) and Instruction (UDI/UID; Burgstahler, 2012; CAST, 2018; McGuire, Scott, & Shaw, 2006; Scott, McGuire, & Foley, 2003). These approaches have been applied to university instruction, however Burgstahler’s (2012) application of UD radiates further into all aspects of university life, including student services, computer labs, distance learning, physical space, conferences, websites, and more. This demonstrates that the original principles offered by the Center for Universal Design (1997) can be adapted to the design of vastly different postsecondary spaces, programs, and environments.

The postsecondary approaches to UD are unified by their intent to proactively plan for student diversity rather than retrofitting for inclusion, but their underlying theory and original purposes yield slightly different principles. The Center for Applied Special Technology (CAST, 2018) guidelines for UDL, for example, have three driving principles: provide multiple means of engagement (the “why” of learning); provide multiple means of representation (the “what” of learning); and provide multiple means of action and expression (the “how” of learning). UDI, by way of contrast, has nine principles. Adapting the original seven UD principles to postsecondary instruction, they add two further principles that promote interaction between learners and faculty and attend to the instructional climate (Scott, McGuire, & Foley, 2003). Orr and Hammig (2009) explained that, in practice, the commonalities between the varied approaches to UD in postsecondary education are more important than their differences.

Despite its potential to transform environments, UD has been critiqued as a false utopia and ripe for neoliberal colonization. Withers (2012) critiqued UD as “arbitrary and fictional” (p. 118), asserting that the finality of the term does not take into consideration people’s shifting needs. Instead, Withers (2012) advocated for a radical access approach that is holistic, intersectional, and collective. Others have agreed, noting that a claim to UD must consider other intersecting forces such as structural racism (Dolmage, 2017; Hamraie, 2013, 2017).

Adjacent to this critique, several UD proponents acknowledged that complete elimination of accommodations is likely impossible, but can be reduced through UD and also planned for to ensure individual adjustments are available and built in to the flow of an educational setting to avoid further marginalization (Burgstahler & Cory, 2008; McGuire, 2014; Scott, Loewen, Funckes, & Kroeger, 2003). Taking this line of thinking further, Dolmage (2005, 2017) argued for UD as practice rather than a procedural exercise, as a verb rather than a noun.

UD, registered as action, is a way to move. In some ways, it is also a worldview. Universal Design is not a tailoring of the environment to marginal groups; it is a form of hope, a manner of trying. (Dolmage, 2017, p. 116)

This approach, then, encourages an ongoing, dynamic process of review and revision, wherein UD becomes a moving horizon rather than a fixed destination (Dolmage, 2005).

Finally, the potential for neoliberal universities to co-opt and strip UD of its radical potential has generated caution about the approach as a panacea (Dolmage, 2017; Hamraie, 2013, 2017). Following neoliberal logics, UD holds appeal as a marketing tool and a sustainable means to manage resources, while simultaneously minimizing investment in the culture change necessary to realize its aims (Dolmage, 2017; Hamraie, 2013, 2016, 2017; Silver, Bourke, & Strehorn, 1998). To counter such movements that neutralize UD and return to assimilationist approaches to disability, Hamraie (2016) argued, instead, for “a discourse of universal design informed by critical disability theory” (p. 303) that “claim[s] disability, treat[s] disabled users as valuable knowers and experts, . . . and foreground[s] the political, cultural, and social value of disability embodiments” (pp. 303-304). To meaningfully implement UD, then, critiques suggest the approach must be holistic, iterative, and maintain a political core grounded in critical disability theory.

Beyond these critiques of UD, scholars have yet to firmly establish its efficacy in higher education learning contexts. Systematic reviews of UD in higher education literature have concluded that, despite a sound theoretical basis, the construct lacks “a substantial empirical research base” (Roberts, Park, Brown, & Cook, 2011, p. 14), suggesting the research is still nascent (Faggella-Luby et al., 2017; McGuire, 2014; Schreffler, Vasquez, Chini, & James, 2019; Scott & McGuire, 2017). Indeed, in their systematic review of the literature, Faggella-Luby et al. (2017) found 44 data-based articles on the topic, with most focusing on perceptions and few on outcomes. They concluded that the existing research indicates the construct value of UD, but strong, replicable research is needed to confirm its efficacy (Faggella-Luby et al., 2017). Drilling into UD literature focused on postsecondary science, technology, engineering, and math (STEM) education, an area closer to medical education, Schreffler et al. (2019) found only four empirical articles on the topic. As these studies had vastly different methods and designs, drawing conclusions about UD in STEM is difficult.

Discussion of UD is scant in the medical education literature. Based on an analysis of a meeting involving 25 Irish health science faculty (from nursing, medicine, and physical therapy), Heelan, Halligan, and Quirke (2015) identified ways to apply UD concepts to clinical education. For example, they emphasized the importance of ensuring equitable design by clearly identifying student tasks in advance and providing perceptible information through modeling templates to support students’ clinical learning (Heelan et al., 2015). Interestingly, in

reference to the meeting observed by Heelan et al. (2015), Scott and McGuire (2017) noted that there was “unanimous agreement [among participants] that certain non-negotiable tasks (i.e., essential standards) were not flexible and could not be waived within a clinical setting” (p. 122). This indicates that at least some existing arrangements are perceived essential to the educational task and, therefore, also perceived as not open for reconceptualization in line with UD. Thus, the UD guidance offered by Heelan et al. (2015) relied heavily on individual accommodations to provide access. The essential requirements or technical standards for medical education are, however, the subject of intense debate, with some suggesting there may be more room for flexibility than the Irish academics contended. In this sense, the perception of inflexibility in standards constitutes a barrier to UD. Other literature advocates UD, but is narrowly framed or provides limited detail about how to implement it in the medical education context (Kezar et al, 2019; Laird-Metke, Meeks, & Clifford, 2016; Meeks, Herzer, & Jain, 2018; Meeks & Jain, 2018; Reiter & Hosterman, 2010). Empirical, practical, and theoretical exploration of UD in medical education is a notable gap in existing research.

By following the anti-ableist practice of attending to and accounting for difference in the design of spaces, practices, and programs, UD represents an alternative to the dominant practice of accommodations. While it has informed theories of practice in higher education, primarily focused on instructional methods, the practice has not yet taken hold. This may reflect the lack of evidence of its efficacy (necessary to foster investment) and the extensive effort necessary for implementation. However, it is also important to recognize that UD is not legally required, whereas accommodations are. In medical education, attention to UD appears especially limited, possibly a product of the assertion that many aspects of educational practice are essential and therefore not open to redesign. Scholars, however, recommended caution due to concerns that UD may be co-opted to paradoxically result in disinvestment in inclusion with a premature declaration of full accessibility. In response, they argued that a UD project that is holistic and iterative, undergirded by critical disability studies is needed.

## **Conclusion**

The chapter began with realist and constructivist understandings of disability and explored the social arrangements that they support. The dominant realist position imagines disability as an individualized fact of the body that requires intervention with a goal of elimination. Informed by this position, social arrangements favor individual, curative interventions and charitable responses. In contrast, constructivist positions assert that the experience of disability is socially constructed. Within constructivist positions, I discussed the social and minority models of disability as connected constructs that seek equal rights and societal change to foster disabled peoples’ inclusion. Among the critiques of this position, a notable point is that these

models tend to seek equal access to existing societal structures, which some argue upholds normativity. In this sense, they work towards equity rather than justice. In contrast, studies in ableism and crip theory examine the production and maintenance of a false dis/ability binary. These theories seek to dismantle and resist this binary, opening new social arrangements that recognize the fullness of humanity.

The political/relational model of disability (Kafer, 2013) brings together aspects of the social and minority models of disability with feminist, ableism, and crip theories. The political/relational model recognizes the embodied and discursive production of disability in relation to human and non-human actors, bound up in power and open to radical new possibilities. These positions illuminate differing conceptions of disability and possible social arrangements that serve as tools to make sense of conditions, perspectives, and possible alternatives.

The chapter then considered the significance of conceptualizations of disability for higher education settings, with attention to medical education. In higher education, two mechanisms for inclusion are discussed, accommodations and UD. Accommodations remain the primary mechanism of inclusion in higher education, with UD offered as an alternative. Accommodations follow from conceptions of disability under the social and minority model that call for societal barrier removal to foster disabled peoples' participation. Although accommodations may increase access to higher education, their efficacy is questioned and barriers to accessing them remain. Furthermore, the performative effects of accommodations include the reinscribing of realist notions of disability. In contrast, UD suggests that educational environments ought to be designed as inclusive from the outset, representing an anti-ableist approach to blur the binary formation of dis/ability. Questions remain about the ability for UD to realize its claims and hold its radical potential in the face of normalizing social forces.

In medical education, discussion of accommodations dominates the literature, largely constituted by commentary, legal analysis, and practice-informed writing. Debates remain about the extent of accommodations that ought to be permitted, under the assumption that existing educational structures are necessary to produce competent physicians. Accommodations are controversial, but students with disabilities, some medical educators, and disability resource professionals remain advocates. Little practical, theoretical, and empirical exploration of UD possibilities has occurred in medical education.

Little qualitative work has considered the lived experiences of students with disabilities in medical education. Only a handful studies use qualitative methods and make some use of social models, and only one in the U.S. context (Meeks & Jain, 2018). Only Bulk et al. (2017) interwove student and school-official perspectives, but their study had few medical-school

participants. Although national and institutional policies impact disability inclusion, only Stergiopoulos et al. (2018) combined policy and communications analysis with students' lived experiences. To my knowledge, no study has examined institutional disability-inclusion efforts holistically, through student and school-official perspectives, as well as policy and physical-space analysis. An examination of inclusion efforts in medical education taken from multiple perspectives within an institution is missing. Application of disability studies theory is also limited in this field.

Given the gap in existing research in disability inclusion in medical education, this study will take a constructivist grounded theory approach to understand how inclusion is enacted in several medical schools. With a relational understanding of the production of disability, the study will include policy and physical-space analysis as well as perspectives of students and school officials. Using theoretical tools from disability studies, the study will exercise a politics of crip futurity to identify the production of constraint and openings for new inclusive possibilities. In the next chapter, I discuss the methods used to build this constructivist-grounded theory in detail.

# **Chapter 3. Building a Grounded Theory: Foundations and Processes**

## **Introduction**

In this chapter I discuss the design and procedures used to build a substantive grounded theory of disability inclusion at four U.S. medical schools. The chapter is divided into three parts. Part 1 details the research paradigm. Following Crotty's (1998) four basic elements of the research process, this part explains the epistemology, theoretical perspective, methodology, and methods used in this study. Throughout, I relate each element to its implications for the project. Part 2 describes the locations and participants involved in the research. This part offers background to contextualize the four schools, as well as the participating students and school officials. The procedures used to select institutions for recruitment, to obtain institutional consent, and recruit participants are also detailed. Part 3 explains the processes for iterative data analysis in line with a constructivist grounded theory approach and discusses the limits of the research findings. Throughout the chapter, I build a case for the rigorousness of the research process. At the end, I reflect on my own positioning as the creator of this research and describe some ways that I engaged in strong reflexivity (Harding, 1991) during the process.

## **Part I. Research Paradigm**

This part of the chapter will detail the research paradigm, or the foundations, upon which this project is built. I follow Crotty's (1998) assertion that this foundation is comprised of the research epistemology, theoretical perspective(s), methodology, and methods, and that each part should be related to the other. While others use different categorizations to organize the paradigm (e.g., Denzin & Lincoln, 2011, suggested ontology, epistemology, and methodology), Crotty's (1998) is more useful here for several reasons. Crotty (1998) argued against ontology as a foundational element, and instead suggested it should be dealt with as it emerges, for example, in discussions of epistemology and theoretical perspective. The matter of ontology emerged in Chapter 2, regarding the nature of disability, and will continue to be discussed as it emerges. Second, Crotty's (1998) paradigm separates theoretical perspective from methodology and methods, a useful breakdown given Charmaz's (2014) continual assertion that grounded theory is flexible, without "rules, recipes, and requirements" (p. 16). There are many ways to construct a grounded theory and Crotty's (1998) framework helps to clearly articulate the various components. This part will describe the epistemology of social constructionism, theoretical perspectives of symbolic interactionism and from disability



studies, the methodological frame of constructivist grounded theory, and the associated methods used to build this research.

### **Epistemology: Social constructionism**

In this project, I adopt a social constructionist<sup>7</sup> epistemology. Social constructionist approaches are linked by several core assumptions:

- a critical stance toward taken-for-granted knowledge;
- historical and cultural specificity;
- knowledge is sustained by social processes, and;
- knowledge and social action go together (Burr 2015, p. 2-5).

In this way of knowing, there is no singular truth, nor are truths completely objective or subjective (Berger & Luckmann, 1966; Crotty, 1998). Rather, we make meaning of things interdependently in communal relation with the world (Berger & Luckmann, 1966; Gergen, 2009). Meaning is, therefore, socially mediated, contextual, cultural, temporal, and discursive. Truth or accuracy is relative to its social utility (Gergen, 2009; Lincoln & Guba, 2013). Meaning informs action; we act towards things depending on how we understand them. Given the potential for a shift in meaning to shift social action, questioning taken-for-granted meanings can unlock new possible futures (Gergen, 2009).

This epistemic grounding extends beyond the interpretations of the researched to the entire research endeavor. The researcher is viewed as an active agent in the research process, who co-constructs meaning with participants (Charmaz, 2014). Recognizing this, the researcher must be critically reflexive, to consider how the research design, data generation, and analysis are influenced by their own positionality and actions. Reflexivity is an ongoing and active process throughout the research.

Recognition of the cultural situatedness of knowledge is important in this research. This invited my attention to participants' cultures of origin, their roles and backgrounds, the broader culture of medicine (J. Taylor, 2003), and the school culture in which they operated. Attending to culturally-produced knowledge was of particular importance given the longstanding contentious relationship between medicine and disability, characterized by multi-layered oppression associated with medicine's biomedical focus on expert diagnosis, pathology, and cure (Clare, 2017; Withers, 2012). As discussed in Chapter 2, social constructionism is central to counter-narratives of disability, generated by disabled scholars and activists, to push back on the limiting, essentialist, and deterministic understandings of

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<sup>7</sup> I use social *constructionist* rather than *constructivist* here in line with Charmaz's statement that her position aligns with social constructionism in "the form it takes today" (p. 14). Like Charmaz (2014), I reject the individualistic and radical subjectivist strands of constructivism.

disability promoted in individual, medical, or “realist” narratives. A social constructionist approach invited consideration of how participants’ socially-mediated understandings informed their interaction with inclusion mechanisms and significant others in the medical education context.

As a non-disabled researcher attempting to conduct socially-just research, this necessitated critical reflexivity. Social constructionism offered this as a core principle. Much research about disabled people’s experiences has privileged individual, biomedical understandings of their circumstances and prioritized non-disabled peoples’ perspectives (Goodley, 2017; Linton, 1998; Oliver, 1992). Acknowledging my positioning and continually considering my actions in the research production was integral to reach towards a more just construction of the project. I will discuss reflexivity further at the end of this chapter.

My consideration of taken-for-granted meanings and the possibility for change during the research process also animated social constructionism in this research. Attention to how and why participants constructed meanings the ways they did opened the possibility that things could be constructed differently, as I will discuss in Chapter 7, Transforming Practice.

### **Theoretical perspectives**

Crotty (1998) described theoretical perspectives as “the philosophical stance informing the methodology, and this providing a context for the process and grounding its logic and criteria” (p. 3). I drew from two main theoretical perspectives in this research, symbolic interactionism and disability studies. This section briefly describes each theoretical perspective and its implications for the research process.

#### ***Symbolic interactionism***

Symbolic interactionism and grounded theory methodology are intimately connected (Charmaz, 2014; Clarke, Friese, & Washburn, 2018; Milliken & Schreiber, 2012; Strauss, 1993). Symbolic interactionism grew out of the Chicago School of sociology, where some scholars were heavily influenced by philosophers of pragmatism, chiefly Dewey and Mead (Blumer, 1969; Charmaz, 2008, 2014; Clarke et al., 2018; Strauss, 1993). Symbolic interactionism is genealogically related to grounded theory. Blumer, who coined the phrase *symbolic interactionism* in 1937, taught Strauss, an originator of grounded theory methodology, who went on to teach Charmaz, who developed constructivist grounded theory (Charmaz, 2014; Strauss, 1993). Mead’s central notion, that individual perspectives are socially grounded, connects social constructionist epistemology, symbolic interactionism, and constructivist grounded theory methods (Charmaz, 2014; Clarke et al., 2018; Strauss, 1993).

Key to symbolic interactionism are human agency, the use of symbols, and interpretation. Blumer (1969, p. 2) identified three premises of symbolic interactionism:

1. Human beings act toward things on the basis of the meanings that the things have for them;
2. The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows, and;
3. These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he [*sic*] encounters.

In this perspective, human interactions construct the self and society (Blumer, 1969). Meaning develops relationally and self-reflexively, emerging and shifting through social practice (Mead, 1934). Meaning is formed and conveyed through shared language and symbols, which precede individuals and are contextual (Charmaz, 2014). Interpretation and action are co-constitutive, shaping and informing each other.

In this project, it became clear that the meaning participants made of things, like disability, were socially mediated and influenced their interaction with institutional inclusion mechanisms. Following a symbolic interactionist perspective, to understand how this was operating I needed to access the interpretative process of participants. Through interviews, I sought the meanings participants ascribed to things, how these meanings had formed, whether, when, and why they shifted, and how they influenced their actions.

A critique of symbolic interactionism has been that its focus on individual interpretation ignores the influence of social structures, power, and relations of gender, class, ethnicity, and disability on interactions leading to a purely micro-sociological analysis (see, e.g., Kushner & Morrow, 2003). This critique brings to the fore the longstanding debate of structure versus agency, which questions whether individual action is socialized or if individuals act freely. Symbolic interactionists do not seem to fall squarely into either camp. Strauss (1993) explained that early interactionists held an anti-dualist position, refusing to separate determinism and anti-determinism. "Pragmatists emphasized that humans were active in shaping their environments, their ways of living, and the evolution of their cultural values—*but* this shaping occurred within the constraints of their extant physical and cultural environments" (Strauss, 1993, p. 42, original emphasis). Charmaz (2014) agreed, insisting that "institutionalized values and practices precede and constrain individuals and set the conditions for possible actions, although how they respond to these conditions can vary" (p. 269). This suggests that in a symbolic interactionist perspective, social conditions contour but do not determine individual practices. Therefore, in symbolic interactionist research, attention to contexts, discourses, and other social forces is not only possible but critical to understand participants' actions and interactions (Milliken & Schreiber, 2012).

In line with a symbolic interactionist perspective, I studied participant actions and interpretations. Through this approach, I identified several discourses that shaped participant actions, chiefly discourses of disability and the capability imperative. These powerful discourses, however, did not completely determine participant actions. Rather, I identified the ways participants interpreted, acted, and interacted in the context of these discourses.

### *Disability studies*

The field of disability studies informs the second theoretical perspective influencing this research project. Disability studies emerged, most directly, from activist movements in the 1970s in the UK and US that moved into the realm of academic inquiry (Linton, 1998; Oliver, 1996; Goodley, 2017). Now a global and interdisciplinary field, the critique of essentialist understandings of disability is central to disability studies theory. This followed from disabled activists who suggested that medical, charity, tragedy, and other individualistic discourses of disability ignored the determining influence of social conditions on disabled peoples' lives. In turn, they asserted that disability is created by social conditions rather than individual impairments (see UPIAS, 1975, for an early example). Subsequent critiques have challenged the de-socializing of impairment, centrality of physical disability, and dismissiveness of the body characteristic of early social model theories of disability (Corker, 2001; Crow, 1996; Morris, 1991; Wendell, 1996). Despite these internal debates in disability studies, commonality appears across the field in the analysis of "external variables: the social, political, and intellectual contingencies that shape meaning and behavior" (Linton, 1998, p. 6). Price and Kerschbaum (2016) synthesized the disability-studies approach, saying it "is not about studying the supposedly broken bodyminds of the abject. Rather, it is about studying broken systems, broken attitudes, broken gazes" (p. 23). I discussed disability studies theories in greater depth in the previous chapter.

Disability studies theory informed the study design and analysis. This required that I acknowledge disabled people as the experts on their own lives and attend to their full participation in the research process. Disabled students were the primary informants on how inclusion was enacted in medical education. In my analysis, I attended to their accounts separately from those of school officials. In line with the call to examine context, the broken systems, attitudes, and gazes (Price & Kerschbaum, 2016), it was necessary to relate these accounts to the larger system and to compare and contrast them with those of school officials, policies, and environments and to identify the interactions among these agents in the medical school environment.

I conceive of disability as a socially constructed, political, and relational phenomenon (Kafer, 2013). In concert with symbolic interactionism, this invited focus on participants' and

my actions, interpretations, and the context to understand how disability was (re)produced and interpreted in the environment. I followed Charmaz's (2014, 2016, 2017a, 2017b, 2019; Charmaz & Belgrave, 2019) assertion that pre-determined concepts should not be forced into analysis. Instead, I practiced *theoretical agnosticism* (Henwood & Pidgeon, 2003), where "researchers take a skeptical view of all possible theoretical understandings of the studied phenomenon, including their own" (Charmaz, 2017b, p. 40). Thus, although I started from a disability-studies informed theoretical understanding of disability, the specific theorists and associated concepts used ultimately had to "earn" their way into the final analysis.

### **Methodology: Constructivist grounded theory**

I used a constructivist grounded theory methodology to develop this research (Charmaz, 2014). Constructivist grounded theory grew out of the classic method developed by Glaser and Strauss (1967) and the version further developed by Strauss and Corbin (1990, 1998). Grounded theory refers to a constellation of methods used to develop mid-range theory that seeks to explain social environments through qualitative, data-driven analysis (Bryant & Charmaz, 2007). Charmaz (2017a, p. 2-3), identified 10 commonalities between types of grounded theory:

1. an iterative process of data collection and analysis;
2. a focus on what is happening, what people are doing;
3. use of the constant comparative method;
4. through comparison, filling out categories and illuminating visible and hidden processes within them;
5. using data to create original and conceptual categories;
6. creating these categories through inductive, systematic coding and memo writing;
7. focusing on category development rather than an empirical topic;
8. constructing new theory;
9. checking theoretical ideas with data, and;
10. stating the implications for policy and practice.

Despite these similarities, research practices differ in variations of grounded theory according to their epistemological and ontological commitments (Annells, 1996; Charmaz, 2017a; Mills, Bonner, & Francis, 2006). Mills et al. (2006) referred to the evolution of grounded theory as a *methodological spiral* with points of departure dependent on these commitments. Evolution of the method along the spiral follows emerging paradigms of inquiry in research (Guba & Lincoln, 1994), suggesting that iterations of grounded theory are reflective of their time of origin (Annells, 1996). Charmaz (2017a) and Belgrave (Charmaz & Belgrave, 2019) described the major groups of grounded theory as *objectivist*, referring to classical grounded theory (Glaser & Strauss, 1967) that Glaser (1978, 1998, 2001, 2011, 2013) continues to promote, *post-positivist*, referring to that

developed by Strauss and Corbin (1990, 1998), and *constructivist*, developed primarily by Charmaz (2000, 2006, 2014). Analysis of the epistemological and ontological commitments of the first two types is contested, given internal inconsistencies within the methods (Annells, 1996; Mills et al., 2006). The methodological spiral suggests movement towards constructivism, with elements of this epistemology appearing until Charmaz (2000, 2006, 2014) firmly articulated a constructivist version of the method (Mills et al., 2006).

Objectivist grounded theory suggests that a researcher can remain objective in the process, “discovering” the truth of social worlds through faithful adherence to emerging understandings of data gathered (Bryant & Charmaz, 2007). Within this version, the researcher is presumed able to hold no preconceptions when conducting research, not engaging in an initial literature review, letting go of “normal citizen bias” (Glaser, 2011, p. 1) related to social categories like race and gender, and resisting extant theories during fieldwork and analysis (Charmaz, 2017a; Glaser, 2011, 2013). Data is presumed objective, not shaped by the observer or creator (Charmaz, 2014; Charmaz & Belgrave, 2019; Clarke, 2005). In this version, researcher reflexivity is viewed as optional and methods as neutral (Charmaz, 2017a). Objectivist grounded theory suggests a realist ontology and positivist epistemology. At the same time, Bryant and Charmaz (2007) argued that even in *The Discovery of Grounded Theory* (Glaser & Strauss, 1967), shades of constructivist thinking exist though they are not central.

Post-positivist grounded theory retained objectivist grounded theory’s position of data as “unproblematic and unidimensional” (Charmaz & Belgrave, 2019). Other elements of the method, however, move away from their objectivist roots to suggest elements of constructivism. In their 1994 explication of grounded theory, for example, Strauss and Corbin explained that researchers bring the “sensitizing possibilities of their training, reading, and research experience. . . that might be useful if played against systematically gathered data” (p. 277), articulating movement away from the no preconceptions dictum of objectivist grounded theory (Glaser, 2013). Strauss and Corbin’s conditional matrix is another example, in that it applies preconceived concepts to the data rather than relying on pure induction (Charmaz & Belgrave, 2019). Strauss and Corbin, furthermore, acknowledged the interpretive nature of analysis that is historically embedded and provisional (Annells, 1996; Strauss & Corbin, 1990, 1994), suggesting elements of relativist ontology and subjectivist epistemology. While this led Annells (1996) to suggest grounded theory could be constructivist, she conceded that “the remnants of post-positivism linger” (p. 389) within Strauss and Corbin’s version.

In the 1990s, some theorists moved away from the positivist roots of grounded theory towards a solidly constructivist orientation (Charmaz, 2014). Constructivist grounded theory adopts the inductive, open-ended, and emergent qualities of the objectivist form of the method, along with Strauss’ iterative logic and the pragmatist focus on action and meaning (Charmaz,

2014). Embodying a relativist ontology and subjectivist epistemology (Mills et al., 2006), however, constructivist grounded theory assumes knowledge is contextual and partial, such that only incomplete knowledge can be formed about a subject (Charmaz, 2014). Charmaz does not assert the absence of external reality or that all representations of reality are equal (Bryant & Charmaz, 2007; Charmaz, 2008, 2014). Rather, in line with its pragmatist roots, constructivist grounded theory assumes “reality is fluid and somewhat indeterminate” and requires that individuals’ perspectives are not separated “from the social realities in which they exist” (Charmaz, 2017b, p. 38).

Within constructivist grounded theory, the researcher is not assumed neutral or value-free and data are treated as problematic (Charmaz, 2014; Charmaz & Belgrave, 2019). Charmaz (2014) explained that “my approach explicitly assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it” (p. 17). The researcher then, is instrumental to the research process, shaping the research design and interview questions, conducting the analysis, determining what to focus on and what to ignore. The research is co-constructed between researcher and participant and inextricably linked to the researcher and participants’ standpoints (Charmaz, 2001, 2014). Adhering to symbolic interactionist theory, the researcher must not only explore participants’ interpretations and actions, but also their own in the research process. This invites *methodological self-consciousness* (Charmaz, 2017b, 2019), “a deeply reflexive gaze on how our perspectives, privileges, and priorities affect our data, actions, and nascent analyses” (2019, p. 3). To do so, the researcher must grapple with their preconceptions, inviting doubt through questioning certainty and taken-for-granted understandings during the research process (Charmaz, 2017a, 2017b). This applies to the researcher’s own assessments of data, but also participant statements, and extant literature and theory (Charmaz, 2017a, 2017b). To enact this, Charmaz (2017b, 2019) advocated that researchers adopt Harding’s (1991) *strong reflexivity*. This requires multi-faceted reflection: understanding one’s own social locations; imagining how participants see the researcher and the research project from their standpoints; standing behind participants to view the research within the larger social and cultural context, and; doing so while looking forward to shape the next steps in the project (Charmaz, 2017b, p. 36). The researcher is continually self-reflexive as well as critical of the project itself, aware of their moral commitments, adjusting their actions and interpretations in line with this reflexivity.

Constructivist grounded theory holds the possibility of pursuing meso or macro analysis, as previously discussed in the description of symbolic interactionism (Charmaz, 2008, 2014, 2016, 2017a, 2017b, 2019; Charmaz & Belgrave, 2019). Whereas, in objectivist grounded theory methods, the researcher focuses on what is happening and how, constructivist grounded theory extends this to ask emergent “why” questions (Charmaz, 2008, 2019). Asking the question, *why is*

*this happening the way it is happening?*, invites the researcher to situate participant meaning and action in larger social structures and discourses to “show the connections between micro and macro levels of analysis and thus link the subjective and the social” (Charmaz, 2014, p. 241; 2016, 2017b). These practices, along with strong reflexivity (Charmaz, 2017b, 2019; Harding, 1991), can bring the research into the realm of critical social-justice inquiry.

### ***Aligning the study with constructivist grounded theory***

This study started with the intention to understand the social world of medical schools for students with disabilities. Following the emergent logic of constructivist grounded theory methodology, the research evolved from the original intent. I started with a series of specific research questions that informed the study design, recruitment of institutions and participants, and the original interview questions:

- To what extent do medical schools create accessible environments for students with disabilities?
- What factors do students with disabilities identify as supporting or hindering their success at medical school?
- What do medical schools communicate to students with disabilities through their policies, and physical and digital environments?
- How do medical school administrators (disability service providers, deans) and faculty create a culture of access (or perpetuate institutional ableism)?
- How do students with disabilities experience medical education?
- What policy implications for creating accessible environments follow from analyzing medical schools and student experiences?

In the course of the study, I reformed the research question to:

- How is disability inclusion enacted at the participating medical schools?

While the original questions follow from the reconceptualized question, and many were subsequently addressed, this more open question allowed me to focus more closely on what was happening in the specific contexts, how, and why. Through this reconceptualization, borne of the iterative process of grounded theory, my attention shifted from the original focus (e.g., physical spaces and digital communications) to a more open focus on participants’ interpretations and actions. This shift increased attention to more fundamental concerns and meanings, that are represented in discourses of disability and medicine. I still pursued relevant physical spaces and policies but did so in an interactive fashion guided by participant accounts.

This shift in conceptualization of the research also came as a result of my reflexive process. Practicing strong reflexivity was particularly important to me as a non-disabled researcher interested in producing socially-just research. One way I achieved this was by attending to the



things I pursued, avoided, and was troubled by in interviews and constant questioning of my analytical conclusions. I explored these through reflective memos and while transcribing and coding, and in relation to extant theory.

Attending more closely to participants' use of language, their meanings, and actions was another strategy that shaped the research, developed through reflexivity. This helped me to check my understandings while co-constructing data. In reviewing my first interview transcript with my supervisors, we identified this practice as necessary to ensure I had clearer understandings of participant perspectives rather than assuming understanding from my perspective. Going forward, this practice deepened interview discussions and encouraged participants to surface tacit meanings. These reflexive activities, inherent to constructive grounded theory methods, pushed me to question the things I believed I knew about disability, inclusion, and medical education throughout the research process. Through reflexivity and analysis, I moved into a new realm of understanding that is grounded in the data. I will discuss reflexivity further at the end of this chapter.

### **Methods**

Charmaz (2014) asserted that the flexibility of grounded theory methods allow for a multitude of tools for gathering rich data about the studied phenomena. She suggested that “data collection methods flow from the research question and where we go with it” (Charmaz, 2014, p. 27). Choice of method and data sought, then, begins with those that make sense given what the researcher aims to study. In constructivist grounded theory, unlike objectivist grounded theory, the researcher may begin with sensitizing concepts borne of the researcher's knowledge of the field and associated literature. These serve as “points of departure” (Charmaz, 2014, p. 30) for the study rather than the destination, reflecting Dey's (1993, 2007) notion of entering research with an open mind not an empty head. The emergent nature of grounded theory suggests that concepts of interest, methods used, and data sought may evolve based on leads the researcher defines in the data (Charmaz, 2008, 2014). This requires that the researcher use an iterative approach to data-gathering and analysis in a logic of *theoretical sampling*, moving towards *theoretical saturation* (Charmaz, 2014). That is, data-gathering is framed by “explicit development of theoretical categories derived from analyses of [the] studied world” (Charmaz, 2014, p. 199).

The central method used to generate data for this study was semi-structured interviews with disabled students and school officials. The purpose of these interviews was to understand participant perspectives, borne of lived experience, on inclusion in medical education. Where interviews and analysis suggested the importance of specific policies, these documents were analyzed. In order to develop a greater appreciation of the contexts in which students learned,

I observed physical environments at each participating medical school. Initially, sites for observation were identified based on my practice experience and additional locations were informed by participant recommendations. In this section, I discuss my approach to data-gathering. Because of the non-linear nature of the iterative process, I also explain how this coincided with analysis towards theoretical sampling and saturation.

### *Interviewing*

Interviewing methods in constructed grounded theory attempt to balance openness to participants' stories and interests with the researcher's goals (Charmaz, 2014). The researcher treats the interview as a co-constructed, interactional space. Using a flexible approach, the researcher shapes the interview with open-ended questions but follows emergent areas of inquiry. Following a constructivist logic, the researcher elicits detailed responses and focuses on participant perspectives, meanings, and experiences. Interviewing begins with a broad focus but subsequent interviews progress to more focused inquiry in line with theory development. Four theoretical concerns affect data gathering: theoretical plausibility, direction, centrality, and adequacy (Charmaz, 2014). These concerns lead the researcher to follow areas of theoretical interest, shift or add interview questions that pursue those areas of theoretical interest, build categories that describe emerging patterns, and then saturate them through increasingly-focused inquiry (Charmaz, 2014). An iterative process of data gathering and analysis guides this focus, through initial coding, focused coding, increasingly theoretical memo-writing, and abduction (Charmaz, 2014).

I began interviewing with an in-depth guide that reflected open-ended sensitizing questions developed from extant literature and my professional experiences with the aim to gather rich descriptions of participants' experiences (see Appendix A for these interview guides). For students, these questions addressed the following broad areas: access and accommodations; disclosure; campus climate, and; supports and challenges. For school officials, the interview guide covered the following broad areas: role, access and accommodations, policies and procedures, challenges and successes, and; campus climate. I started with close adherence to these interview guides, but quickly found that one or two open questions elicited answers to many of the subsequent questions more organically.

All participants engaged in an interview with me via video conference (through Skype or FaceTime) or in-person at a private location (either at the medical school or elsewhere on campus) between May and October 2017. All but one interview was conducted with a single participant, however, two school officials were interviewed together, upon their request. Interviews ranged from 45 minutes to over 3 hours in length, depending on the flow of the interview and interviewee availability. Student interviews tended to last longer than school

official interviews, however, those officials most directly engaged in disability inclusion spoke for longer than other officials.

In these interviews, I followed Charmaz's (2014, p. 88) guidance to "concentrate on participants' views and actions" and "attend to emergent areas of possible theoretical interest." I also sought clarification in the meaning of participants statements, for example, when a participant described her experiences as "battling time," I sought further description of what this meant and explored whether this applied to other aspects of her life, outside of medical school. I took brief notes during interviews that identified items to follow up on during the interview or jog my memory after. After each interview, I wrote a reflective memo that commented on the feeling of the interview, areas of theoretical interest, and items that troubled me. I also began transcribing and initial coding after the first interview and moved forward to constant comparison and focused coding with subsequent interviews. Through these activities, I identified areas to pursue in subsequent interviews. For example, after the meaning of disability and students' relationship to the term appeared salient in initial interviews and correspondence with students interested in participating in the research, I added the question "tell me about your relationship to disability" in subsequent student interviews. When participants discussed experiences that echoed those of other participants, for example, in vivo constructs like "picking my battles" and "battling time," I would inquire further to generate a fuller picture of that concept from the participant's perspective. Similarly, constructs related to the culture of medicine, for example, conceptions of wellness, perfectionism, intergenerational tensions and the "real world" of medicine, began to cluster and demonstrate relevance to participant actions. Conceptions of disability and the culture of medicine suggested theoretical direction given their ties to participant engagement in inclusion. I pursued these concepts in more depth as they invariably arose in interviews, seeking the meaning behind participants' phrasing and seeking examples in order to pursue categorical saturation.

Charmaz (2014, p. 89) explained that, "we may not define the theoretical centrality and direction of the study itself until we have done considerable coding and memo-writing." This echoed her previous assertion that theoretical sampling should occur later in a study to avoid foreclosure and foster openness to the studied situation (Charmaz, 2000). Thus, while I pursued emergent areas of theoretical interest and tentative categories in the process of the initial 45 interviews, it was not until I had conducted extensive coding, memo-writing, engaged in abduction, theorizing, and diagramming of this data that I pursued additional interviews for theoretical sampling, firmly defined theoretical centrality, and assessed theoretical adequacy. I conducted six follow-up interviews for purposes of theoretical saturation in August-October 2019. I will discuss this further under theoretical saturation.

### *Document analysis*

Through interviews and analysis, I identified documents for inclusion as data sources. These included schools' technical standards, school accommodation policies, national medical resident duty-hour policies, and national licensing-exam accommodation policies. In line with the theoretical underpinnings of constructivist grounded theory, documents represented discourses in the studied situation and analyses should explore not just their content but what they do (Charmaz, 2014). I followed Charmaz's (2014, p. 46, 53-54) guidance for document analysis, including consideration of:

- what its originators intended to accomplish;
- the process of producing the document;
- what and whom the document affects;
- how various audiences interpret it;
- how, and to what extent these audiences use the document;
- what realities does the document claim to represent? How does it represent them? What and whose facts underlie this document?;
- what, if any, unintended information and meanings might you see in the document?; and
- how is language used?

I studied the policies and explored participant interactions with them during interviews. I used a back-and-forth process of identifying policies and documents for review based on interviews, analyzing them through coding and memo-writing, and further exploration through subsequent interviews. For example, students described their interpretations of technical standards, which prompted me to analyze technical standards across the four schools, discuss technical standards further with other students, and discuss their creation and use with school officials.

### *Physical space observations*

In order to understand the material conditions under which education occurred, I observed key physical spaces at each medical school. Initially the spaces for observation were informed by my practice experience and additional locations were identified through interviews. The spaces observed included: medical school building entrances, elevators, bathrooms, and hallways; student centers or lounges; lecture halls; clinical skills and anatomy labs; team-based learning spaces; student health centers; libraries; administrative offices; and cafeterias. Certain spaces, such as anatomy labs and clinical skills labs, had restricted access, while others were largely open to the public. At each school, an official gave me a tour of key physical environments. Where possible, additional time was spent in publicly-available spaces without an official present. I took photos where permitted and made field notes to record my

impressions. These notes and photos aided my analysis to contextualize discussions. During interviews, I discussed impressions of spaces to understand their import, genesis, and related action. For example, at one school many officials expressed concern about poor building accessibility. While on-site, I observed these conditions and used these observations to discuss the implications of access concerns with students and plans to address access concerns in subsequent interviews with school officials.

## **Part II. Locating the Study and Participants**

This part of the chapter describes the locations and participants involved in this research. First, I detail the selection of medical schools as possible sites for this research. Then, procedures for institutional consent and the associated conditions of institutional participation are described. Next, I detail the recruitment processes for individual participants. Finally, the participating schools, students, and school officials are described to contextualize the study and participants' social locations.

### **Site selection**

Following the ethos of a strengths-based approach (Saleebey, 1996), I aimed to study inclusion within medical schools that showed promise as exemplars in this area. I was aware of significant variability in practice among medical schools from my professional experiences, as well as research I was engaged in at the time (Meeks & Jain, 2018). A recent prevalence study had found significant variance in the number of students disclosing their disabilities to schools, ranging from 0-12% (Meeks & Herzer, 2016). This variability resonated with earlier reports that schools that accommodated disabled students were likely to attract and admit more disabled students (Moore-West & Heath, 1982; Wu et al., 1996). From my practice experience, I suspected that, in addition to numbers, the work of institutional champions could also lead to greater sophistication in inclusion practices. I wanted to understand what these schools were doing to create a culture of access that might benefit other institutions.

Following this hypothesis and using my practice-based knowledge of disability inclusion in the health sciences and extant literature in the discipline, I developed nine indicators to identify signs of “institutional champions” and “positive disability culture” that might contribute to advanced inclusive practice:

1. affiliated faculty had published scholarly writing regarding students with disabilities in medicine;
2. published disability curriculum initiatives;
3. publicly-identified faculty with disabilities;
4. dedicated disability services provider for the medical school or health science programs;
5. medical school committee on disability-related concerns;

6. disabled students' group at the medical school;
7. inclusion of disability in diversity initiatives;
8. technical standards that stated the possibility for accommodations (Zazove et al., 2016);  
and
9. a reputation for providing good service to disabled students.

I gathered a list of institutions that fulfilled these indicators through web searches, assessment of medical school website information, academic publications, news stories about disabled doctors, and my own professional knowledge of unpublished initiatives or programmatic elements. Informal discussions with leaders in disability inclusion in medical education led to identification of schools with a positive reputation for inclusion. Once I identified a school based on one factor, I assessed their position on the other factors. I used a matrix to collect information about prospective sites and rank-ordered the schools based on the number of positive indicators found. Most schools showed more than one positive indicator. Using this process, I identified a total of 40 U.S. medical schools as possible sites for research.

This approach is inherently limited. The sample is based on published information and my own and expert informants' personal knowledge of program elements. There are likely very inclusive schools that do not publicize their work through web communications or scholarly writing and others of which I am not personally aware. Those schools who do publicize their efforts may not be exemplary in their practices. There may be other indicators that better uncover inclusive programs, though this has not yet been studied. I do not mean to suggest that this approach identified the most progressive U.S. medical schools regarding disability inclusion. Rather, this represents a systematic attempt to identify potential exemplar schools to approach for institutional recruitment.

### **Institution and participant recruitment**

I first sought institutional consent from a medical school leader (Dean or designee) to include an institution in the study. This allowed me to gain access to recruit faculty, staff, and students at that medical school. As part of the institutional consent process, the leader provided assurance that prospective participants' participation or non-participation would not affect their relationship with the university.

To obtain institutional consent, I used a combination of unsolicited emails to the medical school Dean and introductions via a third-party (see Appendix B for the initial email template and associated forms). I began by contacting the Dean of the top three medical schools assessed. If I received response that the school was not interested in participating, I moved to the next school on the list. After several weeks, I also solicited the assistance of a third party. This individual contacted medical school leadership from the developed list where she had

professional contacts. She shared the information about the study and, if they expressed interest, connected them to me for further discussion. She was not informed of the institution's ultimate decision to participate.

Through this process, I contacted a total of 20 schools: six schools declined to participate, nine did not provide a definitive answer, and five agreed to participate. Given time constraints and capacity, four medical school leaders ultimately consented to institutional participation in the study. At two of the four schools, I completed an additional institutional review board (IRB) administrative review or general counsel review of ethics forms prior to receipt of institutional consent. Two of the four schools requested minor modification of participant information and consent forms. These were modified according to institutional requests, with approval from the University of Auckland Human Participants Ethics Committee (UAHPEC, Ref #018365). As part of the institutional consent agreement, the schools participated on the conditions that they not be named in research, and the school was not informed who within the institution agreed to participate.

At each university, a medical school leader sent email invitations (See Appendix C) to all undergraduate medical students (i.e., students in the first phase of medical training to obtain an M.D.) and faculty at each school. The recruitment email to students invited participation from those with self-identified disabilities. Students did not have to be formally registered with disability services or receiving accommodations to participate. All faculty were invited to participate. Interested participants contacted me directly and were provided the respective Participant Information Sheet and Consent Form for their school and role (see Appendix D for sample forms). All participants confirmed their individual, informed consent to participate.

I used snowball sampling to reach additional student participants. At the end of student interviews, I asked if they would share information about the study with any other students with disabilities they may know. Several participating students had already referred peers prior to our interview. Many students did not know any other students with disabilities well enough to share information with them. Two students who expressed initial interest did not ultimately participate in an interview. No students interviewed withdrew their participation from the study.

Only two faculty members responded to the general email call for participants across the four schools. Another tool used to invite school official (faculty and administrator) participation was direct recruitment. I identified school officials with potentially key roles in disability inclusion (e.g., dean of students, disability services representative, dean for diversity and inclusion, ADA coordinator) and directly invited their participation. In pursuit of rich data from knowledgeable community members, I identified additional school officials for direct

recruitment based on participant recommendations and emergent directions in the data. At the end of interviews, I asked participants for their recommendation of school officials to interview to better understand their experiences and disability inclusion at the school. Often, they recommended individuals already contacted, but some were new. Usually students had referred to these individuals in the course of their interview as influential figures on their journey. School officials often recommended individuals with key inclusion roles that were not readily apparent through website information, such as unofficial disability champions or committee participants. Through this process, I identified 51 school officials for direct recruitment across the four schools and sent them up to 3 direct emails to invite their participation. Twenty-five school officials agreed to participate through this process, six declined, and 20 did not respond. Three individuals I had identified as possible key informants based on website information about the inclusion process stated they did not have a medical school role. This was my first indication that website information was not always reflective of the inner workings of disability inclusion processes.

### *Participating institutions*

The four medical schools are located at public universities in the US: one in the South, two in the Midwest, and one in the West. All four schools were ranked across the top 50% of U.S. medical schools for research by U.S. News and World Report (2019). Two of these schools had particularly strong diversity missions and reported that they admit a high proportion (one nearly 50%) of students who are *underrepresented in medicine* (URM).<sup>8</sup>

The physical environments of the four schools differed. Two schools had historical architecture with retrofitted accessibility features, while the other two had newer buildings built according to post-ADA architectural guidelines. Retrofitted architecture often results in limited usability, as existing building structures constrain options for creating access (Dolmage, 2017). This logic played out in the participating institutions. At the more historic campuses, building entrances, lecture halls, and restrooms had mixed usability, even with accessibility renovations. At the newer-construction campuses, these features were generally built for accessibility, though still sometimes limited in usability. Key learning environments, such as anatomy and clinical skills labs, were not fully accessible across the schools. Interior design choices also rendered some spaces inaccessible. Even at the most physically-accessible school, I observed aesthetic choices that assumed non-disabled students. For example, a key classroom space had high tables and swivel chairs that rendered the space inaccessible for

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<sup>8</sup> The Association of American Medical Colleges (AAMC, n.d.) defines URM as “those racial and ethnic populations that are underrepresented in the medical profession relative to their numbers in the general population” (n.p.).



students with many mobility-related disabilities. Physical environment accessibility was, therefore, inconsistent across the four schools.

The structure of disability services also differed across the schools. In the following paragraphs and in Table 3.1, I summarize the structure of disability services at each school. At the first school, the school's Assistant Dean of Student Affairs was the primary contact for students seeking accommodations. A medical school committee determined accommodations. This entailed a group of faculty and administrators from the medical school and key university offices (central disability services office, ADA coordinator) that jointly determined students' disability status and accommodations.

At the second school, the medical school's learning specialist was the key point-person for students seeking accommodations. The central university disability services office confirmed students' disability status and made initial recommendations for accommodations. An accommodations committee comprised of faculty and administrators from the medical school made the final determination on accommodations. Although the administrative staff committee members provided information to aid the committee in decision-making, the faculty committee members ultimately voted on accommodations.

At the third school, the medical school had their own disability services program, conjoined with student learning support (e.g., tutoring, individual learning strategies, board exam preparation). Two specialists in disability and learning support staffed the office and determined accommodations for students, in consultation with faculty. These staff were the primary contacts for students seeking accommodations. They also interfaced with most medical students for other learning support activities.

At the final school, the medical school learning specialist served as the disability liaison for students seeking accommodations. The central university disability services office, however, made all disability determinations and accommodation recommendations. The learning specialist worked with the disability services office and medical school faculty when any concerns arose about recommended accommodations. Although some students went directly to the disability services office to seek accommodations, many were referred there after discussions with the learning specialist. The learning specialist worked with most students, providing individual and group learning services, coordinating tutoring, and assisting students with board exam preparation.

**Table 3.1: School Disability Services Structures**

	<b>Disability Services Structure</b>
<b>School 1</b>	<b>Primary Contact:</b> Assistant Dean of Student Affairs <b>Accommodation Determination:</b> By medical school committee of faculty and administrators including university disability services and ADA coordinator jointly
<b>School 2</b>	<b>Primary Contact:</b> Medical school learning specialist <b>Accommodation Determination:</b> Initial recommendations from central university disability services office; medical school committee of faculty and administrators deliberate; faculty committee members vote on accommodations
<b>School 3</b>	<b>Primary Contact:</b> Combined learning and disability support office at medical school, with two specialists <b>Accommodation Determination:</b> By disability support office
<b>School 4</b>	<b>Primary Contact:</b> Medical school learning specialist (as liaison to university disability services office) <b>Accommodation Determination:</b> By central university disability services office

***Participating individuals***

Nineteen students and 27 school officials participated in this study across the four institutions, for a total of 46 participants. Participants were invited to complete an optional online demographic questionnaire (see Appendix E) to provide background information prior to the interview. Several participants elected to complete the questionnaire following the interview, some did not answer all questions posed, and one school official did not complete it altogether. Tables 3.2 and 3.3 summarize participant demographic information. This information is not separated by school to mask participants and institutions, and because the aim is not to conduct a comparative analysis of institutions.

Student participants represented a spread of disability types, with most (16/19) having disabilities that were not readily apparent and most reporting more than one category of disability (11/19). This aligns with current national prevalence data regarding disability type, however, prevalence studies have not accounted for students occupying multiple categories of disability (Meeks, Case, et al., 2019; Meeks & Herzer, 2016). No participating students identified with sensory disabilities (hearing- or vision-related). To my knowledge, there were no enrolled students with sensory disabilities at the schools at the time of the study. Six students had not used accommodations during medical education at the time of our interview. Some had discussed accommodations with their schools but opted not to pursue them, while others had not disclosed to any school officials. Perspectives of disabled medical students who do not seek accommodations have yet been engaged in research, to my knowledge.

Students also shared other aspects of their identities. It is not possible to relate these demographics to national disabled-student prevalence data, as recent studies have not explored intersectional factors (Meeks, Case, et al., 2019; Meeks & Herzer, 2016). Student participants largely identified as women (16/19). This contrasts with national data which indicated that in 2016, women comprised 49.8% of all US medical school matriculants (AAMC, 2017). Just over half the students (10/19) described themselves as underrepresented in medicine (URM). The AAMC's (n.d.) definition of URM was not provided to participants in the demographic survey, although the term is widely used in medical education. Nine students also described their ethnicity as non-white, six occupied the first generation in their family to attend college, three identified as immigrants, and one as having a refugee background. Three students identified as LGBTQIA+ (lesbian, gay, bisexual, transgender, queer, intersex, asexual, and beyond).

The aforementioned positions (non-white race/ethnicity, low socio-economic background, women, and LGBTQIA+) have been associated with experiences of marginalization in medicine (Ackerman-Barger et al., 2020; Beagan, 2000, 2001b, 2005; Bleakley, 2013; Boursicot & Roberts, 2009; Mansh et al., 2015; Robertson, 2017; Southgate et al., 2017; Webb et al., 2019). Existing research has not yet engaged with the influence of intersectionality on disabled medical student experiences. Outside this area, however, research has demonstrated the salience of intersectionality to understand experiences of disability (Annamma et al., 2013; Erevelles & Minear, 2010; Sins Invalid, 2019; Thompson & Wong, 2016a, 2016b). Attending to this gap, I explored intersectional factors when students raised them in interviews and attended to them in analysis.

School officials served in various roles, such as: associate or assistant dean, clinical and non-clinical faculty (assistant, associate, and professor levels), department chair, disability resources professional, learning specialist, psychologist, academic or clinical coordinator, and librarian. About half (13/27) of the school official participants were trained as physicians and, of these, most actively practiced medicine. Many school officials held multiple roles, as both faculty and administrators, and taught medical students and residents. Many school-official participants had served on ad hoc and standing committees with relevance for disability inclusion, such as equity, accommodation, and policy review. Of the school-official participants who completed the demographic questionnaire (26/27), they were more likely to be white (19/26) and identify as women (16/26). Five school officials identified as having disabilities.

**Table 3.2: Participant Self-Reported Demographics**

	Students	School Officials
<b>Gender</b>		
Women	16	16
Men	3	10
<b>Ethnicity<sup>a</sup></b>		
White/Caucasian	10	19
Latinx/Hispanic/Puerto Rican	5	1
Black/African American	2	0
Asian	2	4
American	0	1
<b>Other Intersecting Identities</b>		
Underrepresented in Medicine (URM)	10	2
LGBTQIA+	3	1
First generation to attend college (FirstGen)	6	6
Immigrant	3	2
Refugee background	1	1
Person with a disability/impairment	19	5
<b>Total Responding</b>	<b>19</b>	<b>26</b>

*Note.* Not all participants completed the demographic survey, and some did not answer all questions. <sup>a</sup> Ethnicity descriptors were self-generated, some categories have been grouped to preserve participant confidentiality.

**Table 3.3: Student Self-Reported Disability Information and Accommodation Use**

	Number of students
ADD/ADHD	11
Psychological	8
Chronic health condition	6
Learning disability	4
Physical or mobility	4
Chose more than one disability category	11
Used accommodations in medical school	13
No accommodation use in medical school	6
<b>Total number responding</b>	<b>19</b>

### **Part III. Data Analysis and Reflective Considerations**

This part describes the procedures for data analysis and reflects on several aspects of the study to further establish rigor and suggests limits to interpretation. I start by detailing the iterative process of analysis in line with a constructivist grounded theory approach, moving from interview transcription through to theory generation. Then, I move to considerations and limitations of the study. This includes a discussion of research ethics, saturation, representation, and Charmaz’s (2014) criteria to evaluate constructivist grounded theory study: credibility, originality, resonance, and usefulness. The section concludes with an exploration of my reflexivity throughout the process.

### **Iterative data analysis**

Under a grounded theory approach to research, the researcher tacks back and forth between data generation and analysis, with each informing and advancing the other. Data analysis begins early in the process of data generation and this helps to sharpen the focus in later data generation (Charmaz, 2014). In this research, the general process of data generation and analysis included the following steps:

1. Conducting interviews, taking sketchy notes while interviewing and writing reflective memos shortly afterwards
2. Transcribing interviews, sometimes writing short analytic memos during this process
3. Verifying transcript with participant
4. Conducting initial line-by-line coding by hand and writing memos about early analytic directions, identifying areas for clarification
5. Uploading transcripts to NVIVO<sup>QSR</sup> for focused coding
6. Continuing memo-writing with increasing theoretical depth
7. Grouping significant focused codes into categories
8. Developing concepts from categories that lead towards theory building

Although I describe these processes in a linear fashion, the actual process was more fluid. I moved dynamically between a granular focus on coding data and high-level theorizing throughout, as per the expectations of the constant comparative method. Furthermore, the conditions of the research journey did not always allow for immediate iteration between interviews and coding. The initial period (May – July 2017), during which I conducted nine interviews remotely from New Zealand followed a more traditional iterative process of interviewing, transcribing, coding, and constant comparison. After I traveled to the US (July – September 2017) to conduct in-person observations and interviews, my ability to move back and forth between interviewing and coding slowed. To seize upon prospective participant interest, with awareness of medical students and school officials' limited time and the possibility for attrition, I prioritized interviews over structured coding. To ensure a connection with the iterative spirit of grounded theory during this time, I continued transcribing and coding when possible and continued to memo after each interview and field observation. Before leaving each school, I wrote a reflective memo on the experience and “feel” of the school, any notable moments of interest, and reflection across interviews.

As described in the section about interviewing in Part 1 of this chapter, I used these analytical techniques to inform ongoing interviews. This kept analysis and initial theorizing active, informing areas to pursue in subsequent interviews when in-depth coding was not possible. Upon return from fieldwork (September 2017), I resumed transcribing and coding

interviews in earnest. In late September – October 2017, I conducted four additional interviews, informed by the developing analysis. In 2019, after extensive, in-depth analysis and theorizing, I conducted six follow-up interviews with participants for purposes of theoretical sampling to reach theoretical saturation. In the following sections, I describe each process in more detail.

### ***Transcribing***

Each interview was fully transcribed, either by me or a third-party transcriptionist. Transcription began immediately after the first interview and I transcribed the first 10 interviews as well as a number of later interviews. I checked each externally-transcribed transcript for accuracy while listening to the audio recording. The slow, methodical process of transcription fully immersed me in the voices of participants. In the early stages, this process allowed me to closely consider my interviewing technique and adjust accordingly. Henwood and Pidgeon (2003) contended that, “Doing one’s own transcription is a way for researchers to start early on the path of thinking analytically about the data and its properties” (p. 142). I often stopped transcribing to write a short memo about a concept, already drawing connections between interviews and noting points of interest for further exploration.

I sent completed transcripts to the participant for review, to add or redact content, and to confirm their willingness to remain in the project. Few participants made changes. Most simply confirmed their satisfaction with the transcript and willingness to remain a participant in the research. Several school officials made small changes, generally to clarify statements with additional details and to correct wording or inaudible phrases. No participants completely withdrew their participation. One school official asked that their interview be used in collective analysis but not directly quoted in publications. This approach to transcription deepened my immersion in the data and sparked analytical thinking through initial memo-writing prior to formal coding.

### ***Initial coding***

Coding “shapes an analytical frame from which you build the analysis” (Charmaz, 2014, p. 113). Once a participant had confirmed their transcript, I began the initial coding process. In grounded theory, coding is inductive rather than pre-determined, labelling segments of data according to the researcher’s assessment of the meaning therein (Charmaz, 2014). Charmaz (2014, p. 120) advised that during coding, the researcher should: remain open; stay close to the data; keep codes simple and precise; construct short codes; preserve actions; compare data with data, and; move quickly through the data. I followed this advice and coded each interview line-by-line, using predominantly gerunds. I preserved participants’ own language or phrasing in this process, where possible. These techniques allowed me to home in on the

language and action of participants, remaining open to their statements rather than imposing pre-determined concepts (Charmaz, 2014). After I completed line-by-line coding of an interview, which often yielded 1000-1500 codes, I sifted through them to compare similarly coded data within and across interviews. This is part of the *constant comparative method* (Charmaz, 2014; Glaser & Strauss, 1967), an analytical technique to identify similarity and variation across data that I used throughout all stages of analysis. I then wrote memos to capture salient themes and emergent concepts from the coding process. While coding interviews, particularly if a participant described a conceptually-dense incident, I would draw a conceptual map to tease out the process at work. I usually followed this with a memo to theorize meaning from this map and to connect it with similar or divergent descriptions by other participants. These techniques helped to identify areas to query in subsequent interviews or to attend to in subsequent analysis.

### ***Focused coding***

In focused coding, the researcher uses constant comparison to identify initial codes that best account for the data, reveal patterns, and have greater analytic power (Charmaz, 2014). Focused codes may represent initial codes that repeat across interviews, or they may be a “telling” code, one “that explains much more than the data from which you constructed it” (Charmaz, 2014, p. 145). Such codes often account for a group of other codes by clustering a larger idea that accounts for implicit meanings or processes, or suggests theoretical direction (Charmaz, 2014).

In early analysis, I reviewed an initially coded interview internally for significant or repeating codes, and then comparing these across interviews. In later stages, I used several additional strategies to aid constant comparison towards focused coding. During this process, I asked questions of the data to advance theorizing, chiefly, “what is happening here?” and “what is this a story of?” (Clarke et al., 2018, p. 356; Charmaz, 2008). One strategy was to segment interview content by prominent broad topic areas or processes (e.g., disability disclosure, accommodations, disability identity, school culture) or by participant type (students, school officials) in NVIVO<sup>QSR</sup>, print these segments of data, and compare them to generate of focused codes. Using this strategy to view participant accounts of the accommodation process, for example, helped me to identify focused codes such as *knowing available accommodations*, *asking for less*, *measuring risk*, and *knowing disability*. This helped me to connect concepts of risk and knowing across areas and compare them, for example, with discussions of disclosure to peers and negotiating disability identity. Analyzing student interviews separately from school official interviews helped me to compare within cohort perspectives (i.e., among students, among school officials), identifying similarity and

variation within each group. Then, I compared across groups to identify similarities and differences. Through this process, I developed insights into, for example, differences in expectations between students and school officials around disclosure and community-building.

The second strategy was to diagram codes. I took initially-coded data from a particular topic area, then used a white board or large piece of paper to map codes that related to each other and see where they might collapse together. This helped me to identify focused codes that captured variations within a process or were related to each other. For example, diagramming initial codes about disability identity from student data allowed me to identify focused codes of *claiming disability*, *distancing from disability*, *overcoming disability*, the variations therein, and their relationship to *conceptualizing disability* and *proving ability*. I also compared key processes, meanings at work in the area, gaps in understanding that required further data, and begin to see how these might connect to each other. I used diagramming at multiple phases of analysis, from focused coding through to theory generation. I took photos of diagrams at different stages and used these to inform memo-writing.

### ***Memo-writing and developing categories***

Memo-writing is a critical analytical space in grounded theory research where the researcher processes what they are seeing in the data, theorizes meaning, and asks questions of the data. Memo-writing moves from early-stage memos that begin to characterize data and identify directions for further data collection through engagement with codes, in vivo concepts, and processes, to advanced memos that categorize data, map and interrogate categories, and reflect increasing theoretical density (Charmaz, 2014).

I engaged with memo-writing at all phases of the research process, from pre-interviewing reflexive memos about my positionality, to ongoing reflective memos after interviews, during transcription, during field observations, coding, categorizing, and theorizing. These memos provide a record of my research process towards theory generation. Milliken and Schreiber's (2012) depiction of the analysis process and the role of memo-writing captured my experiences during this project:

The grounded theorist doing data analysis is thoroughly marinated in data, living, breathing, eating, sleeping, and showering with it. The data are never far from the researcher's conscious mind, and are always present as background noise in his or her [*sic*] thinking. Grounded theorists spend a lot of time reflecting and ruminating, conducting a complex internal dialogue in efforts to gain understanding. One of the most important functions of writing memos is to interrupt the cycle of rumination (however briefly) by putting ideas to paper, allowing the researcher breathing space and the possibility of sleeping uninterrupted by, potentially, profound thoughts. (p. 691)



I used several modes of memo-writing to address the need for immediate recording of analytical ideas. I always carried a notebook with me, in which I wrote memos on the go— on the bus, after a walk, just out of the shower, while in the field. Three notebooks comprise handwritten, dated memos developed over the course of the project. I also used the Evernote app to write short notes on my phone when a notebook was not practical, for example, while commuting by bicycle. This resulted in a long ongoing memo with dated, short thoughts that I followed with a longer memo.

In addition to these more spontaneous memos, I wrote more formal memos that characterized focused codes and developed categories. Categories are “conceptual element[s] in a theory” (Glaser & Strauss, 1967, p. 37) that “explicate ideas, events, or processes in your data” (Charmaz, 2014, p. 189). Charmaz (2014) suggested memo-writing should treat representative focused codes as categories, “giv[ing] them conceptual definition and analytical treatment in narrative form” (p. 189). I wrote memos about all focused codes. This helped me to see which could account for other focused codes and thus might serve as categories. Moving between activities like coding, memo-writing, reading extant literature, and diagramming pushed me to theorize higher level meaning, bringing ideas together and interrogating them. In these higher-level memos I brought in data from other sources (documents, physical space observations) to enrich category development. Through this process, for example, I developed the categories *being selfless superhumans*, *the “real world,”* and *being malleable*. Box 3.1 provides an example of a memo that illustrates the analytic journey, bringing together ideas from data with literature and identifying areas for further exploration as I developed the idea of negotiating the capability imperative.

**Box 3.1: Example Memo**

1/22/19 – Negotiating the Capability Imperative rather than Rupturing Ableism?  
I’m coming back to the analysis I was doing in December and early January to explore the idea of rupturing ableism. As I’m working through my analysis, it feels like what is actually happening here is a negotiation. The other day I came to the phrase of “Capability Imperative” and I am thinking about what students are doing as a negotiation with this capability imperative. I am questioning whether all actions students take in a sense rupture ableism. I need to think about this further – look back at the data.

In an environment that relies primarily on accommodations to achieve inclusion, students are asked to 1) expose themselves as not capable in the current environment, that is, act against the capability imperative, and then 2) negotiate the capability imperative to find ways to either *approximate fixed capability* or *shift capability*, or 3) *do nothing* formal and risk eventual failure. This is primarily an individualized, opaque process due to concerns about confidentiality (upheld by the capability imperative), and also by design. Legal requirements point to an individualized process through accommodations, which in practice supersedes a movement towards UD. This accommodations-focused approach situates disability as a fixed entity to be managed, rather than considering barriers in the environment that could be removed for wider benefit, including to facilitate inclusion.

I need to really iron out what the line is between approximating fixed capability or shifting capability – are they really different? I think this comes back to how I was conceptualizing this previously, as working the mold and cracking the mold; I also wonder if they're not co-occurring processes. I need to work through examples. Possible examples of approximating fixed capability: Get well and come back, find study strategies/self-management strategies that will allow you to fit, get medication, manage your life outside to allow you to approximate – e.g. get up at 4 AM, take on a specific role in group that you can do with disability and without accommodations; shifting capability (cracking or stretching): accommodations, talking about disability. But is there the possibility of overlap or leak? Go back and look at this.

I think negotiating the capability imperative is a process that all players engage in, not just students. School officials also take action:

- formalizing (or improving) and advertising their accommodation process,
- creating a port in the storm for students to discuss their needs and get support in negotiating access,
- formalizing alternate ways to approximate capability through policy (e.g., moving towards functional rather than organic technical standards, or signaling that reasonable accommodations are available to allow students to meet standards of capability)
- negotiating with faculty to understand their duty to consider alternate ways of meeting capability.

They seem to focus their inclusion efforts on *doing accommodations better*. Are these all responsive? Do they shift the capability imperative? What spurs movement from individual change (accommodations focused) to systemic change that transforms capability for all? Have I seen any examples of this? Are there any systemic changes to speak of that don't rely on accommodations or act in service of improving accommodations?

### ***Theoretical sampling***

Once a grounded theorist has tentative categories that suggest theoretical direction, they seek to solidify their theory through *theoretical sampling*. Theoretical sampling entails gathering more data to “elaborate and refine categories in your emergent theory” (Charmaz, 2014, p. 192). One mechanism of theoretical sampling is also *abductive reasoning*, considering all possible theoretical explanations for surprising or puzzling findings and checking inferences through re-evaluation of previous data and seeking new data (Charmaz, 2014). Charmaz (2019) described this as a process of “tacking back and forth between data and [one's] nascent theoretical category” (p.8). It is through this process that a researcher can engage the “why” question that moves the research beyond micro processes (Charmaz 2016, 2017a, 2017b, 2019). Through abduction the researcher may ask why participants make meaning and take action in the ways the data suggests and consider larger social structures, discourses, and extant theory to explicate this, while maintaining a “critical, skeptical stance” (Charmaz, 2014, p. 201; Charmaz, 2019).

I sought theoretical saturation through several forms of theoretical sampling. I followed the logic of abduction to address troubling data that was not accounted for in the developing analysis, re-analyzed existing data, considered extant literature and national policies, and sought new data to clarify and saturate categories. For example, I followed these techniques to: reconsider and more clearly situate resistance in the developing theory; to fill out the category of *the capability imperative* and reach beyond the studied situation to connect the idea to larger structures of medicine; to clarify and more clearly differentiate the categories of action that I had initially grouped as *upholding the capability imperative* and *resignifying capability*, and; to explore and deepen my understanding of the implications of the developing theory.

I conducted six follow-up interviews for purposes of theoretical saturation. The aim was to gain participant feedback on the developing theory, explore the implications of the theory, and further saturate the main categories of action (at that time, *upholding the capability imperative* and *resignifying capability*) and clarify their boundaries. I conducted the interviews via video conference (Zoom or FaceTime) with three students and three school officials across the four schools between August and October 2019. I selected participants for these interviews based on their stated willingness to participate in additional conversations and their potential to assist in further theoretical development. I pursued interviews with school officials most closely engaged with disability inclusion. I selected students who had demonstrated deep and varied consideration of inclusion in their initial interviews. I provided participants with a one-page summary of my developing theory and several open-ended questions for them to consider in advance of the interview. I intended for these interviews to be less than one hour, however, several participants spoke for up to two hours indicating their interest and engagement with the topic. Students displayed a surprising level of consistency across their initial and follow-up interviews, despite the two-year spread. While their interpretations indicated personal development over time and they added new examples from their experiences to advance theorizing, students shared consistent conceptual interpretations and associated actions. I audio-recorded these interviews for purposes of review and quoting participants, if needed. I wrote memos after each interview that identified key directions to follow in subsequent interviews and to finalize the analysis.

These interviews largely confirmed the resonance and structure of the developing theory, providing additional examples of incidents that followed the established categories and identified logics and did not take the theory into completely new directions. They introduced further richness to their conceptualization, including the idea of seeing inclusion as molding versus eroding the medical graduate that played well with the idea of malleability I had already formed during previous analysis. After the additional discussions and further

reconsideration of existing data, I decided to reorganize the categories of action into three overlapping categories that recognized the subversive potential of all forms of action (*upholding the capability imperative, working the capability imperative, and resignifying capability*). These interviews helped to clarify and saturate the theoretical categories and deepened my understanding of the broader implications of the theory.

### ***Generating theoretical concepts***

Thornberg and Charmaz (2012) indicated that “a theory states relationships between abstract concepts and may aim for either explanation or understanding” (p. 41). Through comparing high-level categories, the researcher constructs a more abstract category that subsumes these categories and has “substantial analytical weight” (Charmaz, 2014, p. 247). These weighty categories are known as *theoretical concepts* that “serve as interpretive frames and offer an abstract understanding of relationships” (Charmaz, 2014, p. 248) in order to explicate, organize, and present the data.

Through the process of category development and subsequent theoretical sampling, I identified abstract concepts that subsumed the most prominent categories and focused codes. With these concepts, I constructed a theory of how participants enacted inclusion at the participating schools. The theoretical concept of *the capability imperative* accounted for the categories *being selfless superhumans, the “real world,”* and *being malleable students*. The concept *knowing disability* brought together the categories *conceptualizing disability, legibility,* and *knowing inclusive processes*. *Negotiating the capability imperative* characterized participants actions, informed by their understandings of disability and medicine. This concept brought together the overlapping categories *upholding the capability imperative, working the capability imperative, and resignifying capability*. These concepts hold the variation in participant perspectives, document analysis, and observations, grounded through a multi-layered analytical process. Together, they present theory of disability inclusion in medical education that has implications for practice. In the following chapters, I describe this theory in greater detail.

### **Considerations and limitations**

In this section I discuss several aspects of the study to further explain its rigor and to clarify its limits: ethics, saturation, representation, Charmaz’s (2014) four dimensions for constructivist grounded theory evaluation, and reflexivity.

#### ***Ethics***

All research procedures were approved by the University of Auckland Human Participant Ethics Committee (UAHPEC, Ref #018365, see Appendix F for approval letters). These procedures were amended four times: once to specify the email used to recruit institutions, two

amendments to customize Participant Information Sheets, consent forms, and associated procedures based on institution requests, and one to add direct recruitment of school officials after general email recruitment was unsuccessful. I described procedures for obtaining institutional consent in Part II of this chapter. All participants were adult professionals or professionals-in-training who were able to provide their free and informed consent. All did so prior to their interview and were given the opportunity to reconsider participation after reviewing their interview transcript.

Given the sensitivity of the research topic, I took measures to mask participant and institutional identities. No one within or outside the institution was informed who participated in the research. I do not use participant or institution names in any research publications. I have taken further measures to de-identify participants and institutions while maintaining their individuality. For example, I avoid use of gendered pronouns unless gender is explicitly relevant to the participant's account and, where possible, I do not attribute a specific disability diagnosis to student quotes.

I attended to participant privacy in interview locations. All interviews were conducted in a private space, with the option to interview in person or via video conference (Skype, Facetime, or Zoom). Interviews via video conference gave the participant control over their location. In-person interviews took place in private on-campus spaces. Most school officials arranged the interview in their private campus office.

I took measures to ensure interviews were accessible. I asked all participants whether they needed any accommodations to participate, via the demographic questionnaire or otherwise, prior to the interview. No participants requested any accommodations. I responded to some participants' need for more time to fully express themselves and desire to share their experiences by not regulating the interview length. At the same time, I checked in with participants periodically during the interview to ensure they had sufficient energy and desire to continue, offering the option to re-schedule or resume the interview at another time.

Finally, I attended to reciprocity in this project. Many students explained their participation was motivated by an interest in policy, practice, and systems change. To maintain confidentiality of participant accounts and encourage openness, however, I did not offer institutional leaders a school-specific report of research findings. Instead, I will provide all participants, which includes high-level administrators at all four institutions, a link to the completed thesis and any subsequent publications. I also plan to disseminate the research through outlets that will reach disability-inclusion practitioners and the larger academic medicine community. To this end, I have already presented initial findings in a 2019 keynote for the Disability Access in Health Science Education Symposium, a conference attended by many disability service professionals and health science administrators.

### ***Saturation***

One mark of rigor in qualitative research is saturation (Morse, 2015). In grounded theory, the aim is *theoretical saturation*, where “no additional data are being found whereby the [researcher] can develop the properties of the category” (Glaser & Strauss, 1967, p. 61). Unlike other notions of saturation that look simply for repeating patterns, theoretical saturation seeks “conceptual density” (Glaser, 2001, p. 191) of these patterns (Charmaz, 2014). Attending to saturation is an ongoing process throughout research, while simultaneously remaining open to new directions in the field to avoid foreclosure (Charmaz 2014; Morse, 2015).

I attended to saturation throughout the process of analysis. As I conducted interviews, I followed topics of possible theoretical interest to ensure I had rich and varied data to allow for dense categorization. I sought additional school-official participants who would bring knowledgeable and varied perspectives to the data. While I coded data, conducted comparisons within and across interviews, and moved to higher levels of theorization, I was continually attentive to repetition and variation, seeking to build strong categories. Where I encountered puzzling data or “negative cases” I adjusted my categories, recoded previous data, or sought fresh data to explore this further. The final six follow-up interviews represented the final phase of theoretical sampling. In these interviews, I reviewed the developing theory with participants to gather feedback on its resonance and sought additional accounts to finalize the key categories of action (*upholding the capability imperative* and *resignifying capability*). Their additional accounts added richness to my understanding of the theory but did not take it into entirely new directions. Rather, once I had adjusted the categories of action (to: *upholding the capability imperative*, *working the capability imperative*, and *resignifying capability*) these were able to hold existing and new data. I was then confident that the categories were sufficiently abstract and conceptually dense to account for varied participants and situations.

### ***Representation***

The goal of research within a constructionist epistemology is not generalization, thus in constructivist grounded theory sampling is oriented towards contextualized theory generation. This study explicates the perspectives of some disabled students and school officials at four U.S. medical schools. I provided detailed information in the section Participating Individuals, to locate the situated knowledges (Haraway, 1988) represented in this study. The findings are not representative of all disabled medical students, medical school officials, or medical school conditions. These schools were selected for their potential to serve as exemplars of inclusive practice. Although I do not suggest that these schools represent the best in the US for disabled students, they may represent better conditions for the reasons discussed in the section Site

Selection. Furthermore, as is the crux of constructivist grounded theory methodology, this research has been constructed and interpreted through my own perspective. I have taken measures to follow participants' perspectives in interviews, stay close to their accounts in analysis, and practice strong reflexivity (Charmaz, 2017b, 2019; Harding 1991) throughout the research process. Nonetheless, this research is my interpretation of participants situated accounts, constructed from my perspective. The research tells a collective story, but it does not tell every story. There are many more stories left to be told.

With these caveats in mind, the research draws from rich, in-depth discussions with school officials and disabled medical students that add to existing understandings of disability inclusion in medical education. The perspectives from disabled students who are also ethnically or racially underrepresented in medicine represent a cohort not yet well-explored in research about disability in medical education. Participants also include disabled students who opted not to seek accommodations, another cohort as yet underrepresented in the discourse. The interaction between school official and disabled student perspectives regarding inclusion has been explored in one cross-health profession study in the Canadian context (Bulk et al., 2017), but not yet in a medical-education specific study, to my knowledge. For these reasons, this study brings new perspectives to disability inclusion in medical education that add to the discourse and can inform practice.

#### ***Credibility, originality, resonance, and usefulness***

Charmaz (2014, p. 337-338) offers four criteria, *credibility, originality, resonance, and usefulness* that can be used to evaluate constructivist grounded theory studies. In this section, I suggest how this study meets these criteria, pointing to areas of the study that address items in greater detail.

Markers of credibility include:

1. the research achieves intimate familiarity with the setting or topic;
2. data are sufficient to merit claims;
3. systematic comparisons are made between observations and between categories;
4. categories cover a wide range of empirical observations;
5. strong logical links between data, argument, and analysis; and
6. sufficient evidence for reader to assess and agree with claims (Charmaz, 2014, p. 337).

Throughout this chapter, I have described the data gathered and processes for constant comparison, theoretical sampling, and saturation, which I believe address points one through four. Regarding point five, I have conducted analysis with constant grounding in interview, document, and observation data to ensure that the data, analysis, and arguments are closely

linked. Throughout the chapters that follow, I include direct participant quotes and summaries of participant perspectives to provide evidence of my claims, addressing point six.

Markers of originality include:

1. fresh categories that offer new insights;
2. new conceptual rendering of the data;
3. social and theoretical significance; and
4. challenges, extends, or refines current ideas, concepts, and practices (Charmaz, 2014, p. 337).

I believe the categories and concepts introduced in this study offer fresh insights into inclusion in medical education that have the potential to push practices in new directions. Concepts bring together ideas touched on in existing research, but their rendering provides a new way to think more broadly about how inclusion occurs. Throughout Chapters 4-8, I relate the categories and concepts to extant theory and literature, primarily that of disability studies, sociology of medical education, and queer theory, demonstrating how this work challenges, extends, and refines current ideas, concepts, and practices.

Markers for resonance include:

1. portrays the fullness of the studied experience;
2. reveals both liminal and unstable taken-for-granted meanings;
3. draws links between larger collectivities or institutions and individual lives, when indicated by the data; and
4. the theory makes sense to participants or people who share their circumstances, and offers them deeper insights about their lives and worlds (Charmaz, 2014, p. 337-338).

I have taken care to construct the theory to account for the fullness of the studied experience. I have read, coded, and considered the data many times to ensure that the final version portrays the complexity of the studied situation, making adjustments and gathering additional data to this end. Attention to participant meanings in interviews, constant comparison across interviews and documents, and critical analysis in consideration of extant literature allowed me to reveal taken-for-granted meanings of constructs such as the “real world” of medicine. In my analysis I have engaged the “why” question—why are things happening the way they are?—to link individual accounts to larger collective and institutional implications. In theoretical sampling interviews, participants indicated that the developing theory resonated with their experiences. When I have presented aspects of the theory at several conferences, medical school officials and disabled students have indicated similar resonance with lived experiences.



Markers of usefulness<sup>9</sup> include:

1. offers interpretations that people can use in their everyday worlds;
2. sparks further research in other substantive areas; and
3. contributes to knowledge and making a better world (Charmaz, 2014, p. 338).

I believe the research offers interpretations that practitioners in disability inclusion and other school officials can use to inform their practice. Students may also find the interpretations useful to see collectivity in their individual experiences, a condition that has the potential to build critical consciousness and politicize understandings of disability (Freire, 1968/2000; Kumagai & Lypson, 2009; Linton, 1998). I believe the research has the potential to spark further research in disability inclusion in medical education and that the theory of *negotiating the capability imperative* has potential for broader resonance in medical education and other spaces with high performance requirements. While preparing for an academic job interview, for example, my supervisor and I quickly realized that we were negotiating the capability imperative as we carefully formulated questions to uphold my capability while asking about early-career support programs. This, along with other examples I have observed since developing the theory suggest its possible application in other contexts. My hope is that the everyday usefulness of the interpretations made in this research, along with suggestions for transforming practice offered in Chapter 7, contribute to a more inclusive world.

### ***Reflexivity***

A key aspect of constructivist grounded theory is acknowledgment of the researcher's role in constructing the research. As Charmaz (2014) explained, "what we bring to the study also influences what we *can* see" (p. 27) requiring researchers to examine how their "privileges and preconceptions may shape their analysis . . . [and] the findings they can identify" (p. 13). Charmaz (2017b, 2019) has conceptualized this in line with Harding's (1991) *strong reflexivity*, which I defined previously, in the Methods section. Strong reflexivity requires the researcher to engage with doubt and methodological self-consciousness during the research process (Charmaz, 2017b, 2019). Throughout this chapter, I have discussed some of the ways I engaged methodological self-consciousness. In this section I locate myself and my commitments as a researcher and discuss two areas in which I continually engaged with strong reflexivity in this work.

I identify as a biracial, cisgender, currently non-disabled woman. I am the daughter of an Indian immigrant man and a white American woman, born in the US, who grew up upper-middle class in the suburbs of Buffalo, NY. I am married to a first-generation Croatian-

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<sup>9</sup> I have eliminated two points that Charmaz includes for cases where categories or theory suggests generic processes. I do not contend, at this stage, that they do. Further research may suggest otherwise.

Australian man. I am an immigrant in Aotearoa New Zealand. I was trained as a rehabilitation counselor at Boston University, where I was first introduced to disability studies. I have worked for 13 years in the field of disability inclusion in health science education, first at Columbia University, then at the University of California, San Francisco, and more recently in an independent capacity. I had a short stint as the manager of Auckland Disability Law, a free legal service run by and for disabled people in Aotearoa New Zealand. I am a board member of the Coalition for Disability Access in Health Science Education. I am a feminist, who strives to live and work in ways that are anti-ableist, anti-racist, anti-cis/hetero/sexist, and decolonizing. I share these social locations as they all contribute to who I am, how I see the world, and as Charmaz (2014) suggested, what I can see.

Harding (1991) described those who do not embody the social locations that we aim to change the conditions of as having “traitorous identities and social locations” (p. 288). As a temporarily non-disabled researcher and practitioner in disability studies and inclusion, who wishes to work against ableism, I fit this description. To do this work, Harding (1991) explained, one must learn how to “overcome—get a critical, objective perspective on—the ‘spontaneous consciousness’ created by thought that begins in one’s dominant social location” (p. 287). She suggested that this requires starting from other’s perspectives to gain insights on to your own privileges, and then, to generate your own analyses, using others insights (Harding, 1991). I have spent much time learning from disabled people—friends, clients, students, activists, and scholars—and with these learnings I continually critique my own practice. This has given me insight into my own privileges within the system of ableism and my duty to work toward dismantling the system. In this research project, I started from disabled student perspectives and interpreted findings through disabled peoples’ scholarship. The larger focus of the study, the main object of critique, was the system of medical education and practices of inclusion. This follows the call from disabled scholars (e.g., Campbell, 2009a; Oliver, 1992; Price & Kerschbaum, 2016) to focus research on examining able-bodied society, with the aim of dismantling ableism, rather than on disabled people. Thus, my goal with this research is not to offer ways for disabled students to better fit within medical education but to consider how current practices (of students and school officials) are shaped by social conditions and how those conditions might be changed.

Another aspect of this research in which I wrestled with my spontaneous consciousness was to question what I was able to see and the conclusions I drew through analysis. I conceive of this through two “outsider” positions. First, as a non-disabled person interpreting disabled peoples’ accounts. Second, as an outsider examining practices separate from institutional constraint, while also having been in this position in the past. To address this, during analysis I continuously engaged with doubt. Charmaz (2019, p. 5) explained that, “the willingness to

doubt one's convenient explanations takes reflexivity to a deeper level and simultaneously can spark new conceptual insights" (see also, Locke, Golden-Biddle, & Feldman, 2008). I will describe some of the questions I wrestled with from each position and the ways I worked through them in the following paragraphs.

As a non-disabled person interpreting disabled people's accounts, I frequently asked myself, how does my positioning influence what I can see and how I can say it? To what degree do my conclusions represent a naïve non-disabled person's perspective and in what ways is this an asset and a problem? As someone for whom inaccessibility is not a constant concern, I have the privilege to step away from this issue and have personal distance from it. As a researcher looking across students, school officials, and institutions, I can see patterns and practices that may not be readily discernable to an individual necessarily focused on their own interests. This may offer me the gift of perspective, but it is different from one inextricably steeped in the issue. My voice may be heard more neutrally, while a disabled person arguing for the same changes may be viewed as too angry or demanding. I do not hold the same personal risk of speaking out. At the same time, without lived experience, I may see intolerabilities in the status quo that someone with lived experience may see as tolerable. From this perspective, do I create risk for others by speaking up or create problems where there are bigger problems to address? I wrestled with these questions in ongoing ways using techniques of grounded theory. I checked my understandings with and across participants, engaged in abduction, sought more data, and considered interpretations in light of extant theory, in particular that developed from disabled peoples' perspectives. I also discussed aspects of my interpretations with disabled activists, non-participating disabled medical students, and colleagues to gain further perspectives. Throughout, I engaged with memo-writing to think through ways forward.

As an outsider examining institutional practices, but with experience leading disability inclusion in similar institutions, I also wrestled with what I was able to see. As someone not imbedded in the everyday constraints of institutional inclusion, what could I see differently from those currently imbedded and what was I forgetting? What could I say or amplify that others could not, given their imbedded roles? When was I centering my own experiences and established understandings of the way things "should" work? Was I sufficiently considering how others were doing things, why, and the associated implications? In what ways had my own work (e.g., Meeks & Jain, 2016) influenced others and what were the consequences? Once again, the techniques of constructivist grounded theory that encourage criticality of, immersion in, and closeness to the data helped me wrestle with these questions throughout the process. Critically reflecting on early interviews during transcription and initial coding was valuable to ensure I was not foreclosing participant perspectives. Seeking clarification about

why practices were the way they were, as well as participants views of strengths and limitations, helped me to consider school culture and local interpretations. I also (re)considered my interpretations based on ongoing engagement with the field, for example, with professional listservs, discussions at conferences, following social media accounts, communication with students, and conversations with colleagues in the field.

Across both perspectives, I also wrestled with current conditions as a constraint on what possible futures we might collectively imagine. Continual engagement with doubt, treating data and my own interpretations as problematic, helped me to push back on my spontaneous consciousness and critically examine those of the participants. Although I entered the research with openness, I suspected that I already knew what I would find. I was wrong. Engaging these processes while conducting this research has changed me and my understanding of inclusion, requiring me to see the work anew.

## **Conclusion**

In this chapter I have shared the foundations, structures, and mechanisms of this research project and built a case for its rigor. This constructivist grounded theory of disability inclusion in medical education is built upon social constructionist epistemology, informed by theoretical perspectives of symbolic interactionism and disability studies. With this foundation, the study represents an interpretation of contextual perspectives of disabled students and school officials at four U.S. medical schools. With disability studies theories at the heart of this study, I understand disability as social, political, and relational. Following the symbolic interactionist tradition, I have sought to understand how participants understood disability inclusion, how these meanings informed their actions, and how meaning and action were socially mediated.

Using constructivist grounded theory methodologies, I attended to how my own perspective, meanings, and actions shaped this research. I used several methods to gather data: interviewing disabled medical students and school officials, analyzing extant documents, and observing physical spaces. This combination of methods brought richness to the data, with interactions between the three as I identified documents and spaces for analysis and discussed them with participants. Gathering, analyzing, and theorizing the data was iterative. Through procedures of coding, memo-writing, categorizing, and constant comparison, I immersed myself in the data. I stayed close to the data in my interpretations, while engaging in the creative process of theorizing. As a non-disabled researcher and former disability-inclusion practitioner, I wrestled with questions of what I can see and the implications of this in ways that informed my research practice and analysis.

Having laid this foundation, in the next chapter I will begin presenting the substantive theory of negotiating the capability imperative. I begin by discussing knowing disability and how these knowings interacted with the inclusion process.

## Chapter 4. Knowing Disability: Navigating Inability and Legibility

### Introduction

The previous chapter outlined the epistemology, theories, and methods used to build this constructivist-grounded theory. It also introduced the four medical schools that served as sites of research and the participating students and school officials. In the course of covering the study's methodological orientation, my core research question was articulated: how is disability inclusion enacted at the participating schools? In this chapter, I begin to address this problem by focusing on disability. To be more specific, I examine the ways that participants knew disability and how this informed their interactions with disability inclusion mechanisms at their schools.

Chapter 2 drew attention to the many ways to know disability, which stem from competing interpretations of its underlying ontology. The scholarship of disability studies explains that these discrete interpretations link to different individual and social responses. While the scholarly analysis of disability tends to assume a consistent theory of disability, underpinned by a singular ontological positioning, participants held multiple, sometimes conflicting conceptualizations of disability simultaneously.

This chapter will present participant understandings of disability and how they informed inclusion in three respects: implications of the disability label, legibility, and action (navigating inclusion processes). At the base are differing discourses of disability, each of which appended specific connotations to disability as a label. I identify four competing conceptualizations of disability as described by participants and unpack their implications. Building from these discourses to the educational context, I then develop the construct of *legibility*. Legibility informs whether and how participants understood an individual's disability experience and prescribed actions to facilitate inclusion. I explain that certain experiences of disability held more legibility and, therefore, more legitimacy than others. At this point, I also discuss how legibility interfaces with intersectionality. Moving to the realm of action, I then characterize how participants navigated inclusion processes, informed by discourses of disability and legibility.

Ultimately, I argue that while alternate ways of knowing disability were discernable, a discourse according to which disability is synonymous with inability effectively overshadowed participant accounts and their actions. At the same time, to be sure, participants evidenced sparks of resistance, navigating and at times subverting the dominant discourse of disability as inability, countering it with the idea of designing for inclusion.

## Conceptualizing Disability

Four conceptions of disability influenced participant action towards inclusion:

- individual inability
- contextually produced
- valuable difference, and
- legally defined.

Individual inability constituted the dominant discourse of disability. Against this were two counter narratives: disability as contextually produced and disability as valuable difference. Rarely did participants accept one of these conceptualizations absolutely or exclusively. Rather, they grappled with these perspectives, often expressing conflictual understandings of disability in the course of an interview. Rejected conceptions retained influence over participant actions. Even when they did not personally accept a conception as true, the understandings that others were presumed to hold shaped anticipatory action. Despite these varied conceptualizations, the legal definition of disability ultimately unlocked access to inclusion processes. In this section, I describe each conceptualization and its associated implications.

### **Disability as individual inability**

The central animating discourse of disability was that of individual inability. This conceptualization equated impairment with disability, suggesting that the cause of inability was located within the person and had little to do with context. Disability was all-consuming, suggesting a spread effect (Wright, 1960) that impaired a person in all ways at all times and could contaminate a setting, spreading burden to others. This aligned with realist conceptions of the individual or medical model of disability, described in more detail in Chapter 2 (Goodley, 2017; Kafer, 2013; Linton, 1998; Oliver, 1996). In these conceptions disability is framed as *negative ontology*, “a straightforward and obvious departure from [taken-for-granted] normalcy” (Titchkosky, 2007, p. 105), where bodyminds are “delineated by negation. . . *not* perfect. . . *not* reading. . . *not* walking” (p. 124). That is, disabled bodyminds are understood by what they cannot do in reference to an assumed norm. This conceptualization upheld the abled/disabled binary essential to ableism, wherein disability represents the unthinkable, unhuman other against the abled, normal, typical, and fully human (Campbell, 2001, 2009a). This bifurcation obscures the actual complexity of human experiences and, thus, was understandably at odds with students’ lived experiences. As a result, some students felt they could not or would not claim disability, as illustrated by the following quote:

*I just think when you put disability next to your name, people are already thinking you can do less than other people, you know? It’s automatic. It’s like, that is what the word*

*is, dis-ability, it's like you don't have the ability to do certain things and thus, you can probably do less . . . but then I think when given the right resources we can do just the same.* (Participant 44, student)

As this quote demonstrates, many students grappled with their simultaneous internalization and rejection of the inability discourse. The saturation of this discourse in wider culture and in historical experiences, however, reinforced its legitimacy, causing students to expect its acceptance and act accordingly. Furthermore, the discourse was locally reified through interactions, institutional policies, and other arrangements that positioned disabled students' abilities as questionable (see, for example, the discussion of technical standards in Chapter 5, *Knowing Medicine*). Three implications followed from this discourse: because inability is counter to the status of medical student, disability is a potentially disqualifying characteristic; individual solutions are necessary to overcome disability or normalize, thereby erasing the social context and depoliticizing disability; and disability is a potential burden on the system. I illustrate each through a specific manifestation of the implication, though these were not the only examples offered by participants.

The disqualifying potential of disability became evident during the admissions process. Students with apparent disabilities felt it was necessary to disclose their disabilities in their applications to demonstrate their trustworthiness. At the same time, they took significant measures to counter the inability discourse during the process, through partial disclosure, careful study of technical standards, and advance identification of possible accommodations. Students with less-apparent disabilities were largely advised not to disclose their disabilities on their applications, as many were told this would raise questions about their ability to conduct patient care. The relative invisibility of their disabilities offered them the option to avoid immediate detection. Whether students disclosed in spite of this type of advice varied. Those students who disclosed against advice tended to situate their disabilities as something they had overcome in their life, for example, to illustrate improved academic performance after diagnosis, treatment, and accommodation. This strategy unfortunately reinforced the individual inability discourse, as it positioned disability as a threat to academic performance that was now managed.

The second implication, that students with disabilities should seek individual solutions to cure or normalize their behavior, was evident in discussions about medical leaves of absence. For students with psychological disabilities or chronic illnesses, some school officials suggested that leaves of absence were the best method of accommodation. Certainly, leaves are appropriate at some times for some students (Grant et al., 2019; Meeks & Murray, 2019). The suggestion that students ought to *“take time off and come back healed and whole”* (Participant 11, school official), however, centered medical or psychological treatment as the



primary solution and equated lack of disability with wholeness. Although medical treatment was essential for many students, this assessment subverted elimination of structural barriers that might allow students to continue their training. Linton (1998) explained this is part of *medicalization*, wherein the appropriate response is to “‘treat’ the condition. . . rather than ‘treating’ the social processes that constrict disabled people’s lives” (p. 11). One student described their frustration with this approach:

*It felt really black and white, like you’re going to stay in the system and somehow suck it up and deal with things and figure your shit out or you’re going to go on a year leave. And that seems very extreme to me, I feel like there are other ways to do it in this world, there are ways to make medical school not impossible for people and it’s just not being employed. (Participant 1, student)*

Even when a leave of absence was warranted, students often encountered a lack of support to identify accommodations or other structural supports upon their return. This suggested an assumption that approved absences were curative in focus with an unspoken but powerful subtext that environmental adjustments were unnecessary and unlikely to be acknowledged.

The implication that disability burdened the educational system manifested in discussions of students with disabilities as a burden on human resources and team efficiency. Several school officials discussed the increase in human resources necessary to determine and implement accommodations as a challenge on top of already-heavy workloads. Although some school officials had plans to balance staffing and workloads, some participants feared “burden thinking” would remain attached to particular students related to increased workload and cost of accommodations. For example, one school official suggested the cost of disabled-student inclusion might breed resentment among non-disabled peers already in debt due to the high cost of medical education. In a system ruled by competition and where resources are constructed as limited, differential resource consumption raised questions of fairness. Perception of burden was also evident in team-based learning environments (discussed further in Chapter 5, *Knowing Medicine*) and represented in the following quote:

*Students who do not have disabilities, who come to see me for study help, complain about people in their group. And I happen to know what’s the matter [that the peer has a disability]. It’s the stress. It’s like nobody wants anybody—you don’t want a tire on your car that doesn’t have enough air. You know, if all three work and one doesn’t. (Participant 34, school official)*

This troubling description of students with disabilities as a “flat tire” in a team follows from a conception of disability as individual inability and abnormality. Rather than questioning the accessibility of classroom activities, or the group’s ability to work together, the disabled student is constructed as burdensome. Aware of these perceptions, disabled students were on

high alert to minimize their accommodation needs and find ways to demonstrate their contributions and capabilities.

### **Disability as contextually produced**

Most students did not experience their disabilities as complete individual inability. While participants were influenced by this dominant discourse, the more resonant understanding was that their experiences were contextually produced. That is, their experiences of disability were deeply affected by the structure, culture, climate, and policies of medical education. This was most clear when participants identified barriers in the environment that created their difficulties, rather than their impairment itself, as demonstrated in the following quote:

*With ADHD, while it makes it harder it doesn't prevent me. . . It's not like I can't, I just need tools in place to be able. And also, the only reason why I need all those tools is because everything is based on these models that we already have proven are not great for anybody. One percent of people really learn from lecture and nothing else, if that. . . So, I just feel like most people struggle with these types of things. (Participant 30, student)*

This student described the contextual production of their disability, asserting that they are not rendered unable as a result of ADHD, but rather by the pedagogy favored at their medical school, one they noted is likely not effective for most learners. Thus, the structure of education was the disabling barrier. This way of understanding disability more or less aligns with constructivist theories of disability, wherein disability is produced through inaccessible social arrangements that have not taken normal human variation into account (Connor & Gabel, 2013; Goodley, 2017; Oliver, 1996; Scotch & Schriener, 1997; Ware, 2001). Recognizing the ways socio-cultural arrangements produce disability, students troubled the abled/disabled binary and questioned the validity of disability when construed as individual inability.

Most students had no formal exposure to constructivist discourses of disability, though many explained their own experiences as shaped by context, time, and other social factors. Not aware of other theories of disability, however, this realization prompted some to reject disability as a term to describe their experiences.

*I don't like using it [the word disability] at all because I feel it identifies me as someone that—I don't know. Like, I got into medical school, so it's difficult. . . whenever I think about the word disability I think about that other side of the spectrum where you can't—you're not able to get as far as medical school. So, I don't like saying that I have disabilities because I'm not—like my advisor said, I'm not crippled [sic] like that. I'm able to think, able to study and take exams and read, so I don't really like using that word. (Participant 8, student)*

Although Participant 8 had previously described their experiences as shaped by inaccessible educational arrangements, they were not aware of constructivist discourses of disability. This

lived understanding of disability as contextual did not align with dominant conceptions of disability as all-encompassing inability.

A cohort of students developed a politicized understanding of their experiences through their recognition of disability as contextually produced. The dissonance between their lived experiences and dominant conceptions of disability, combined with recognition of barriers produced by contextual factors, fed their desire to shift the attitudes and structures of medical education and the medical field. This was most prominent among students who developed relationships with disabled peers and became “critically emboldened” (Fricker, 2007, p. 168), akin to Fricker’s (2007) depiction of the power of consciousness-raising in the face of hermeneutical injustice, or Freire’s (1968/2000) conception of critical consciousness. Those students who recognized disability as contextually produced were more likely to engage in micro and macro social change efforts, for example, through acts of *political disclosure* (Jain, 2020b), discussed in more detail later in this chapter.

The few students who came to medical school with a constructivist understanding of disability did not see this model “living” in the medical education context. This incongruence shaped how they engaged with their peers. For example, one student compartmentalized their disability-oriented action outside of medical school settings, noting that their peers acted disinterested in knowing disability differently (Participant 9). Another student selectively disclosed her disability, fearing that, in medical school, disability would be perceived an immutable barrier that discounted her capability:

*I don't talk about it [disability] as much because I don't want people to view me any differently. . . let's say I'm studying with a group and I don't understand something, they would work with me. . . But I feel like if they knew [about my disability] they might give up, they might say, “Oh, she just doesn't get it, it [her disability] is just a barrier, I'm not going to spend time.” (Participant 42, student)*

As represented in this quote, without shared understanding of the contextual production of disability among peers, Participant 42 did not share her disability status beyond a close circle of friends. Nevertheless, Participant 42 retained a private understanding of disability as contextual that framed how she viewed academic challenges: that the problem of access lived in the inaccessible context rather than within herself.

School officials recognized the role of context for students with disabilities when they described how the culture, climate, curriculum structure, clinical demands, and physical environment could create barriers. Their identified solutions, however, were centered around individual accommodations rather than widespread socio-cultural or institutional change. This was justified through assertions that either the conditions of medical training and practice were essential or unlikely to change, at least in the short term. Systemic change was only executed

in service of improving physical access or adjustments to policy, process, or communications to “do accommodations better.” Interventions to change attitudes were also suggested, but none of the schools had undertaken this work explicitly. Most school officials deemed unlikely the possibility to address contextual barriers, such as the tight schedule or pedagogy of pre-clinical education. Indeed, at two schools with significant curriculum-change efforts underway, disability inclusion was not prioritized in their redesign. This resulted in increasingly compressed schedules and inaccessible pedagogy. Only one concrete depiction of contextual change towards inclusive pedagogy (Skidmore, 2002) was offered, by a school official who worked with faculty to redesign their courses:

*As we've gone to more active learning modalities, things that are not purely lecture-based, helping faculty think about, okay, if you have a kind of like a quiz opportunity or an assessment opportunity in class, what does that look like in terms of time for a student to demonstrate their learning? How they give feedback on that? . . . And that's kind of an ongoing conversation that we've tried to have with faculty as they shift their courses.*  
(Participant 19, school official)

Opportunities to do this inclusive redesign work, however, were dependent on faculty interest. Inclusive design was not required or built into course-design processes. The primary response to inaccessibility was through individual solutions. Thus, even when school officials recognized the contextual production of disability, this conceptualization did not drive their work with students, nor was it centered in the design of institutional arrangements.

### **Disability as valuable difference**

Some participants conceptualized disability as valuable difference, unique ways of thinking and being in the world that would benefit learning and medical practice. Campbell (2001), borrowing from Wrigley (1997), described the positive conceptualization of disability as an *oppositional* or *outlaw ontology*. Given the pervasive understanding of disability as negative ontology, Campbell (2001) wondered, “What space, if any, can be made for this fugitive and dissident body? Is there any future for the queering of disability within the confines/purview of ableist fictions of disability?” (p. 55-56). Indeed, participants infrequently held a conception of disability as positive and valuable, as demonstrated in the following quote:

*I guess it's not perceived as something that one can be proud of. You know? Whereas perhaps other groups, like groups centered around a particular ethnicity or a religion, it's part of their identity, but it's part that they can be prideful of. Because someone can say, “Yeah! Brown pride!” But you don't really see anyone saying, “ADHD pride!”*  
(Participant 4, student)

Embedded in Participant 4's statement is another implication, one that other participants also described: that disability pride was unthinkable, not something they saw alive in their communities, nor a possibility they were aware of in existence elsewhere. Participants

understood disability as valuable less frequently than other conceptualizations. When students spoke of disability as valuable, this was often a privately-held belief they did not see shared by others. The conception of being valuable, nonetheless, remained an undercurrent that animated some students' dissatisfaction with negative conceptions of disability. Among school officials, those with lived experience of disability were most likely to invoke the conception of valuable difference. Those officials without lived experience who expressed the discourse had usually developed this perspective working alongside disabled students or colleagues. Despite individuals reading disability as valuable, such a conception was rarely codified within institutional frameworks, with only one school activating disability in institutional diversity efforts. Participants characterized disability as valuable in terms of disability epistemology and its effects on physician-patient concordance, near-peer learning, grit, and potential for innovation through creativity.

Participants saw concordance between physicians and disabled patients as beneficial through the power of *disability epistemologies* (Garland-Thomson, 2017; Scully, 2008) and *ontologies*, ways of knowing and being in the world developed through living in a disabled bodymind. One school official witnessed this benefit while training alongside a fellow resident with a physical disability.

*It became clear to me when we'd have a child with a spinal cord injury how much they identified with him and not me. I remember one little boy who was maybe 5 or 6 who said, "How'd you get like that?" and "Did you have to wear one of these braces like mine?" . . . they got into an animated conversation and it was like, there is something really quite magical about this, because this little boy is going to have an image of a man who is a doctor, and his spinal cord injury has not prevented him from being able to consider still using his brain. (Participant 31, school official)*

As recounted in this quote, the physician's disabled embodiment offered a point of connection with similarly-situated patients and exemplified possible positive futures for a disabled person in the world. Participants imagined other benefits to patient care from disability epistemology, including strong listening skills, empathy, and lived insights such as intimate knowledge of disability support systems (e.g., special education, social security, vocational rehabilitation). These findings align with scholarly arguments for the benefit of disability inclusion in medicine (Iezzoni, 2016; McKee et al., 2013; Meeks, Herzer, & Jain, 2018; Mogensen & Hu, 2019; Ouellette, 2013). Indeed, several studies have found that marginalized patients, with regard to race, ethnicity, and gender, experienced better care and higher trust when they worked with a concordant physician (see, e.g., Bertakis & Azari, 2012; Saha & Beach, 2020; Traylor, Schmittiel, Uratsu, Mangione, & Subramanian, 2010). Focused research has not yet explored the benefit of disability epistemologies in health care. I return to the matter of disability epistemology with regard to health care in Chapter 7.

Disability was also described as valuable beyond the doctor-patient relationship. Participants proposed that learning alongside a disabled classmate or teacher, or working alongside a disabled colleague, could offer insight into the realities of disability experiences and benefit the medical field. This follows the logic of contact theory (Allport, 1954; Meeks, Poulos, & Swenor, 2020). School officials exemplified this potential when they recounted how their thinking about disability changed as a result of working with disabled students or colleagues. Several school officials with disabilities exemplified this potential in their depictions of teaching students and peers about their own health care experiences and assistive technology, and their influence on inclusive-policy change at their institutions. Several students also exemplified this potential when they taught peers about their disabilities to fill absences in formal curriculum and enacted other forms of political disclosure (discussed later in this chapter). Similar to recent findings (Battalova et al., 2020; Stergiopoulos et al., 2018), however, students did not have guidance or structured opportunities to put their epistemologies into practice. Their engagement with such activities depended on individual comfort and opportunity. Although some students shared their lived experiences with peers, they sensed these activities were risky as exposure was always attached to possible negative consequences.

Recognizing the obstacles students have faced on their road to medical education, some suggested that they had *grit*. Duckworth and colleagues (2007) define grit as “perseverance and passion for long-term goals. . . despite failure, adversity, and plateaus in progress” (pp. 1087-1088). Grit is an individual factor that is not linked to intelligence but accounts for vocational and avocational achievement (Duckworth, Peterson, Matthews, & Kelly, 2007). Multiple school officials involved in admissions processes explained that grit is a desirable quality in applicants:

*If someone has reached the level of being able to apply to medical school and has been able to overcome hurdles like that, that says something about their grit factor, which we put a lot of value on. The ability to overcome hurdles in life. And so, in many ways, that is a plus. (Participant 37, school official)*

Students similarly asserted that their journeys to and through medical school required persistence against the odds and they were proactive in utilizing support services as a result, suggesting resilience. The value of grit was positioned as an asset against views that disability amounted to inability or greater vulnerability under pressure. Valorizing grit, however, can risk the traps of “overcoming” narratives, wherein disability is Otherized and disabled people are implored to, “Respond! Respond well; respond so well that we forget (look beyond) what you are responding to” (Titchkosky, 2007, p.187). That is, valorizing grit can assign individual responsibility to disabled people’s responses to life experiences rather than highlighting social

structures that continue to disable (Linton, 1998; Tefera, Hernández-Saca, & Lester, 2019). In the previous quote, for example, whether the school official constructs “the hurdle” as the impairment or the social conditions that disable is ambiguous.

The creativity borne of disability was another manifestation of it being valuable. Students made daily adaptations physically, cognitively, and interpersonally to make their way in an inaccessible world. Creative thinking facilitated unique connections between concepts that aided studying and patient care. The associated benefits of thinking and living differently through disability led one student to refer to their disability as a superpower (Participant 30, student). For many students, however, this line of thinking was not without ambiguity. While their disabilities were associated with benefits, they also entailed challenges or limitations in other respects.

### **Disability in legal terms**

The framing of disability in relation to rights-based legislation is the final conceptualization of disability that informed participants’ understanding and action. The definition of disability contained in the ADA (2008) is as follows:

*A physical or mental impairment that substantially limits one or more major life activities. . . ; a record of such an impairment; or being regarded as having such an impairment.*

*In general, major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.*

*A major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions. (Sec. 4a)*

This definition was distinct from how students and school officials colloquially understood disability. Whereas participants tended to conceptualize disability narrowly, including only certain embodiments, the ADA definition is intentionally broad. This disconnect between colloquial and legal definitions generated uncertainty about who counts as disabled and is eligible for inclusion-oriented services. Differences in understanding also existed regarding the implications of disability rights legislation. While most participants were aware that there was a legal basis to the provision of accommodations and that this was related to the ADA, the legislative requirements for schools and afforded students was less clear.

The legal definition of disability under the ADA was not widely understood outside of those school officials directly responsible for determining accommodations. Several participating students, for example, did not recognize that their diagnoses “counted” as a

disability under the law, reflecting Miller et al.'s (2009) findings. In their study of disability at Aberdeen medical school, Miller et al. (2009) found that after students were provided the legal definition of disability, the number that considered themselves to have a disability doubled. While some students learned they may qualify for disability resources through school officials, peers, or therapists, several others had not been referred to their school's disability resource professional to discuss possible accommodations, despite disclosure. From a compliance perspective, this was particularly concerning. School officials are considered agents of the institution and, thus, are responsible for knowing about disability resources and referring students accordingly upon disclosure (*North v. Widener*, 2012). The students who had disclosed, but were not referred to disability resources, had not sought accommodations at the time of our interview. These students interpreted the non-referral to mean they were likely not eligible for accommodations or that no accommodations were suitable for them. The lack of referral, however, may have simply reflected a school official's lack of knowledge about disability policy rather than a reasoned decision about eligibility or accommodations. Complicating this issue, institutional information about disability resources did not always unpack the definition of disability to increase understanding. This suggested an assumption that those who would be eligible for accommodations under the law were already aware of legal definitions. For students with recent diagnoses or who had not previously sought accommodations, however, this was a barrier to support services.

Some participants, both students and school officials, believed the legal definition was specific to educational settings, despite its dominion across many areas of U.S. life, including workplaces and public spaces. This shaped participant perceptions of the possible consequences of inclusion when transitioning to residency and employment. Those who believed the legal definition and associated inclusion measures, such as accommodations, did not carry into future settings were skeptical that students would be equipped to function beyond medical school. These beliefs fueled doubt about the appropriateness of accommodations in medical education, discussed further in Chapter 5, *Knowing Medicine*, in the section about the "real world" of medicine.

Even when students understood the legal definition of disability to include their embodiments, they tended to resist its connotation of individual inability. At the same time, they were compelled to accept the legal definition in order to gain access to the educational environment. Despite the ADA's promise to emancipate disabled people, scholars have critiqued the legislation's definition of disability, stating that it biomedicalizes and homogenizes disability, defines it as individual lack, and upholds the ab/normal binary (Donoghue, 2003; Skyer, 2019). Skyer (2019) powerfully asserted that the ADA, "strips citizens of their right to define themselves as capable and independent" (Key Findings section,



para. 3). Students were more likely to claim their diagnostic label, category, or other alternate framing (e.g., ADHD, chronic illness, neurodiversity, use accommodations) than they were to “claim” disability given its presumed association with inability, as exemplified in the following quote:

*I was talking to this first year [student] today . . . I didn't say disability right away, I said, “I did it with accommodations” because I feel like that sounds better than “well, I'm disabled” and [the usual response is] like “What? But you're going to be a doctor!” I guess saying that “I have accommodations” makes more sense to people, because then they still have in their mind that you're capable. And when you say disabled, you're kind of saying, “I'm not capable.” (Participant 5, student)*

This quote demonstrates the types of strategic moves students made when discussing disability with others, shaped by competing discourses of disability. They held situated understandings represented in the discourses of contextual production and disability as valuable. At the same time, the subjugation of those alternate framings and the necessity of capability in medicine (discussed further in Chapter 5, Knowing Medicine) meant student actions were always informed, in whole or in part, by the inability discourse. Although Participant 5 discussed accommodations with peers and desired more openness about disability, the student resisted using the term disability in order to manage others' perceptions of her capability.

The most dominant discourse of disability, the individual inability discourse, conflicted with the other three (contextual production, disability as valuable, and the legal definition). Participants developed these alternative ways of knowing disability (as contextual, as valuable, as entitled to legal protection) through their lived experiences and interactions. Through these understandings, new possibilities for self-knowledge and inclusion became possible. The overarching dominance of the individual inability discourse, however, tempered the possibilities presented by alternate discourses. The inability discourse, therefore, represented a gravitational force that participants always had to resist or manage in the pursuit of inclusion. Alternative ways of knowing disability, especially when shared, fueled students' ability to persist against the inability discourse. For school officials, alternate discourses supported resistance to disabled-student exclusion.

### **Legibility and Legitimacy**

The competing discourses of disability described in the previous section do not fully account for how participants knew disability and pursued inclusion. Here, I offer the notion of *legibility* as a way to understand how multiple factors converged to influence how individuals knew disability and responded to it. Legibility entails three dimensions:

3. recognizing the experience as disability (connecting one's experience to the construct and associated rights),

4. making sense of it (anticipating the barriers one might experience in medicine), and
5. understanding possible action towards it (understanding possible accommodations or adjustments to foster inclusion).

Legibility encapsulates an individual's understanding of their own experiences and possibilities as well as depicting others' understandings. In the context of medical education, several dominant factors most readily conferred legibility: biomedical recognition, visibility, and adherence to disability stereotypes. Other factors could also influence legibility, including knowledge of the ADA definition of disability and legal parameters for disability compliance, access to and trust in disability specialists, consciousness-raising efforts, and relationships with similarly-situated students.

Although legibility existed on a spectrum and was unfixed, relational, and contextual, participants described distinct trends in legibility across three groupings of disability experience. The greatest legibility was associated with experiences of disability that conformed to cultural stereotypes, for example, someone who used a wheelchair or other visible assistive device, or who was blind or deaf. These were often referred to as "real" disability, speaking to the legitimacy that accompanies legibility. Those with less-apparent disabilities deemed biomedical, usually classified as chronic illnesses such as diabetes, cancer, or Chron's disease, occupied a liminal status. The medical recognition of their diagnoses offered legitimacy, but their legibility tended to be hampered by uncertainty in the realms of recognition and action. The association of chronic illness with sickness rather than disability deterred recognition and perceived unpredictability of symptoms clouded understanding of possible action. The lowest legibility was associated with less visible and less biomedical characteristics, typified by disabilities often deemed "cognitive" or "mental" (e.g., learning disability, psychological disabilities, ADHD). These experiences seemed to lack biomedical authority and were least understood by physician participants, leading to limited anticipation of inclusion mechanisms.

The benefit of being (and/or not being) legible to others was equivocal, dependent on the recognition of aspects of disability experience and the sense, or interpretation, made of it. While greater legibility conferred legitimacy of one's disability status, it did not map directly onto a wholly positive experience in medical education. Participants with greater legibility described beneficial and detrimental effects of this status, caught as they were between legitimacy, inescapability, and stereotype. Those whose experiences were less legible to others were more likely to have their legitimacy and rights questioned and they experienced lower institutional confidence in determining accommodations. At the same time, their ability to "pass" as non-disabled afforded some freedom from immediate judgement. Those students with intersecting marginalized identities of varying visibility (e.g., race, gender, and sexuality)

described nuanced implications for legibility. Legibility had implications for inclusion, including whether students disclosed their disabilities and how others responded to disclosure and accommodations. In the following sections, I describe the consequences of legibility under conditions of “high” and “low” legibility, and aspects of legibility and intersectionality.

### **Living “real” disability**

Participants characterized certain embodiments as the automatic representations of disability: someone who used a wheelchair, who was blind or deaf, who required visible assistive devices (e.g., cane, walker), or whose experience of disability was otherwise readily apparent. Taken together, these characterized the experiences with the most legibility, which participants often referred to as “real” disabilities. Students who embodied “real” disabilities, however, described the associated burden of their legibility. On the one hand, their disabilities were treated as evident and thus the existence of barriers and need for their removal was, in some sense, unquestionable. With this recognition, however, also came the inescapability of disability categorization, which could immediately associate them with the individual inability discourse. This could result in overestimation of possible barriers and questions about the possibility or advisability of barrier removal for reasons of perceived cost or impact on patient care.

Experiences of legible disability were far less common than other forms of disability at the studied schools, as is the case nationally (Meeks & Herzer, 2016; Meeks, Case, et al., 2019). Students in this category, therefore, occupied a *token status* (Kanter, 1977) at their medical schools and in clinical spaces, often the only visibly disabled person. Their high visibility and novelty in the environment could result in a feeling of surveillance, of being *under a microscope*, as one student described:

*If you have a white jacket you might just blend with the others. I can't do that, and so if I come in 10 minutes late, “Oh that's the person, oh that's her, I remember her” and because I have a physical disability you are more likely to be remembered as having done that than somebody else who doesn't look different, they might forget your face. So, with me, they are not going to forget and so you are under a microscope. (Participant 44, student)*

Being immediately memorable meant always needing to be “on” and exhibiting peak performance. Students felt unable to be average, let alone do poorly, as this would be remembered and possibly logged as an inability indicator. These students anticipated that their performance would determine the possibilities of other students deemed like them to enter medicine. That is, how others came to understand their disability and potential to succeed in medicine would shape the legibility of similar others as viable candidates. Thus, the pressure was significant to appear capable and likeable.

With legibility came greater attention to systemic barrier-removal and anticipatory attention to individual accommodation needs. School officials conveyed greater confidence in their ability to identify accommodations for students with “real” disabilities, noting their greater understanding of students’ disabilities and the barriers they might face. One school, for example, employed an in-depth, proactive, team-based approach to identify accommodations and adjustments for their students with apparent physical disabilities, as recounted in the following quote:

*We sort of have a team of people that worked on accommodations for the first two years and so I think we all had on our radar like there were certain clerkship directors that I needed to talk to . . . I certainly didn’t feel solely responsible for directing that, I had a lot of support in that, and I also didn’t feel like I was being told. I knew that was something I needed to do. . . ahead of my surgery rotation, and I felt like I had the right support to say, “Who is the clerkship director for surgery and when do I need to meet with them?”* (Participant 10, student)

In this partnership approach, the group systematically reviewed technical skills required in clinical settings and developed adaptations, shadowing opportunities, and worked out any alternatives a student might need to participate in skill-building labs and clinical rotations. While incredibly valuable and representative of exemplary practice, there were some limitations. The attention was focused on the physical tasks of clinical work, the most legible barriers students would encounter. The less obvious structural barriers, such as early start times and long clinical days, remained outside the anticipatory process. This is representative of a common issue among school officials. Their ability to conceive of physical access concerns often overshadowed other structural barriers. From a student perspective, however, physical access was only one genre of barrier they experienced and, in many cases, the one they were most readily equipped to manage given their everyday adaptability.

The relative legibility of “real” disabilities did not guarantee favorable treatment. The students in this category reported relatively good relationships with their schools and positive attention to accommodations, but all recounted stories about their difficulty gaining admission to medical school related to legibility. For example, one student’s acceptance at a school was rescinded related to faculty concerns about accommodation possibilities, while another was only admitted to one medical school. While school officials asserted that disability information is not used to exclude students from admission, some nonetheless described lingering uncertainties that students with “real” disabilities had the capability to become a physician. This often manifested as an imagined ceiling of inclusive possibilities in medicine, such as the following:

*I think it would be very difficult to have somebody who was blind in medical school. I do not see how you can do that without being sighted. . . . I don’t mean just like legally*

*blind; I mean truly blind. From teaching the anatomy. . . I cannot imagine how you could make it happen. You have to read psychology; you have to be able to look at slides. . . . In fact, I think that that would truly be the only thing that at this point keep somebody out of the medical school environment, otherwise I think pretty much anything else is educable.* (Participant 11, school official)

While the specifics of the imagined ceiling varied by person, this phenomenon suggested the limits of legibility as a benefit. Taking this statement for example, despite the recognition of visual impairment as a disability, limited understanding of inclusion possibilities remained, thereby hampering the legibility of blindness as a viable physician trait. Blindness was suggested by multiple participants as the ceiling point, despite the existence of at least two physicians who successfully completed medical training while blind and currently practice psychiatry in the US (Hartman & Asbell, 1978; Smith, 2011). The imagined ceiling was often shaped by an individual's assumptions about disability experiences and possible accommodations rather than deep knowledge of disability experiences and inclusive possibilities.

### **Being “illegible”**

Students whose disability experiences were less legible to others could avoid immediate negative stereotypes of inability but had a greater burden to prove their disability, barriers, and identify possible accommodations. Furthermore, their experiences were often not legible to themselves as disability, despite having a diagnosis and experiencing barriers to access. Thus, many described multifaceted hesitancy to claim the stigmatized label of disability. This experience is summarized in the following student quote, which also highlights the lack of clarity offered by schools to demystify disability and accommodations:

*The only time they really advertise that there is such a thing as accommodations is each year when we have an orientation they have a slide that has three paragraphs, a little statement of ADA. . . they're like, “Oh yeah if you have accommodations just make sure you email this person.” That's as far as they go to tell people what ADA is. And to me, when I first heard about it, I didn't really know what that was for. I kind of just thought it was for people that had difficulties with, I don't know, something very debilitating, for example if they're in a wheelchair they would need certain accommodations for that, making sure there's ramps or something. I never really thought about it as depression and anxiety being a disability.* (Participant 8, student)

This student's account links the inability discourse with the concept of “real” disabilities that, together, tended to cause students outside those parameters to question their own disability status. The student also highlights the problem of *assumed knowledge*, whereby school officials assume students already know what the ADA is, who is covered, and what accommodations might be possible. Thus, policies or communications that failed to clarify the breadth of coverage and possible responses moderated the legibility of certain experiences.

Unless students had used disability services in previous schooling, it was often not until they disclosed a diagnosis to a knowledgeable and trusted school official, peer, or other support person (e.g., a therapist) that their experience was made legible to them as a disability, eligible for accommodations.

Further diminishing the legibility of these experiences was school officials' discomfort anticipating the barriers students might encounter in clinical settings, as well as a general lack of understanding about their diagnoses. Many school officials, despite awareness of the legal definition of disability and their medical training, did not understand learning disabilities, psychological diagnoses, and AD/HD nor possible accommodations to support them. This is a notable concern given the high prevalence of students with these kinds of disabilities in medical education (Meeks & Herzer, 2016; Meeks, Case, et al., 2019). The discomfort was exemplified through school-official statements such as the following:

*It would be a lot easier if there were more people with common physical and sensory disabilities where . . . it was very clear what the student was capable of and was not, and you could have a focused discussion about why this was or wasn't important to their training as a physician. It's much harder to do when what you're dealing with is a neuropsychology report on someone's learning disability. It's just harder. (Participant 6, school official)*

Without strong understanding of these disabilities, school officials were less active in the barrier identification and removal process. The illegibility of these experiences for school officials prompted several different responses. Some school officials questioned the validity of students' disability experiences and subsequently the necessity for accommodations. This could create tension between faculty and disability experts, or students and faculty. Another group of school officials recognized their limited expertise and were satisfied to delegate responsibility to disability experts and trust their decision-making. This was favorable to the prior outcome, but sometimes resulted in faculty disengagement with access concerns. A third group represented school officials with responsibility for accommodation decision-making on committees, but who did not understand these disabilities or possible accommodations. This final group was particularly concerning, as without a knowledgeable student or school official to intervene on decision-making, this resulted in poor service for students. Some school officials were aware that students with less legible impairments were not as well served by their schools. Many, however, were less aware of their interpretive limitations, and simply did not anticipate that these students might require accommodations beyond exam settings.

Under these conditions, illegibility of disability experiences heightened the burden for students to self-identify barriers and prove their access concerns. However, unless students had an in-depth, open discussion with a knowledgeable peer or school official, attuned to the clinical environment, disability, and accommodations, they often could not anticipate possible

barriers and remedies until they entered the environment. This meant students might not realize that they required accommodations until they were in the thick of intensive clinical experiences. For several students who found themselves in this type of situation, accommodations were reactive. The students described this process as painful, negatively affecting their clinical performance and requiring disruptive bureaucratic processes to work out what accommodations were needed and possible. This reactive practice particularly disadvantaged students who were less confident self-advocates, with less trust in school administration, and who did not fully understand their legal rights. While it is true that, under the law, schools have no obligation to anticipate the accommodations students may need, this responsive approach was in stark contrast to the proactive, collaborative experiences described by students with more legible disabilities.

### **Juggling legibility**

Anticipation of how others would “read” their disabilities occupied space in students’ consciousness and influenced their actions. Previously, I described this as “anticipatory action.” Students contended with the possibility that stigmatization (Goffman, 1963) might follow from others’ meaning-making, if their disability was made legible to others. In the already demanding performance context of medical education, one student described this as a heightened juggling act:

*I just wanted you to know that there is an additional thing that we have to juggle. We have an extra ball in the air.*

Neera: *Yeah, that stigma piece, people finding out, people knowing.*

*Right, and how it’s going to affect you. I don’t mind talking about it [my disability experience] or sharing if someone wasn’t going to use it against me later. (Participant 36, student)*

This student’s characterization of having an “extra ball in the air” was common among participating students, akin to Du Bois’ (1903/1994) concept of *double consciousness*. The ways students grappled with legibility were always twofold, their own meaning-making from their lived experience and the anticipated meaning-making of others. This double consciousness influenced their actions and, as this student described, took up extra cognitive space in an already taxed environment.

Double consciousness was multi-faceted for students with intersecting marginalized identities, who contended with multiple stereotypes. Particularly for the participating students of color, who were all women, their intersectionality informed their relationship to legibility. Most had less-apparent disabilities, thus, their most visible identities were racialized and gendered in ways already associated with inability. One student described the heightened performance consequences that followed:

*It makes me very nervous about having to perform in front of others, especially attendings. Especially men. Especially white men. My anxiety pretty much goes through the roof and that's where the best of the best really just starts, I have to prove way too many compartments of myself right now. (Participant 5, student)*

This student's perceived need to prove herself as "the best of the best" to assert her right to be in the room as a disabled woman of color, in the presence of the most powerful actors (white men in attending-physician roles), was repeated among similarly-situated students. This characterization suggested an amplified proving exercise when compared to white disabled peers that added consequences to legibility. In response, some students of color did not disclose less-apparent disabilities to others out of fear that this would further diminish their accomplishments. For example, a student who entered through an underrepresented minority admission scheme feared that revealing disability and associated academic challenges would fuel racist judgments about affirmative action. Others disclosed their disabilities readily to make their multifaceted experience more legible to others in the hope of "getting ahead" of assumptions. For example, if one's disability was more legible to others, this might invite interpretation of one's delayed responses in the clinic as disability-related and quell racist judgements about intellect. These interwoven concerns of racism and ableism left students of color in a bind. To reveal non-apparent disability might invite a positive discussion about accommodations, or it might diminish one's perceived capability and simultaneously invoke further racist stereotypes. These experiences illuminate the complicated effects of the co-constitutive nature of sexism, ableism, and racism (Annamma et al., 2013; Erevelles & Minear, 2010). In Bailey and Mobley's (2019) words, "racism, sexism, and ableism share a eugenic impulse" (p. 21). That is, constructions of ability are most readily assigned to whiteness and to men, while disability and assumptions of inability have been attributed to women and people of color to justify their denied citizenship (Annamma et al., 2013; Baynton, 2001; Erevelles & Minear, 2010). Those positioned at the intersections, then, contended with additional implications of inability that were interwoven between disability legibility, race, and gender.

The construct of legibility builds upon the competing discourses of disability to conceptualize additional dimensions of knowing disability with implications for inclusion. Legibility helps to account for students' differential experiences within the same school. The three-part process of recognizing a student's experience as a disability, anticipating barriers to access, and imagining barrier-removal strategies presented opportunities and risks, lending some experiences more legitimacy than others. Students might connect (or be connected) or disconnect (or be disconnected) from disability-support services, reveal their disability, or seek support depending on their legibility as disabled and the associated implications. In the



following section, I delve further into the ways students and school officials navigated disability inclusion in relation to discourses of disability and legitimacy.

## **Navigating Disability Inclusion**

The conflicting discourses of disability and principles of legibility described in the previous two sections converged to influence participant engagement with disability inclusion. The primary mode of disability inclusion at all four schools was through individualized accommodations. As one official stated, “*At the medical school? Access is accommodation*” (Participant 20, school official). This is perhaps unsurprising given the centrality of accommodations as the mechanism for equal access in disability-rights legislation. Students and school-official actions strategically minimized perceived risks associated with accommodations. Beyond accommodations, some participants challenged dominant discourses and shifted the conditions for inclusion. This section describes these strategies and discusses the circumscribed nature of the struggle for inclusion.

### **Students managing risk**

Conflicting conceptualizations of disability underpinned how students interacted with inclusion processes. The dominance of the individual inability discourse informed student hesitancy to align themselves with the construct of disability. Against this, understanding of the legal discourse of disability and subsequent rights as disabled people in educational settings supported student engagement with accommodations. At the same time, deeply felt understandings of disability as contextually produced and valuable generated friction between widely-held negative and individualizing views of disability, animating a resistant spirit among some students.

Students’ positioning on the legibility spectrum, as described in the previous section, also informed their engagement. Their experience of disability, ability to anticipate barriers in medical education, and strategize their removal was further moderated by the level of proactive support offered at their schools, their understanding of accommodations, historical experiences, and their disability social networks. Furthermore, intersectional identities, in particular, racialized and gendered identities informed the ways students navigated disclosure and the implications of legibility to others. Thus, student actions both contributed to and were reflective of legibility.

In response to their understandings of disability, their experiences of legibility, and in the context of medical education (discussed at length in Chapter 5, *Knowing Medicine*), students revealed or minimized aspects of their disability experience in pursuit of their inclusion. Students’ perceptions of the implications of disability disclosure in medical education created a dilemma. If they revealed their disability experiences, they risked

appearing less capable, or worse, revealing immovable barriers. Simultaneously, however, disclosure held the potential to unlock adjustments that allowed demonstration of their abilities and might mitigate failures. Students navigated accommodations in three ways: non-engagement, engaged-legible, and engaged-illegible (the latter two being varieties of engagement).

### *Non-engagement*

Several students did not formally disclose their disabilities to their schools, nor seek accommodations. These students generally did not believe that accommodations would address the barriers they encountered or believed that accommodations would negatively impact their perceived capability and thus their professional reputation. All of the participating students who fit this pattern had experiences of disability that fell into the “illegible” category.<sup>10</sup> Whether these students understood their experience as covered by legal definitions of disability was mixed. Most of these students, however, had not discussed their experiences with someone knowledgeable about disability inclusion and their understanding of accommodation options was limited. These students attempted to overcome the barriers they encountered through self-management techniques characterized as *making do*, such as moderating how they studied and participated in class, worked extra hours to complete required clinical tasks such as record-keeping, developed behavioral strategies in therapy, and moderated medication use. For example, one student sought alternate resources to supplement course books and lectures, which often did not match their learning style:

*That is really hard for me, trying to learn from reading. So, this summer I have spent a lot of time looking at licensing exam prep resources . . . where [the information] is more organized. A lot of them are video lectures and flash cards, which I do better with because reading for me what happens is, I'll space out . . . So, it is easy to miss things and kind of miss the whole picture, whereas a video if I play it a bunch of times . . . [I am] processing it at some level. . . I can rewind them, “what are they talking about?” rewind a few minutes, you know? (Participant 29, student)*

The aim of these techniques was to evade detection and academic consequences, in spite of the extra time required and the underperformance, exhaustion, and frustration that often followed. Although these students did not seek accommodations, they also did not distance themselves from disability altogether. Their decisions not to seek accommodations reflected a desire to avoid the stigmatizing potential of the individual-inability discourse. Several of these students, however, identified with valuable and contextual-production discourses and enacted political disclosure (discussed later in this chapter).

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<sup>10</sup> Several participating school officials knew of current students with “real” disabilities who had not yet sought accommodations. These students did not participate in this research, therefore, their perspectives cannot be included.

### *Engagement: Legible and illegible*

Students who sought accommodations moderated their disclosures. The in vivo concept, *picking battles*, encapsulated students' careful selection of which access concerns to reveal. Students raised only those concerns that they could not self-manage and would otherwise impede their success. They were careful not to appear too needy, costly, or unable to manage, unless absolutely necessary. That is, students aimed to fit into existing structures through *making do* while maintaining academic standing and positive relationships. The decision to reveal barriers or ask for more accommodations generally occurred when students already believed that the needed change was possible or when they believed their academic standing would suffer without change. These revelations were facilitated by trusted school officials, therapists, peers, or mentors who suggested possible accommodations, assured their beneficial effect, and reinforced student rights to change. Thus, students strategically discussed their disability, barriers, and accommodations in light of perceived possibilities and consequences. There were qualitative differences in the experiences of students with "real" disabilities (engaged-legible) and those whose experiences were less legible to school officials (engaged-illegible).

Students with "real" disabilities were most legible to others. School officials were more likely to attribute the discourse of disability-as-valuable to their experiences and readily understood their legal protection under the ADA. School officials most often attributed the contextual-production discourse to their experiences of physical access barriers. Their legibility prompted these students to disclose their disabilities during application and to actively pursue accommodation solutions prior to matriculation to get ahead of the inability discourse. They also encountered more proactive support from school officials. Nonetheless, these students moderated their accommodation requests.

*I operate under the assumption that it is not going to be an ideal world and asking for enough things to make it an ideal world makes me a pain in the ass, and I want them [the school] to want more students with a disability and the way they want more students with disabilities is if I'm low impact in terms of the resource and time that I need. (Participant 10, student)*

As Participant 10 describes, students with the most legible disabilities felt a duty to raise only insurmountable barriers in order to appear an easy student, preserve their relationships with their schools, and open opportunities for other students like them in the future.

Students who sought accommodations, but whose disability experiences were less legible to others (engaged-illegible), included those with learning and psychological disabilities, chronic illnesses, and AD/HD. The inability discourse shaped their engagement with accommodations in line with practices of making do and picking battles, but these

students had come to understand their experiences were covered by legal protections and they were eligible for accommodations. Some of these students had benefitted from accommodation use in the past and others had supportive therapists, peers, and school officials who encouraged them to seek accommodations. Several had experienced academic difficulty in medical school that had prompted their use of accommodations. These students readily received accommodations for pre-clinical written exams, the most legible accommodation possibility for them. The opportunity for accommodations in clinical or practical lab settings was often less clear. The school officials they worked with generally did not actively pursue these options with them until the student raised concerns. In line with patterns of making do and picking battles to evade the inability discourse, however, students hesitated to bring these concerns to school officials. In their private understandings, many of these students interpreted their experiences as congruent with the valuable and contextual-production discourses.

These findings largely align with previous discussions of disability disclosure in higher education and health professions education. Similar to a systematic review of postsecondary disability disclosure research (Lindsay, Cagliostro, & Carafa, 2018), barriers to disclosure included stigma, lack of knowledge of supports, and disability type. Students' decision-making followed conceptualizations of disclosure as an agentive, ongoing process of perception management oriented towards legitimization as a health professional (Easterbrook et al., 2015; Olney & Brockelman, 2003; Wood, 2017b). Unlike the findings of Easterbrook et al. (2015), who found students needed to engage in additional advocacy to access approved accommodations, in this study it seemed that once accommodations were approved, accessing them was straightforward. The tension here was in the process of asking for accommodations. Indeed, many students depicted accessing accommodations as surprisingly seamless relative to past experiences and expectations. Following Yoshino (2006), however, even once they disclosed and successfully accessed some accommodations, the perceived duty to cover aspects of their disability experience remained. This demonstrated the strong cultural pressure to approximate normativity.

### **Institutions managing risk**

School officials, like students, varied in their understandings of disability and accommodations. Aside from a small cohort of participating school officials who had a deep understanding of disability law and believed in the contextual production of disability, it was not uncommon for school officials to understand disability as individual inability and operate with a limited understanding of legal obligations. The predominance of the inability discourse, the limited legibility of disability experiences, and the capability imperative (to be explored in Chapter 5), fed incertitude regarding the lengths schools should take to accommodate students.

Aware that the pursuit of accommodations presented risk of stigmatization, school officials with oversight of disability inclusion took measures to minimize these effects. In support of inclusion, these school officials challenged their colleagues to rethink traditional practices. To address faculty concern about the risks to the profession presented by disability inclusion, three schools decentralized some or all accommodation decision making. In this section, I discuss institutional efforts to minimize risk to students, the institution, and to the profession.

### *Minimizing stigmatization*

School officials made efforts to minimize the risk of stigmatization associated with accessing accommodations through two strategies: naturalizing accommodation use and firewalling information. These practices responded to the predominance of the individual-inability discourse of disability. The perception that disability and use of accommodations was a risk to one's professional reputation followed from their association with inability, an undesirable quality in medicine. These practices were somewhat paradoxical. Naturalizing use sought to make services more visible, part of the expected fabric of student support, while firewalling sought to make disability and accommodations less visible to others.

*Naturalizing accommodation use* encapsulated actions such as discussing accommodations in the context of other "standard" campus support services during orientation sessions, workshops, and explicitly stating their possibility in policy documents such as technical standards. These efforts attempted to raise awareness of accommodations, however, their effectiveness appeared limited by the level of information shared. As previously described in this chapter, these messages rarely detailed the meaning of disability and accommodations in the medical school context. Thus, these messages seemed effective only for students already familiar with academic accommodations. Although in most cases this may have been an unintended effect, at one school the low level of detail was described as intentional, following concerns that students might "develop ideas" through this practice. Indeed, the lack of information hampered students' abilities to connect their experience to disability and see potential means to remove barriers through accommodations.

*Firewalling*, practices that made disability and accommodation use invisible to others, was the second group of actions intended to address possible stigma. Across schools, officials had made adjustments to policy, procedure, staffing, and even physical spaces to increase student privacy regarding disability and accommodations. The intention of these practices was to shield students from possible stigmatization, thereby facilitating accommodation use.

*I try to reassure them just by the structure of the policy. . . their application [for accommodations] never comes to Student Affairs; it goes directly to the [accommodations] Committee. None of their health records are ever intertwined with*

*their academic records. So, I try to reassure them that there's no "paper trail" so to speak.* (Participant 2, school official)

According to students, these practices quelled fears about professional harm. Firewalling is also consistent with existing practice recommendations for disability inclusion (Meeks & Jain, 2016). At the same time, these practices obscured the legibility of some disabilities and accommodations to others. For example, a school official suggested that firewalling practices heightened faculty complacency about accessibility. Unaware that disabled students existed in their midst and regularly encountered barriers, the need to design courses for accessibility was not an active faculty concern. Furthermore, these practices had the potential to re-stigmatize disability by upholding the notion that disability is undesirable and risky to one's career. Although responsive to stigma, the underlying conditions remained unaddressed.

### ***Rethinking traditional practices***

In order to advance inclusion through accommodations, responsible school officials needed to provide assurances that making changes to educational environments did not affect academic integrity. Beyond the few accommodations generally accepted and thus deemed "standard,"<sup>11</sup> school officials needed to explore academic requirements and legal responsibilities to determine the appropriateness of change. The school's identified point-person for accommodations generally led this process.

The case for accommodations followed the discourse of contextual production, suggesting that the environment should change to include disabled people, and the discourse of legal rights, that students were entitled to consideration of accommodations under the law. Successful accommodation advocacy challenged the fixity of the educational environment. The individual nature of accommodations, however, tended to provoke the individual inability discourse. Resistance to accommodations followed a perception that accommodations are for an otherwise unable person with limitations rather than to remediate an inaccessible educational context. This resistance underscored the perception of risk to the medical profession that might result from the implementation of accommodations and inclusion of students with disabilities. The legibility of disability experiences to the respective school official also informed their perspective in these debates. The more readily apparent the need for an accommodation was, the more easily it was accepted. Furthermore, when school officials could provide examples of peer institutions allowing the accommodation, this could support its validity.

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<sup>11</sup> The only accommodation that all schools deemed standard was extended time for written exams. At some schools, other accommodations such as notetaking and extended time for lab or clinical skills exams were also considered standard, but this varied.

School officials responsible for inclusion used the legal consequences of non-compliance as a stick to garner support for better practice and to counter resistance. When discussions about inclusion remained entrenched, invoking the legal parameters for inclusion, for example, the actual limits of reasonable accommodations suggested by case law, could force advancement. School officials responsible for accommodations primarily attempted to sensitize their colleagues to their legal responsibilities one accommodation decision at a time. When this did not garner support, supervising leadership were enlisted to add pressure on the basis of legal compliance. To build this support, one school official regularly notified school leaders of recent legal actions and their consequences:

*Every time a school screws up or anything, I announce it to the Assistant Dean, Associate Dean, I send out another one. I mean, I've got the law on my side. I'm not breaking the law. I am abiding the law. . . I keep saying, [do] you want a \$400,000 penalty/sanctions? You have the choice . . . and of course, their eyes get bigger.*  
(Participant 13, school official)

The viability of this strategy depended on a school official able to stay abreast of the latest legal decision-making, educate colleagues, and apply principles to practice. This was most evident at the school with a dedicated disability expert, reflecting arguments for such expertise (Haverstick, 2018; Meeks & Jain, 2018; Meeks, Jain, et al., 2019). The risk of this strategy was heightened risk-aversion towards disabled students and resentment towards disability inclusion rather than viewing inclusion as beneficial.

Successful experiences extended the reach of what might be possible for future students and built school-official support for inclusion. As one school official described it, "*It paves the way for openness*" (Participant 38, school official). That is, regardless of any initial skepticism, each student's successful use of an accommodation shored up its validity. When students demonstrated their potential with accommodations, this built support for disability inclusion. This success relied upon a process of making fixed ideas of disability and educational requirements malleable. Whether this malleability could be maintained for other students seemed dependent on the dissemination of successful instances and their retention in the institutional memory. When this did not occur, the case for inclusion needed to be built anew. Furthermore, the benefit of success stories was limited by the depth to which stories were known to others. Publicized success stories generally obscured persistent challenges, including those that students deliberately shielded from their schools. This boosted a positive case of inclusion, that was beneficial for building openness, but this limited schools' ability to realistically assess their inclusion efforts.

### *Decentralizing decision-making*

Three institutions decentralized some or all decision-making about disability inclusion in an effort to advance faculty buy-in and to address faculty concerns about academic integrity. Rather than a disability service office or expert professional developing policy and leading decision-making, this power was dispersed to a committee of faculty and administrators.

Two examples of this strategy were accommodation committees and policy-change committees. Accommodation committees had been implemented at two schools to address distrust in the central university disability service office's ability to make decisions for medical education contexts. Two schools had also convened policy-change committees to revise a specific policy related to inclusion, for example, technical standards. The outcome of decentralizing strategies varied. In some cases, the outcome was greater faculty awareness and acceptance of accommodations through learning about standards, hearing student stories, and dialogue with knowledgeable colleagues. In others, these efforts simply entrenched resistance to accommodations. Committee processes could result in conservative decision-making through consensus, or worse, a complete lack of consensus. At one school, for example, a committee to explore expansion of accommodations for OSCEs (standardized clinical skill exams) built faculty resentment when the school implemented accommodations in line with legal best practice rather than committee member agreement. According to participant accounts, the nature of the outcome was moderated by the group's makeup: members' pre-existing beliefs about disability inclusion, the persuasive abilities of the involved parties, and their knowledge of inclusive practice and legal standards.

A further drawback of committees was their limited engagement with disabled-student voices. This was of particular concern for accommodation decision-making committees when limited engagement with students prevented the trust-building and knowledge-sharing necessary to foster discussion about barriers and solutions. This reflects Laird-Metke's (2016) arguments against accommodation committees, which noted issues of privacy, the potential for bias, and insufficient interaction with students. Although faculty engagement was critical to ensure determination of accommodations suitable for academic settings, whether decentralizing decision-making advanced buy-in, trust, and inclusive outcomes for students remained mixed.

### **Beyond accommodations**

Participants engaged with disability and inclusion through several other notable activities that affected disability-inclusion potentialities. These included political disclosure, organizing, and UD. These represented efforts beyond the realm of accommodations to shift discourses of



disability against stigmatization, towards valuableness, rights, and a shift in the context towards inclusion.

*Political disclosure* (Jain, 2020b) entailed participant disclosures of disability for collective benefit in resistance to ableist pressures to normalize or otherwise conceal their disabilities. These acts included open disclosure of lived experiences to peers and in the case of disabled school officials, to students and the general public. These actions contributed to community-building efforts, filled lived-experience gaps in the curriculum, countered everyday ableism, and supported policy-change initiatives. The impetus for political disclosure was often affective, a deep sense of frustration with discourses of inability that did not match one's lived experience and fostered marginalization. Perhaps the most powerful outcome of political disclosure, then, was to counter the stigmatizing possibility of disability.

*There actually has been one student [at my school that] I'm very grateful for. . . one day he sent an email to my class detailing his life experiences . . . that was amazing in the sense that, here is one medical student who isn't ashamed of telling people what he went through . . . In my mind, I feel like I'm the only one struggling.* (Participant 32, student)

As this student described, an act of political disclosure opened the possibility that disability is something that could be shared and is likely to be a collective experience. One student's political disclosure tended to invite others to disclose and built informal disability community. School officials with disabilities who engaged in political disclosure did so to teach students about working with disabled patients and to teach others that it was possible to do medicine differently. For example, some school officials shared their stories publicly through panels, memoirs, online profiles, in news stories, and to aid schools—including their own—to improve their inclusion efforts. Through a national organization, several school officials also contributed to mentoring, consulting, and legal action.

Formal organizing efforts sometimes followed students' political disclosures. For example, one student developed a disabled-student society to share experiences, strategies, and foster change. Through this group, students developed camaraderie, shared strategies for navigating accommodations, and identified issues for systemic change. These connections fostered realizations of commonality and, in some cases, a political awakening. School officials alternately discouraged or deemed impossible organizing efforts given their stigmatizing potential. Thus, their existence was left up to motivated students.

Another way participants pursued inclusion was through UD efforts. As discussed in Chapter 2, UD is a strategy to build spaces, policies, and practices that are maximally inclusive, thereby minimizing the need for individual accommodations (Burgstahler, 2015). For example, one student leveraged her position as a student leader to reform food-purchasing practices for school events towards a UD approach. Herself having dietary requirements due to

disability, she recognized the intersecting need for better food options, labeling, and handling across disability, religion, allergy, and ethical preference. This action opened space for collective difference without marginalization and was institutionalized in new administrative practices. In another example, a school's librarian ensured their furniture, spaces, and digital materials were maximally accessible, and continually enhanced the library environment based on student feedback. These UD efforts exemplify the transformative potential of considering disabled people as valid and valued community members. This way of working was not, however, built into policy and practice: instances of UD were opportunistic. This left the consideration of students with disabilities to chance, requiring that someone bring disability into the conversation. Changes to policy and practice regularly occurred without regard to their effect on students with disabilities. Participants described, for example, major projects like curriculum redesign efforts that did not prioritize disability inclusion, as well as smaller changes to the exam schedule that did not consider the impact on students using accommodations. The continuous omission of disability at the foundation level of decision-making left retroactive accommodations the primary way schools fostered inclusion.

## **Conclusion**

I have argued that the ways participants knew disability affected their interactions with institutional inclusion mechanisms. The ways of knowing were underpinned by competing conceptualizations or discourses of disability. Most dominant was the discourse of individual inability, in which people construed disability as immutable inability and a problem located predominantly in individual actors (as opposed to cultural or structural conditions). In competition with individual inability were the discourses of contextual production, valuableness, and legal rights. The legal discourse of disability was the operative framing that shaped inclusion policy, however, individual students and school officials were not always aware of legal definitions and parameters. This fractured knowledge limited students' connection to access-oriented services. Variable knowledge and acceptance of these alternate discourses, in relation to the dominance of individual inability, framed how students understood their own experiences and projected how others would interpret them. School officials, similarly, demonstrated variable understanding and acceptance of the competing discourses of disability and understood the individual inability discourse to overshadow all others.

The construct of legibility had the scope to reinforce or reconfigure understandings of disability. Legibility brings together ascription of disability, perception of barriers, and perception of solutions. The positioning of these moving parts determined whether students were perceived by themselves and others as disabled, in need of support and accommodations,

and able to be included within medical education. Furthermore, students with marginalizing, intersecting identities considered the implications of legibility in ways that demonstrated the co-constitutive forces of ableism, racism, and sexism.

In the context of discourses and legibility, students and school officials navigated disability inclusion in various ways. The primary site of action was in the realm of accommodations, but some activities also occurred beyond this realm. In the space of accommodations, risk overlaid participants' engagement, informed by the stigmatizing potential of the individual inability discourse. Students moderated the degree to which they sought change in line with their perceptions of accommodation possibilities and consequences. School officials acted to moderate the perceived risk of accommodations to students and to the medical profession. Beyond accommodations, students and some disabled-school officials engaged in activities of political disclosure that aimed to shift collective understandings of disability. Organizing among disabled students further countered the dominance of the inability discourse. The very act of organizing asserted that experiences were not shameful and, in demonstrating collectivity, raised political consciousness. Alongside these efforts were selected examples of UD that aimed to build disability into the community fabric.

These findings represent the circumscribed debate of institutional efforts towards disability inclusion. The taken-for-granted position was that disability amounted to inability and, therefore, exclusion is to be expected. The permissible opposing position was that accommodations to existing standards allow people with disabilities to meet existing expectations. This reflected an understanding of disabled people as having limitations that may be ameliorated through contestable modifications. Thus, the realm of legitimate debate revolved around strict interpretation of legal requirements: whether an accommodation was reasonable or not.

The implementation of accommodations countered a discourse of complete inability and logical exclusion, making the allowance of accommodations appear radical. The law, however, permits institutions to do more than basic compliance for disabled students and does not bar programs from reimagining their structures in deliberately inclusive ways, but these actions are not required. Legal requirements became a ceiling that limited the bounds of possibility rather than a floor from which to build. Questioning standards and structures of medical education altogether, and reorienting them for inclusion, was outside the realm of legitimate debate. Inclusion by design was opportunistic, but not institutionalized practice. Such an approach would fully recognize disability as produced through restrictive social arrangements that enforce normative standards. Part of the reason this approach remained beyond the permissible is the deeply-rooted and omnipresent expectation for hyper-ability in medical education. In the next chapter, I explore how participants knew medicine and how this

further shaped their understandings of disability and engagement with inclusion, through development of the concept of the capability imperative.

## Chapter 5. Knowing Medicine: The Capability Imperative

### Introduction

The previous chapter presented various understandings of disability amongst participants, each of which had implications for the disability label, legibility, and navigating disability-inclusion processes. I argued that a discourse which equated disability with inability informed participant actions, regardless of their belief in its veracity. At the same time, belief in alternative, emancipatory discourses of disability underpinned by constructivist ontologies and epistemologies animated resistant actions. In this chapter, I turn to the second major area of findings, the ways participants knew medicine.

Participants' experiences of medicine were underpinned by what I have termed the *capability imperative*. The capability imperative can be understood as a cultural force, or logic, that sets expectations around performance and behavior for those within and who aspire to a profession. In the medical context, it enforces the characteristics and requirements of a good physician: one who is supremely able while showing no weakness. Building from McRuer (2006), the capability imperative is a condition of *compulsory hyper-ablebodiedness* and *ablemindedness* that emerges within the system of ableism in a context with high-performance requirements. The capability imperative establishes and justifies institutional arrangements. Further, it seeks to produce a student who is able to conform to institutional and professional expectations.

I use the term “capability” to illustrate that the imperative does not just demand that one has acquired the ability to do something, as is suggested in “competence,” but that they have the potential to do things if and when demanded. For example, in the admissions process, prospective students must convince schools of their capability to become a good physician, although they are not yet competent. The capability imperative can be understood to consist of three motifs:

- *physicians as selfless superhumans*;
- *the “real world” of medicine*; and
- *the malleable student*.

These three motifs have implications for the individual, the structure of medical training, and the interaction between the individual and structure. The motifs interact with and support each other. These motifs are manifested through participants' lived experiences, cultural representations of medicine, and the *hidden curriculum* (Hafferty, 1998; Hafferty & Finn, 2015; Hafferty & Gaufberg, 2013; Hafferty, Gaufberg, & O'Donnell, 2015). Broadly defined, the hidden curriculum is “the attitudes and values conveyed, most often in an implicit and tacit fashion, sometimes unintentionally, via the educational structures, practices, and culture of an

educational institution” (Hafferty et al., 2015, p. 131). As one participant noted, *“I think it is the most powerful part of how our students experience their entire profession, the informal and the hidden parts of it”* (Participant 21, school official).

Although the capability imperative was hegemonic, it was nonetheless contested. Together with the understandings of disability detailed in the previous chapter, these three motifs illustrate how the capability imperative rendered students with disabilities as questionable actors in medical education and, more broadly, in the medical profession. Throughout their discussions of the capability imperative, participants continually questioned its veracity. Thus, while the capability imperative loomed as reason for disabled people’s exclusion from the medical profession, participants debated how accurate, fixed, or beneficial this imperative was—particularly given how impossible it seems for any person, disabled or non-disabled, to achieve. As McRuer (2006) suggested in his discussion of compulsory able-bodiedness, perhaps this is because the idealized, hyper-able-bodied and minded, physician identity can never actually be fully achieved. Furthermore, as I will discuss with regard to wellness, the capability imperative may, in fact, be dangerous to all physicians and their patients. Although the capability imperative disciplined participant actions in medical education, participants also resisted through attempts to resignify capability. These attempts had the potential to open possibilities for disabled-student inclusion. In the following sections, I will explicate the three motifs of the capability imperative: the Selfless Superhuman, the “Real World” of Medicine, and the Malleable Student.

### **Selfless Superhumans**

Participants often discussed the expected, idealized physician as a selfless superhuman. Selfless superhumans were capable of all things, no matter how difficult, and fully dedicated themselves to the altruistic goal of patient care. To uphold their position, they could show no weakness. Physicians had no personal needs, were able to put themselves last and push themselves to the limit for the purported good of the patient. Should such a physician find themselves “in need,” the imperative was that they master these needs in order to continue in their superhuman endeavor. That is, they must achieve with little to no change in the context. This motif of the selfless superhuman was built from cultural mythologies of physicians and was also reinforced and recreated through behavioral expectations taught informally and codified through policies and structural arrangements. The construct of the selfless superhuman, in shaping expectations for good physicians, set the bar for individual capability.

The rationale for selfless-superhuman behavior among physicians was that they hold public responsibility for patients’ lives. This public trust necessitated that physicians know and

do everything possible to avoid public harm. One school official succinctly summarized this expectation:

*The weight of the world is on a physician. . . you can't screw up, it's people's lives.*  
(Participant 11, school official)

Although the responsibility to patients is unquestionable, individualizing capability tends to obscure the structural factors that determine it. Lingard (2009) identified terms like “competence” and “patient safety” as *rhetorical trump cards* in health professions education, representing the “last word in debates about how health professions education should function” (p. 625). They are irrefutable, no one would want an incompetent, unsafe or, I would add, incapable physician. Lingard (2009) noted that such terms, while reflecting reality also select and deflect reality. I argue that these terms select the individual as the locus of interest while deflecting the structural conditions that disable them. Under the capability imperative, the individual must embody a person capable, competent, and safe within the conditions as they are.

### **Being and doing all things**

The superhuman physician motif was produced and codified through technical standards. Technical standards, the non-academic requirements for admission, retention, and graduation in medical school programs, set up the initial and ongoing bar for students to demonstrate precision in their bodyminds. As discussed in Chapter 2, all medical schools must maintain technical standards for accreditation purposes, but each devises their own. As such, technical standards vary considerably between institutions (Argenyi, 2016; Zazove et al., 2016). Zazove et al. (2016) studied technical standards across U.S. medical schools and determined that many were out of compliance with the ADA on grounds of their lack of ready availability, lack of statements about accommodation availability, and proscription against intermediaries. Schools generally provide students with the technical standards upon admission and ask for acknowledgment that they understand and, in some cases, endorse their ability to meet the standards “with or without accommodations.” Technical standards were initially mentioned in Section 504 of the Rehabilitation Act of 1973 and the associated federal guidance to clarify that “qualified handicapped [*sic*] persons” must meet essential non-academic admissions criteria, as well as any academic criteria (Nondiscrimination on the basis of handicap, 1977). If one does not meet the technical or academic standards, they are not “otherwise qualified” and, thus, have no grounds to claim discrimination. As discussed in Chapter 2, scholars have debated technical standards in medical education due to their tendency to exclude students with disabilities in their reliance on outdated concepts and their lack of consideration for the potential value of disabled physicians (Argenyi, 2016; Association of Academic Physiatrists

[AAP], 1993; DeLisa & Thomas, 2005; Kezar et al., 2019; McKee et al., 2016; Reichgott 1996, 1998; VanMatre et al., 2004; Stiens, 1987; Wainapel, 1987b, 2015; Zazove, et al., 2016). Most of this concern has focused on the exclusionary effects of technical standards on those with physical and sensory disabilities, although technical standards include behavioral and cognitive components that also present potential barriers to those with learning, psychological, and chronic health-related disabilities.

Woven into the debate about technical standards is the question of “What is a physician?” In considering technical standards, critical questions arise regarding the essential role of a physician, what must they be independently capable of, and how this relates to modern medical practice. At play in this contested area is the principle of *undifferentiation*, which has plagued disabled-student inclusion in medical education for decades (AAP, 1993; DeLisa & Thomas, 2005; Hartman & Hartman, 1981; Moutsiakis & Polisoto, 2010; Schwartz, 2009; VanMatre et al., 2004; Wainapel, 1987b, 2015). Central to the contestation are divided perspectives on whether medical education should produce pluripotent graduates or graduates with broad medical knowledge. In the former, graduates would be capable of entering any specialty and thus can do every task (i.e., *undifferentiated graduates*). In the latter, graduates would have broad medical knowledge and be capable of understanding but not doing every task, given the predominance of specialization in practice (i.e., commitment to an *undifferentiated curriculum*). These contested questions rattled throughout discussions with participants, many believing that they remained unanswered and insufficiently explored in the field. The lack of a clear resolution regarding how to think about undifferentiation presented a central tension in discussions about inclusion. Without clarity, physicians and medical educators had to think critically about the realities and possibilities of the profession, as well as wider public perceptions and expectations for physicians. The social contract, centered around the public’s high degree of trust in physicians, made patient safety an unquestionable principle in the education of medical students. Whether or not accommodations risked patient safety was, therefore, an ongoing primary question in the process of inclusion. Participants noted, in line with Lingard (2009), that patient safety is often used as a rhetorical trump card in discussions of inclusion, an easy and unquestionable route to “no.” Against this, some have argued that accommodations to technical standards do not pose risks to patient safety (DeLisa & Thomas, 2005; McKee et al., 2016). Participants weighed commitments to the profession, to the public, and to inclusion. The following quote illustrates the types of questions that arose when school officials considered their position on undifferentiation, technical standards, and inclusion:

*What happens if a student graduates from this medical school and is not able to do compressions on a chest? Does society expect that every physician should be able to. . .*



*resuscitate a patient? We had to have those kind of philosophical discussions and they are not resolved.* (Participant 21, school official)

Despite the stated uncertainty about the essence of physician capabilities, analysis of the technical standards in place at the four schools at the time of fieldwork (mid-2017) nonetheless suggested a level of certainty that conformed to traditional ideas of the superhuman physician. While the technical standards did not follow Zazove and colleagues' (2016) concerns about ADA compliance in that all were readily available online, mentioned accommodations, and did not per se disallow intermediaries, the language signaled constraint and ambiguity with regard to disability inclusion. The standards left students without clarity or security of their place in medicine.

Across the four schools, the technical standards outlined expected skills in the areas of observation, communication, motor functioning, cognition, and behavior that generally followed the language of the AAMC (1979) Advisory Panel report's recommendations. The standards gave the impression that all must be in pristine working order to function as a medical student, resident, and physician. Most (three schools) explicitly stated a commitment to an "undifferentiated degree" despite any candidate's intention to specialize narrowly or not practice clinically. Technical standards across all four schools included a version of the following statement:

[Technical standards] *consist of certain minimum physical and cognitive abilities and sufficient mental and emotional stability to ensure that candidates. . . are able to complete the entire course of study and participate fully in all aspects of medical training.* (School 4, technical standards)

In all of the schools' standards, they also essentialized the conditions of medical education and practice through statements such as "*must be able to effectively handle and manage heavy workloads*" (School 2, technical standards) and those statements that necessitated functioning physically, mentally, and emotionally over "*long hours, going without sleep*" (School 3, technical standards; sustaining abilities over long hours was also mentioned in standards for schools 1 and 4). Through these requirements, the standards problematized disability rather than the disabling aspects of current environments.

The standards across the four schools used, for the most part, *organic* rather than *functional* language to explicate essential abilities. Organic framing generally occurs when technical standards necessitate normative sensory, motor, and cognitive functioning in order to participate in medical education (McKee et al., 2016). For example, one school's standards for communication state:

*A candidate should be able to speak, to hear, and to observe the patients in order to elicit information, describe changes in mood, activity, and posture, and perceive non-verbal communications* (School 3, technical standards)

This represents just one of many organically-framed statements across the four schools' standards that specified "how" (in this case, using one's voice and hearing) rather than "what" students must demonstrate. The effect of organic language is that if one used the standards to evaluate a student's ability to meet the requirements, they would "highlight students' limitations or deficits rather than their abilities" (McKee et al., 2016, p. 995). To illustrate the difference between an organic and a functional approach, consider this possible alternative to the previous example, "Candidates must exhibit interpersonal skills to accurately evaluate patient conditions and responses and enable effective caregiving of patients" (Kezar et al, 2019, p. 526). This reframing emphasizes the "what" or the purpose of the standard, for a student to accurately evaluate patients and provide effective care, without dictating exactly how they must achieve it. Through the use of organic language, the schools centered normative physical, cognitive, sensory, and psychological functioning. In their entirety, the standards emphasize hyper-ability, through the requirement that students can do all things, without sleep, with heavy workloads, under time limits, and under stressful conditions, while demonstrating "*compassion, integrity, concern for others. . . interest, and motivation*" (School 3, technical standards).

While all the schools stated that accommodations are possible in order to meet their standards and three schools explicitly stated non-discriminatory values, they nonetheless enforced the superhuman standard through organic language and positioning of accommodations as contestable. Language about accommodations was qualified across the schools. Accommodations must be reasonable, preserve patient and colleague safety, not substantially alter program or academic standards, nor present undue hardship. This language, alongside the laundry list of abilities presented as rational and necessary for medical practice, sent a mixed message about inclusion, calling out disability as an "*excludable type*" (Titchkosky, 2011, p. 78). Titchkosky (2011) explains that disability is commonly represented as justifiably excluded, and these justifications act as a barrier to inclusion. The standards gave little impression of inclusive possibilities, instead focusing on organic abilities with little description of what is meant by disability and only describing the limits to accommodations rather than possibilities. The technical standards, thus, seemed to assume students already knew what constituted a disability, an accommodation, and associated rights. As discussed in Chapter 4, however, this was often not the case. Even policies that noted the possibility of meeting standards in alternate ways placed the onus on the student to already know how they

might do so. For example, one policy used the following language after each description of an organic expectation:

*In any case where a candidate's ability to . . . [do the outlined task] is compromised, the candidate must demonstrate alternative means and/or abilities to . . . [do the task].*

(School 2, technical standards)

Given that students sign the document upon matriculation, this could be interpreted as a need to demonstrate their ability to achieve a skill they have not yet learned to do to gain admission (e.g., complete and interpret the physical findings of patients), rather than having the opportunity to develop alternative means in partnership with the school. Indeed, one student with physical disabilities described working with an occupational therapist prior to admission to identify alternate means to meet technical standards in order to be prepared to prove their abilities. Notably, this implication operated in direct contrast to the school's practice. In practice, school officials worked in partnership with their students with physical disabilities to devise alternate means to meet technical standards. Mismatches between policy as described in technical standards and practice on the ground were identified across all but one school. Two schools' technical standards described processes that offered students less privacy of their disability documentation than actually available. Ambiguity about the role of accommodations in technical standards was highlighted in discussions with students. They were often uncertain about how to interpret these policies, as summarized in one student's account:

*While I was applying to medical school, there was also the issue of the [technical] standards, and that was kind of scary to read through those and be like, I don't know, just not knowing if I would truly fit the standard, because in some ways it's kind of vague, and it kind of depends on what's happening with me that day, so for [my medical school], I kind of held off [pursuing accommodations] because I wasn't really sure what I needed to do . . . there wasn't really a lot of information about what would happen if you said, "Hey I don't know if I can meet these [technical] standards." Because it's like oh, can I not go to medical school anymore? Or is it like, what do I have to do? (Participant 33, student)*

The fluctuating nature of this student's disability made them uncertain whether they could meet the requirements of the standards at all times. The authority of technical standards presented the possibility of exclusion as a result of revealing anticipated challenges and created an initial barrier for several students to discuss accommodations with their schools. Many students also deduced that their school's technical standards excluded students with any physical disabilities from medicine. Thus, the technical standards enforced a characterization of the superhuman medical student who must be able to do all things, with few exceptions. This not only served as a barrier for current students, but likely presented barriers or

unanswered questions for prospective students. Technical standards also served as a reminder that students with disabilities were admitted conditionally and could be justifiably excluded, if they were found unable to meet the standards. As a frontline statement of a school's disability-inclusion practice, technical standards tended to uphold the capability imperative, even when on-the-ground practices might resignify capability. This meant that, in many cases, students had to overcome the barriers presented by technical standards to learn about inclusive possibilities.

### **Showing no weakness, having no needs**

Beyond codified requirements for superhuman abilities, the *informal curriculum*, experienced through relationships and interactions (Hafferty & Gaufer, 2013), also embodied the capability imperative. Interactions with peers and teachers informed notions of expected behavior. These interactions, when combined with structural conditions such as clinic schedules, suggested that medical students and physicians show no weakness and have no needs. The elite status of physicians necessitated this front to maintain their authority as a capable practitioner. Given the hurdles one must traverse to attain medical school admission, those successful few must completely excel in their coveted position. Despite the support services provided by the medical schools, such as learning specialists, wellness programs, and counseling services, students understood that they should use services to optimize their functioning but never reveal deep personal or academic struggles to peers or teachers. This capacity distinguished the physician from the patient. It suggested that if a physician revealed human vulnerabilities, their capability would come into question. One school official summarized this as follows:

*There is a culture here of toughness and you don't want pity, you don't want looking down on you, you don't want anyone thinking that you're not qualified or confident. . . they feel that is going to doom them. (Participant 16, school official)*

This culture of no weakness was buoyed by a competitive climate. Under pressure to display peak performance to gain competitive residency slots, secure recommendations, and achieve the highest scores on the Step 1 licensing exam, many students felt in competition with each other. These factors seemed to counter movements to engender cooperation among students through institution of pass/fail grading in pre-clinical years, peer-support programs, and team-based learning curricula. For example, at one school students described an incident where several students had complained to school officials that their peers were sharing too many resources with each other and that too many students were passing. Students heard their peers describe classmates who were struggling as having taken a place from someone more worthy. Within team-based learning groups, students deemed lower-performing were dismissed or discounted. At the same time, institutional actions sent mixed messages about

competition, a condition that subverts the aims of collaborative learning (Kohn, 1992). For example, by announcing top-performing students in each class via email and providing students access to data about their academic standing relative to peers. Such an atmosphere necessitated continually proving one's superhuman worth to remain in the profession.

The demand to show no weakness was also promoted through interactions with supervising residents and attending physicians. Students witnessed overworked and overwhelmed physicians in their clinical rotations who did not discuss their difficulties nor seemed able to address them. Instead, they quietly pushed on, as this student described:

*People don't complain outwardly. . . I even see residents that you can see are stressed but are never going to tell their attendings or even their peers . . . it's that culture of "you just need to suck it up and do it." Sometimes I can see on people's faces that they are really struggling and what are you going to do? You ask how they are doing and they say they are fine and I do the same thing. "I am fine." The less people know about me the better. I don't want them to know, then everyone else knowing "she's struggling."*

Neera: *If people knew you were struggling, what would that mean?*

*You're not competent enough and that is still the culture.* (Participant 18, student)

Seeing teachers and peers model suppressed emotion, working while unwell, and persistence despite being overwhelmed reinforced the expectation to show no weakness. This student's description also highlights how the expectation for selfless superhumans to show no weakness supported silence about the conditions that overwhelm, as this might suggest one's lack of fitness for the field. This aligns with research that showed medical trainees believed that revealing fatigue or illness would be perceived as signs of weakness that threatened their reputation as committed and capable (Grant et al., 2019; T. Taylor, Raynard, & Lingard, 2019).

The corollary to the superhuman physician who shows no weakness is that the physician has no personal needs. This physician (or physician-in-training) is wholly focused on patient needs. This expectation was crystalized in the frequent refrain about the transition to the clinical phase of training:

*In the first two years the students are in classrooms and they are the center of our universe. . . then they transition to the third year and it becomes about the patient and they are secondary. . . their learning is not—it's a component, but it's really not the primary thing that's on the table. It's addressing the patient's needs and the patient's safety.* (Participant 41, school official)

This imagined singular focus on patient needs, while noble, requires that physicians (and medical students) maintain an air of supreme perfection and capability, lacking their own individual needs, in order to fully focus on the "needy" patient. Indeed, Ginsburg, Regehr, and Lingard (2003) identified this tension as the *disavowed curriculum*, where medical trainees are

taught to “deny, disclaim, or denounce” (p. 1020) implications for themselves in clinical learning encounters, as this “indicates selfishness, and is dangerously inconsistent with the ideal of altruism” (p. 1020), despite the importance of self-protection for survival and their central interest in their own educational progress. Trainees understood that they should deny their personal needs in clinical learning. Although Ginsberg et al. (2003) identified the disavowed curriculum in their exploration of professionalism, the concept also has implications for students with disabilities who may have “needs” to counter barriers in the clinical environment. For example, they may need a patient to sit on a chair instead of a high non-adjustable exam table to more easily conduct a timed physical exam. Such needs were questioned by school officials as appropriate accommodations given their reflection of the student’s need rather than the patient’s, even when the need arose due to inaccessible infrastructure, or did not negatively affect the patient. Furthermore, students hesitated to reveal barriers when they anticipated the solution would make them stand out from their peers as “needy.” This resonates with studies of medical student socialization, which have found the learning environment demands students only stand out as interested, competent, and capable (Beagan, 2001a; Haas & Shaffir, 1987; Han, Roberts, & Korte, 2015; MacLeod, 2011; T. Taylor et al., 2019).

Productivity expectations also suggested a superhuman physician with no needs. Regardless of the nature of a clinical encounter, the schedule implied that the physician needed no time to personally process or recover between appointments. Students understood this as a demand to “*flip a switch*” (Participant 1, student) in the course of their roles. They participated in incredibly stressful, even traumatic medical events, such as delivering bad news, witnessing births and deaths without any opportunity to process their own emotions from one event to the next. When the often-extended duty hours in clinic were through, they went home to study in preparation for the next day in the clinic, where they did it all over again. One student’s description conveys the relentlessness and emotional toll of the clinical schedule:

*If every 15 minutes you have someone coming and telling you something completely drastic . . . [for example] patients that came from the Vietnam War, Vietnamese, they said they remember running and hearing their mom’s voice say “Run, run, run, hide, hide, hide,” and then just seeing their entire villages blow up, you know, little brothers here and there. . . and they’re crying and so I’m crying and then how am I going to like, how? Puffy eyes and then see the next patient and be like “Oh, so hey, how are you doing?” Like no, those feelings stay. It stays with me.* (Participant 36, student)

The lack of allowance for in-the-moment acknowledgment of the emotional impact of clinical experiences, or flexibility for short periods of recovery, compelled students to bracket the experience and move on to the next one. As this student described, meeting this expectation

went against their humanity, *the feelings stay*. This enforced bracketing suggested a divide between the patient and the physician: the needless physician and the needy patient.

This separation between physician and patient was learned in the classroom and clinic. For example, one student expressed frustration about how patients were treated as a separate species, a “*strange and foreign group of people. They [have] the problems that doctors don’t have.*” (Participant 10, student). Other students noted that the mood changed after they disclosed their disability-related experiences in the classroom, as if they had taken off their medical student disguise and revealed a patient was listening in. Klitzman (2008) described the socialization of the patient-provider divide, noting that “medical education leads doctors to distance themselves, build defenses, and feel immune from death and suffering around them” (p. 12). He argued that this separation from patients is necessary, lest physicians become consumed by exposure to the existential threats inherent to the work and succumb to burnout (Klitzman, 2008). As one school official put it, many physicians maintain a tough exterior in order to “*keep the boat going*” (Participant 16, school official), underscoring the belief that the boat (the physician) might sink if they admitted any level of weakness. Students feared that this bracketing simply pushed down human emotions that did not go away, instead building up over time. Through his study of physicians with significant illness, Klitzman (2008) demonstrated how this imagined divide led physicians to engage in behaviors that harmed their wellbeing, including avoidance of medical care due to the sincere belief that as a physician, they could not become ill (thanks to their “magic white coat”) and non-adherence with necessary treatment regimens that conflicted with their physician schedule. In this divided world between patient and physician, there seemed little space to simultaneously occupy both roles let alone enter medicine actively occupying the patient role.

The patient-provider divide further emphasized the expectation that physicians have no needs. While students learned about how to teach patients to maintain optimal health, they observed minimal allowances within the structure of medical education for them, and their physician teachers, to do the same.

*It’s so funny, getting all the 1st and 2nd year lectures . . . and all of it is about how to have our patients be healthy, and yet we can’t do it ourselves. At all. You know, it’s like, “Oooh, we don’t have time.”* (Participant 1, student)

This divide in expectations between medical trainees and patients aligns with Stergiopoulos et al.’s (2018) discussion of the conflicting “good patient” and “good student” roles in medical-education discourse. Their “good student” role comports with the idea of a superhuman, “one who juggled rigorous academic demands with active social commitments while maintaining excellent evaluations. This student could regularly forego sleep and exercise in the face of higher-priority demands like studying or social activities” (p. 1553). In contrast, the “good

patient” was one who “managed their condition by limiting their activities to prioritize health and self-care” (p. 1553). Similar to the findings of Stergiopoulos et al. (2018) and Klitzman (2008), the students in this study struggled against the conflicting demands of their “student” and “patient” roles, feeling unable to live up to either. Unlike the participants in Klitzman’s (2008) study, who were primarily physicians at later stages in their careers and thus further enculturated into the medical world, the students in this study firmly questioned the wisdom of the patient-provider divide and its effect on medical professionals. As individuals who, for the most part, entered medicine with experience of disability and in some cases because of it, they wondered whether such a divide was beneficial for anyone.

Students tied the expectation that doctors do not get sick to what they characterized as a crisis of burnout, depression, and suicide among physicians and medical trainees:

*You know, we have the highest suicide rate. Ugh, so scary. . . And I feel like the biggest issue is that we can’t come out and say, “Oh, you know, I’m bipolar” and it’s like, “Oh, it’s not a big deal” . . . it’s very difficult to find an actual MD who puts it out there.*  
(Participant 5, student)

Many saw the unacceptability of border crossings between superhuman doctor and needy patient as partially responsible for creating this crisis. They viewed the lack of structural means to allow for self-care and cultural taboos against demonstrating human vulnerability as contributors to the crisis. They believed these institutional factors were at least partly responsible for pushing doctors into states of burnout, depression, and suicidal ideation. Many participating students, like Participant 5, cited the statistics about medical student and physician mental health as a clear outcome of the superhuman standard and a significant concern for their personal prospects. Some of these students entered medicine with a pre-existing mental health diagnosis. If others were becoming unwell under the conditions of medical training and practice, they wondered how they might fare into the future. Extensive research into burnout, depression, and suicide among physicians and trainees, also labeled a crisis by leaders in the field, has found that environmental factors are the major drivers (Dyrbye & Shanafelt, 2016; Dzau, Kirch, & Nasca, 2018). Aligning with some of the items identified by participants in this study that add up to the superhuman standard, a 2016 narrative review identified the following contributory environmental factors for medical students: three or more tiered grading systems (i.e., not simply pass-fail), poor peer collaboration, dissatisfaction with the learning environment, and suboptimal behavior by faculty and staff (Dyrbye & Shanafelt, 2016). Although Dyrbye and Shanafelt (2016) concluded that curricular and clinical hours may not drive medical-student burnout, I suggest that these factors may affect disabled students more significantly than their non-disabled peers (this is discussed further later in this chapter, under The Singular Path).



## The “Real World” of Medicine

The capability imperative is produced and rationalized in relation to the idea of a “real world” of medicine. That is, a site of training and practice that exists outside the protected realm of medical school. Because medical schools educate students to become professionals, eventually students would need to enter this realm and reckon with the conditions therein. This mindset justified orienting practices and educational structures in relation to it. Central to the motif of the “real world” of medicine is that this future place is one that is inflexible, where accommodation of disability is unlikely, or at least significantly more limited than what might be possible in medical school. This reality prompted thinking along the following lines, offered by a participant discussing the prospects of a student with a known disability:

*So, the discussion with the physicians was, “Yes, this is medical school. She will be cocooned here. She will be coddled. But when you put her in the real world, in a residency program that is fast paced, how is she going to survive? Are we doing her a favor by accepting her in medical school knowing that when she goes out into residency, they’ll eat her up and spit her out?”* (Participant 35, school official)

While the school eventually admitted the student in question, who went on to be highly successful in medical school and residency, this depiction typifies the angst prompted by the “real world.” Imagining a student’s potential as a future physician amounted to fortune telling. Following admission and throughout this and other students’ journeys, the angst continued, with each barrier identified and accommodation requested prompting a return to the question of the “real world.”

The “real world” is constructed from situated knowledge, largely that of physicians or medical students with limited or no exposure to disabled physicians’ lived experiences. Thus, the “real world” tended to effectively erase present and historical inclusive realities. For example, as mentioned in Chapter 4, the perceived impossibility of a blind physician erased the long history of blind physicians (Hartman & Asbell, 1978; Hartman & Hartman, 1981, 2008; Keeney & Keeney, 1950; Smith, 2011; Wainapel & Bernbaum, 1986). Without broad understanding of the ways physicians with disabilities have succeeded in training and practice, participants projected a real world based on their own limited understanding of what might or might not be possible.

Furthermore, these perceptions of the “real world” tended to suggest practices were stuck in time, negating the possibility of a different future. For example, when participants anticipated that a student would not be able to maintain the pace of residency, they often also assumed no accommodations were possible. This assumption could limit a student’s opportunities for accommodation in medical school when faculty deemed it important to adequately prepare a student for the “real world.” Or, as several participants described when

recounting a contentious decision at one medical school to permit extended time accommodations during Objective Structured Clinical Examinations (OSCEs, standardized clinical skill exams), this sowed discord among faculty who believed the accommodations were problematic, given their incongruence with “real world” requirements. As described in Chapter 4, in contrast, those with connections to or awareness of physicians with disabilities noted how these experiences, where positive, “*pave[d] the way for openness*” (Participant 38, school official) to disabled-student inclusion. Positive direct experiences with physicians and residents with disabilities, even shared stories of these individuals’ experiences, could assuage fears about future implications. Where lived experiences of inclusion in residency and employment were not positive, however, this could entrench commitments to an inflexible “real world” vision that demanded a superhuman physician.

In summary, the “real-world” construct colored participant expectations for medical students, possibilities for accommodation, and projected futures. The perception of a “real world” raised questions about disabled students’ capability to take on the full range of activities required for the next stages of training and practice. This contemplation occurred despite the legal requirement that schools focus decisions about accommodations on the stated requirements of the current educational program (Laird-Metke, Serrantino, & Culley, 2016). The ways participants viewed residency and practice conditions, in concert with their understanding of disability and inclusion, as discussed in Chapter 4, influenced their engagement with inclusive measures at the level of undergraduate medical education (UME). Even when participants saw inclusive possibilities in UME, many questioned how this would affect the student’s long-term prospects given the perceived fixity, intensity, and inherent inaccessibility of future phases. These perceptions suggested a ceiling to accommodation possibilities that some suggested should be enforced early, even given consideration in admissions decisions so as to not set up students for failure and debt. In relation to their understandings of the “real world,” some students hesitated to access accommodations thinking they should learn to perform without them to prepare for future phases. Even when students did access accommodations or find workable solutions for medical school, they often expressed looming concerns about the next phases of study. That is, perceptions of the “real world” informed the capability imperative. Participants most prominently discussed the “real world” in relation to the residency training environment. In the following section, I describe this domain of the “real world” in order to illustrate how it operated in discussions of inclusion.

### **Surviving the next phase**

Perceptions of residency conditions were central to depictions of the “real world” of medicine. Medical education was only the start for students, to actually become a physician they would need to pass through this high-intensity stage. Although some participants imagined how students could eventually succeed in medical practice, residency represented a pinch point in the learning trajectory that governed access to a more permissible environment. In residency, the trainee is learning but also has service obligations, that is, they also function as an employee. This condition results in significant responsibilities with respect to time and patient care. Participants frequently raised several aspects of residency as “real world” concerns: the broad training requirements within the specialized field, ambiguity of accommodation availability, and duty hour requirements.

Residency represents an opportunity to self-select into a specialty that matches one’s interests and abilities. This specialization led many participants to question the commitment to undifferentiated graduates who must be able to do all things in UME rather than having broad general knowledge and exposure to all areas. Residency training, however, still requires broad learning across a specialty area that may eventually lead to diverse sub-specialization at the fellowship stage.<sup>12</sup> This broad scope of learning in residency was the first factor that shaped ideas of the “real world.” In order to progress through this phase, learners may require accommodations that are later unnecessary due to specialization. Whether residency programs might deem these accommodations permissible was an unanswered question, as this school official described:

*You can easily imagine a radiologist doing general imaging, reading films, reading MRIs, doing most of what a radiologist does with limited manual dexterity for example. But the fact is, to go through a radiology residency and meet all the requirements of a radiology residency, you have to do interventional radiology, you have to do [other areas of radiology] and I don’t think at the specialty level, we haven’t come to the same point of understanding of what’s essential training. (Participant 6, school official)*

The lack of certainty about “what’s essential training” within specialties suggests that determination of accommodations will be uneven across programs, depending on those making decisions about essential components in a local context. Furthermore, in the absence of shared understanding about what is essential in residency and how to evaluate this, all aspects of residency could be construed as essential and, therefore, unalterable in the “real world.” With this viewpoint, participants wondered whether students could succeed even

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<sup>12</sup> Fellowship is the period of training following residency in which a physician elects to complete in-depth, specialized training in a specific area. A physician who completes their residency in internal medicine, for example, may complete a fellowship in cardiology, oncology, or infectious diseases, among other options, to become a specialist in that area.

within a specialty that allowed for more focused practice post-residency. Although participants did not discuss this directly, the risk of such a viewpoint is the possibility of restrictive vocational counseling. That is, without deep exploration, students might be discouraged from pursuing a specialty deemed to have aspects of residency training that could not be accommodated and encouraged to pursue specialties known to be friendlier to disabled applicants.

The ambiguity of accommodation availability in residency was a second factor that shaped ideas of the “real world.” Many participants, students and school officials alike, believed that accommodations were not possible in residency settings and that residency programs would look down upon applicants who needed accommodations in medical school. For example, one participant suggested that the more competitive the residency, the less likely accommodations would be possible, as summarized in the following quote:

*If you're asking for accommodations you better be going into family medicine. Like, the more competitive the specialty, you know? . . . you can't take longer on your residency, you really can't. It's very difficult to get an accommodation.* (Participant 34, school official)

Ideas like this suggested that in the “real world” accommodations were unlikely. When school officials supported these impressions, this perpetuated the question of whether accommodations should be offered to students in clinical settings in medical school. Furthermore, repeating these notions to students reproduced fears of residency and fear of requesting accommodations. Residencies are, indeed, covered by the ADA and must consider accommodations, however, these accommodations need not alter or exempt employees from “essential functions” of the job. Evidence exists that residency programs provide accommodations (Fitzsimons, Brookman, Arnholz, & Baker, 2016; Meeks, Poulos, & Swenor, 2020; Takakuwa, Earnst, & Weiss, 2002), however, a recent study suggested that residency programs are underprepared to provide accommodations for learners with disabilities (Meeks & Jain, 2018). The authors along with four interested physicians sounded a call to action with suggestions for improved practices to this end (Meeks, Jain, et al., 2019). This gestalt of the broad requirements, limited specificity of essential requirements, and perceptions that residencies do not allow accommodations, rendered residency as a fixed place in which students would need to find ways to fit. Should they need accommodations, they would need to find a less competitive residency that might have more built-in flexibility. For unproven UME applicants with known disabilities, prospects for success in the “real world” were more questionable.

Duty hours for residency also suggested a fixed requirement in the “real world” that raised questions about inclusive possibilities. Under the current “Common Program

Requirements” specified by the Accreditation Council for Graduate Medical Education (ACGME, 2018), U.S. medical residents work approximately 80 hours per week, with one in seven days off. Programs can also schedule residents for up to 24-hour shifts, plus four additional hours towards activities such as transitioning patients (ACGME, 2018). That is, in residency, trainees may work up to 28 continuous hours within an 80-hour work week. This policy represents an increase in possible continuous hours for first-year residents that began in 2017. Prior to this, first-year residents could not work more than 16 continuous hours.

According to participants, these maximum workload standards define how residency programs manage their workforce, in anticipation that residents can fully meet them. This expectation makes a reduced pace (e.g., fewer work hours over a longer period of time) as an accommodation appear impossible. If one resident does not fulfill the standard full-duty hours someone needs to pick up their workload, a condition that participants noted would create resentment among already overworked residents. Furthermore, several school officials suggested that the intensity and pace of the residency schedule was essential to learning. The ACGME noted their expectation that the increase from 16 to 24 maximum hours instated in 2017 would permit first-year residents “to more fully participate as members of the health care team, with appropriate supervision” (ACGME, n.d., “VI.F. Clinical Experience and Education,” para. 3). This statement implied that longer shifts benefit learning, following research studying the impact of duty-hour reduction that showed duty-hour restrictions negatively impacted resident education and did not improve patient care (Bolster & Rourke, 2015; Dyrbye & Shanafelt, 2016).<sup>13</sup> Acknowledging the intensity of residency duty hours, one school official suggested that students should simply accept this as inherent to a necessary, but time-limited, developmental stage of learning and let go of expectations for balance or wellness during this time.

While foregoing balance and wellness may be the route many medical residents take, for students with disabilities that affect stamina, or that are negatively affected by insufficient sleep, the required duty hours could appear impossible if not physically and psychologically damaging. For students who took medication with time-limited effect, for example, those with AD/HD, they wondered how they would be able to balance the medication (in)effects with the

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<sup>13</sup> The National Academies of Science, Engineering, and Medicine (2019) report *Taking action against clinician burnout*, however, pointed out that the potential benefits of duty-hour restrictions may have been obscured in research. Noted reasons include work compression, i.e., maintenance of educational requirement and patient care duty levels despite reduced hours (Ludmerer, 2010); stress related to perceptions of reduced preparedness due to reduced opportunities for repetition, exposure, and supervisor impressions; and excessive paperwork and electronic health record demands (Domaney, Torous, & Greenberg, 2018; Eckleberry-Hunt et al., 2009). Furthermore, recent research by Desai et al. (2018) contradicted earlier findings that suggested diminished educational outcomes under duty-hour restrictions.

required schedule. These conditions not only assume a superhuman, who can perform safe patient care under grueling conditions, but also set up conditions for a resident with a disability to be constructed as a problem in the healthcare machine. As summarized in the following quote, many students questioned their ability to succeed in residency if, in fact, the “real world” of residency was as inflexible as constructed.

*I think the main concern as a medical student with the future and whatnot is residency, because we now are able to be scheduled for 24 or 28 hour shifts and my conditions are triggered by stress and unbalanced lifestyles, and unhealthy eating all that stuff that goes on with working a 24 to 28-hour shift. So . . . now I've been looking at options of not doing a residency because of how kind of frightening that future is for me, but that is definitely the biggest concern, that when I get to that point it will just set me over the edge. (Participant 9, student)*

As this student described, the prospect of the “real world” of residency was so frightening, and potentially impossible, they were considering alternatives, despite their strong drive to practice medicine. The “real world” of residency would have significant consequences for their health. Others questioned whether they should take measures such as weaning themselves off medication to avoid “crashes” when medication wore off in order to cope with the required schedule. This was a concerning proposition, given that these students also stated the life-changing benefits they experienced as a result of medication. Concerns about the required duty hours in residency became a reality for one participant who transitioned to residency during the course of this project. In a follow-up interview, the participant discussed the challenges of residency. The program did not have an established process for requesting accommodations. The participant, however, negotiated accommodations to the schedule. The results were not perfect and continued to evolve. The participant’s experience successfully arguing for alternatives to long duty hours, however, demonstrated the unfixed, changeable nature of residency experiences not generally represented in renderings of the “real world” of medicine.

Concerns about the “real world” were heightened among students who were not connected to school officials or peers who were knowledgeable about disability in medicine. Dominant constructions of the future ruled their thinking. Those few with connections to learners or physicians in later stages of training with similar disabilities, in particular, had greater confidence about how they might manage in those settings. That is, the “real world” of residency expanded. They were able to have informed discussions about possible accommodations and the realities of training to guide their preparation. One school official informally connected students with alumni currently in residency with similar disabilities when possible. He recognized that this effort to support informal mentoring was limited, but that he hoped it would offer students better insight into possibilities in residency. Other students actively sought relationships with residents and physicians with disabilities similar to

theirs, a task more fruitful for students with visible disabilities due to the greater likelihood of a public profile among these physicians. Outside of the Association of Medical Professionals with Hearing Losses (AMPHL), formal peer mentorship programs for U.S. medical students with disabilities are not currently available. The Society for Physicians with Disabilities offers a listserv, but this is not very active. The recent social media campaign, #DocsWithDisabilities and the associated podcast have attempted to broaden the public profile of physicians with disabilities and facilitate informal mentoring, including those with less-apparent disabilities (Meeks, 2019; Meeks, Liao, & Kim, 2019; Panzer, Maraki, Cross, & Meeks, 2020).

Reproduction of a fixed “real world,” that did not allow for the flexibility required for disability inclusion, upheld the capability imperative. Kafer (2013) suggested that “the futures we imagine reveal the biases of the present; it seems entirely possible that imagining different futures and temporalities might help us see, and do, the present differently” (p. 28). Indeed, in those situations where participants imagined a different future, new possibilities for medical education opened. Despite concerns about the “real world,” schools admitted and educated students with disabilities with a belief in their possible futures. At least one of these students went on to create new possibilities in a residency program not accustomed to providing accommodations. Still, the most persuasive shifts in “real world” thinking occurred when exposed to inclusive success in practice. To get there, however, often required an individual student who doggedly pursued their own inclusion despite a clear roadmap or guarantee of openness on the part of others. One school official’s statement exemplifies these circumstances, suggesting a passive orientation on the part of the school to imagine new futures:

*I think that it is a culture of access for those who are willing or able to advocate and sort of claw the door open and plant themselves there and say, “Okay, I’m going to participate in this, let’s figure it out.” . . . You can access the culture, it’s not a culture of access. (Participant 19, school official)*

## **The Malleable Student**

Thus far I have outlined the demands placed on the individual and the production of structures that exemplify and reinforce the capability imperative. Within this cultural logic, the individual must be a superhuman, capable of operating in the “real world” of the medical profession. What follows is that the student must fit into the educational structure designed with “real world”-ready superhumans in mind. That is, students must be malleable to the demands of medical education. This was particularly evident through the singular path available to progress through medical school and the approach to wellness that emphasized individual responsibility.

Challenged by the existing structure, which demanded certain hyper-normative physical, psychological, and cognitive performances, students with disabilities often felt like misfits:

*I'm like a round peg trying to go in a square hole or something like that, and because of that then it makes me feel like I don't fit.* (Participant 36, student)

Students, nonetheless, attempted to be malleable, to make themselves fit, or were hammered into shape to fit the existing structure in order to achieve their goal. They did so by acquiring tools to help them fit in, by opting out of fixed environments to do things their own way, or by hacking the existing environment to meet their needs. In chapter 4, I characterized some of these activities as “making do.” In this section, I describe additional strategies students used to achieve malleability. Likewise, school officials designed programs aimed at facilitating students’ ability to fit the environment, including retrofitting accommodations, counseling and wellness programs, and coaching students on study strategies. The experience of misfitting, as Garland-Thomson (2011) suggested, was also fertile ground for politicization, or in Freire’s (1968/2000) term, conscientização, or critical consciousness. Some students, in the face of the capability imperative, recognized their misfitting not as a problem with themselves, but with an environment that had not considered their possibility. In these moments, they attempted to resignify capability, which I discuss further in the next chapter. School officials, at times, joined students in these efforts by pushing against the capability imperative to further a student’s inclusion, or in rarer cases, to shift systems.

### **The singular path**

Under the capability imperative, the expected route through medical education was singular. The system assumed a certain kind of learner who could fit the path, and little flexibility was available to deviate from it. The singular path imagined a student who could start classes early in the morning and sustain learning throughout the day and into the night, over and over again without break. This learner could withstand a barrage of information, able to select the most important information, memorize it, and put it to use. Able to read and process information in harmony with their peers, they learned easily as a group, together with little support. Like clockwork, a class of learners on the singular path could proceed through tasks uniformly, completing notes and interacting with patients, identifying structures on a cadaver, presenting a patient flawlessly without notes. Those who could not fit the path could seek services or remediation to aid their ability to fit. Programs scrutinized these accommodations to ensure one did not diverge greatly from the path, for the path became steeper and narrower, with cliffs on either side during residency. The learner must be ready for the path to come.

This description of the singular path and the cookie-cutter learner is grounded in participant accounts of disabled-student inclusion in medical education. Students described



how the singular path made them feel like “misfits”; it implied a lack of congruence between their bodyminds and the educational environment (Garland-Thomson, 2011). To illuminate the expectation of the malleable student, I will illustrate the most prominent experience of misfitting described by participants: *battling time*.

Battling time was an experience of being out of sync with program schedules and pacing as well as the pace of non-disabled peers. This entailed a constant race against the clock to attend required classes, learn material, maintain clinic duty hours, and contend with inaccessibility. Battling time was pervasive and encompassed the challenge of doing medical school, developing mastery of material, and demonstrating knowledge.

Doing medical school necessitated maintaining (or ignoring) activities of daily living, while accomplishing the schedule demanded of medical students. This could be particularly challenging for students whose daily living needs were lengthy or non-negotiable to avoid symptom flares or secondary health conditions. For example, one student described how their morning physical care routine differed from that of peers and how this interfaced with other requirements of medical student life as follows:

*Just the time schedule . . . the fact that I have to get up at four [A.M.] to get to class at eight [A.M.], other people don't have to do that so they can stay up until midnight or one and roll out of bed and go to class or do what they want to do. So, I feel like I have to be much more responsible with my time. And I'm very worried that that's going to—like even if I am responsible there may be some weeks where I struggle to pass a quiz just because I have no time to study. (Participant 46, student)*

As this student described, their daily regimen butted up against a schedule that assumed a student who could stay up late studying and get to class or clinic early. Between the in-person requirements of the curriculum and the realities of this student's physical routine, little time was left. Many students described how the equation between required time to do medical school plus their baseline non-negotiable needs left little time for things that could enhance their lives, like school-related extra-curricular activities that would bolster their residency applications or exercise that could preserve their well-being. None of the participating schools offered a part-time curriculum option. Some students were able to access accommodations that extended their rotations to allow for a slower pace or skip a block to have a recovery or study period. In the pre-clinical curriculum, all students moved together through “blocks” of course content through the year (e.g., spending several weeks studying the immune system from various perspectives), plus longitudinal courses that extend across the year. This design left few options for diverse bodyminds, reflecting an assumption that students could sustain physically and cognitively in the set schedule. One strategy students used to fit the time restrictions of environment was *using time double*, finding ways to work while resting or study while undertaking other tasks. For example, one student would try to find a bed to rest in

during clinical rotations and read academic articles during that time to keep up; another student re-listened to course lectures while getting ready in the mornings to make more time for studying. Many students noted this type of multi-tasking or other strategies of strict time management as ways to try to fit, but there were limits to the sustainability of these measures with a finite amount of time and energy.

The battle to master material reflected assumptions about the speed and manner that students could process information. Students encountered a high volume of lecture content, readings, and supplementary materials, often characterized in medical education as “drinking from a fire hose.” Notably, an unadvisable, if not impossible, task. Many participants explained that students were expected to learn how to cope with the torrent of information without explicit instruction of how to do so. While it is a challenging process for all students, those who processed information at different rates than the expected norm often felt constantly behind. One student tried to benchmark their learning against their non-disabled peers in an attempt to gauge how much more time they needed to spend outside the classroom in order to match up. They understood this as a continuous process of battling time, with new material constantly piling up.

*I know that things just take a longer time for me and I have to accept that, but it's hard when there are still things piling up. So, if it is taking someone—like they know 80% and I'm at 50%, then I need to know a little more so I have less time, so I am battling time.*  
(Participant 42, student)

In response, students used available resources to facilitate their ability to fit, including learning specialists, which offered individualized strategies to approach learning, and peer tutoring, which offered alternate explanations of course content. Many participating students used a strategy of *opting out*, they did not attend lectures in-person and instead used this time in ways that worked better for their learning. They watched lectures at alternate speeds, supplemented content by moving back and forth between lectures and explanatory videos, websites, books, and creating hands-on materials in ways that filled in gaps, answered questions, and otherwise stimulated their learning. This strategy was used most often by students with learning disabilities and ADHD. Students with physical disabilities and chronic health conditions often maintained strict attendance at lectures despite challenges with time and fatigue as this seemed to better help them with time management. Of course, opting out only worked for components that did not have attendance requirements.

Team-based learning and clinical settings also involved expectations for a certain speed and manner of engagement for students to demonstrate their knowledge. In team-based learning, for example, materials were often presented in one way (e.g., spoken with no visual component) or presented in writing on one computer screen shared by a group. In clinic,

students also had to conform to a specific way of working. The patient presentation was a clear example, where students were expected to orally describe a patient and suggest a diagnosis and plan for care with no notes. In these scenarios, students were often asked spontaneous questions, frequently on a noisy hospital floor. The misfit was clear in students' depictions of their experiences trying to engage with spontaneously-presented written or spoken material or memorize and present patients in specific ways. Often the design of the encounter plus group member or clinical-teacher expectations did not align with the cognitive diversity of the student group. As a result, students often did not have enough time to participate meaningfully with the group learning process, an experience one student described as *being out of sync*.

*For me, small group learning was just awful. . . people would be reading something and before I had the chance to finish they would just scroll beyond it and move on to something else, and it's like, okay, so now I'm not learning anything, so basically it feels like I'm out of tune with the rest of the group and there's nothing I can do about it. And I get criticized for it, I'm trying my best to do better, but people just get tired of it. So, it's like, being out of sync with the group because of my condition is just frustrating.*

(Participant 15, student)

This student's experience reflects not only their own frustration but that of their peers, who expected synchronicity in group-member functioning. The misfit created group discord, a situation that multiple students described in their team-based learning groups. Notably, this student attributed the problem to "my condition" rather than the structure of the exercise, reflecting their understanding of the malleable student expectation. The frustration was directed inwards, frustration with oneself and one's inability to fit (as this student described, "I'm trying my best to do better") within a system that expects a malleable subject. This type of statement depicts the power of the unquestionable singular path. Students who did not fit had questionable worth and were constructed as problems. The structure was essential, a lack of fit reflected a problem with the individual rather than the environment.

In response, students tried to fit themselves in to these environments or fly under the radar of expectations. Students worked with learning specialists to develop strategies such as those to help engage in team-based settings, improve their presentation skills in clinic, and pragmatics training to help them perform expected social behaviors in clinical interactions. One student hacked an existing support service, peer tutoring, to access needed support for clinical skill development that was otherwise unavailable. A few students also used a strategy of *disengaging* from required, non-clinical activities, attending but effectively tuning out knowing that they would not get much out of the encounter. This strategy was especially troubling, as it meant students lost valuable time not learning, risked being clocked by others as disengaged and therefore unprofessional, and required more time later to catch up on

material or develop skills others learned in the moment. At the same time, these students perceived disengagement as the only useful solution, as it avoided revealing oneself as experiencing difficulty fitting in.

Time is a prominent construct in both disability studies and medical education. In disability studies, scholars have recognized how assumptions centered around normative conceptions of time (e.g., time to complete an exam, time to learn something, time to get somewhere, time in a day when someone can get things done) leave disabled people continually behind and cast out of time (Kafer, 2013; Price, 2011). *Crip time*, in contrast, is a radical challenge to the normative speed of the world. As Kafer (2013) described, crip time can reflect the additional time needed to traverse ableist barriers, slower speeds of movement or thinking, but is an “exploded” version of flex time. Crip time is not just giving more time to accommodate difference, it is rethinking normative expectations for being and doing in the world. Kafer argued that, “rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (p. 27). In medical education, the amount of time needed for training has been a longstanding and ongoing debate that reveals the constructed nature of current conditions (Whitehead, 2011). The current challenge to the predominant time-based model of education is a competency-based time-variable model that focuses on the outcome of, rather than time spent in, education (Lucey, Thibault, & ten Cate, 2018). In its inherent recognition of human difference regarding learning, the time-variable model holds some promise for inclusion against the singular path. A recent exploration of time-variable education indirectly acknowledged the potential for disabled learners, noting that in this model “Learners whose personal circumstances, abilities, and life goals allow or require them to master competencies at a different rate than their peers can do so without the fear of failing” (Lucey, 2018, p. 30). Despite the crip-time potentialities of time-variable education, however, Hodges (2010) argued that “much of the current motivation for outcomes-based education is about increasing efficiency, shortening training time, and reducing the overall cost of medical education” (p. S37). Such motivations would disadvantage disabled learners who seek to bend the clock lengthwise rather than compressing it. Current discussions about time-variable education do not directly reference disabled learners and their potential within such a system. Furthermore, reliance on an individualist construction of competence has pitfalls for all (Hodges, 2010; Lingard, 2009), but in particular for disabled learners who may rely on interdependence to achieve competence, for example, using intermediaries or physician extenders (VanMatre et al., 2004). Given Hodges’ warnings and the known pitfalls of design without disabled people in mind, greater engagement is needed to ensure reforms do not engineer disabled people out and instead harness the potential of criping time for all. Furthermore, real change to benefit students with disabilities would likely require more than

just reorienting time; a fundamental rethinking of the capability imperative on multiple axes will be required.

### **Individual responsibility for wellness**

Under the capability imperative, students are required to maintain their wellness in the face of intense and emotionally-draining work. This expectation was directly codified as part of professionalism requirements listed in a school's technical standards. For example, one school's standards stated that "*Candidates are reasonably expected to: demonstrate. . . emotional stability required for full use of their intellectual ability . . . function effectively under stress. . .*" (Technical standards, school 1). A version of this statement appeared in all of the schools' technical standards. This requirement suggested that it was an individual's responsibility, regardless of the structure, culture, or other environmental factors that comprise medical education, to maintain their emotional wellness and manage stress.

Recognizing the crisis of burnout, depression, and suicide in the medical field (Dzau et al., 2018), the participating schools all had wellness programs that offered workshops, individualized support, and events for students. Common activities included tips for healthy eating, painting classes, massage, or training in mindfulness and meditation. Counseling and wellness coaching services were also offered. Some schools had also integrated wellness-related seminars into the curriculum, for example, one school had a panel where more advanced students, faculty, and administrators shared their struggles with burnout, depression, and suicide in an effort to break the stigma of talking about mental health. Students, however, often referred to wellness programs at their schools as "yoga and puppy dogs," mocking the inadequacy of program offerings. At one school they placed wellness-oriented items around the building for community members to use, such as sleep pods, treadmill desks, and biofeedback monitors. School officials explained this was part of an effort to cultivate a culture of wellness, to provide reminders about the importance of wellness and give community members easy access to tools to take charge of their wellness. Review of the websites for participating schools' wellness programs revealed they often promoted their services with terms like "optimizing wellness," suggesting wellness was another thing students must excel in, reflecting findings in Canada by Stergiopoulos et al. (2018). Furthermore, program websites often framed wellness as a responsibility that students must master in spite of and because of the environment. That is, they acknowledged that the stressful environment of medical education and practice might inhibit wellness but nonetheless was crucial to safe patient care.

Aside from counseling services, students characterized the wellness interventions available at their schools as "nice" but ultimately insufficient and momentary. While petting a

dog might help in the moment, it did little to fundamentally change a system that actively worked against their well-being. Students recognized that activities such as healthy eating, regular sleep, exercise, therapy, and social interactions with friends supported their wellness. In fact, students often discussed the indispensable nature of wellness activities to their own wellbeing. In a setting where they were already battling time, however, it felt unfair that their schools promoted wellness maintenance through a personal-responsibility ethos. Students were to find time to engage in these things alongside everything else required during their education. Structural support for wellness engagement was mixed across schools during pre-clinical years, and almost non-existent in the clinical years. At two schools, wellness seminars were required, while at the others, they were optional. At one school, they built in days off between curriculum blocks for rejuvenation and encouraged a culture where students were not always on campus studying. Even at schools that structured wellness into the pre-clinical years, however, the clinical realm left little room for enacting tenets of wellness. Nonetheless, as this student describes, the messages continued:

*I felt like they [the medical school] did really emphasize having balance. . . but when you get to the clinic, we had a session. . . it was surgery rounds, and these guys come up (and they're like, all guys), and they're like, "Yeah, so what I do is that I wake up at 4:00 [A.M.], and I go for a swim at the Y before I come into the OR" and it's like, that's really helpful! That's great advice for wellness, you know, "What?! This isn't helpful!" it's almost like wellness is—they talk about it a lot, but it's just this auxiliary thing that you do to make it okay to deal with all the shitty things you have to deal with.*  
(Participant 28, student)

Despite the long and intensive duty hours during clinical years, the message students received was that they held a personal responsibility to maintain activities of wellness. This mindset suggested that those who do not engage in exercise, healthy eating, and sleep on top of their duties in training are simply not resourceful enough. This was reflected in Derman, Liu, and McLawhorn's (2015) development of an exercise routine that residents could implement during 24-hour call using tools readily available in the hospital, such as kettle bells assembled from irrigation bags, a stockinette, and perineal post-foam. They note, "even with a work week limited to 80-h[ours], residents may find it difficult to routinely dedicate their free time to exercise" (Derman et al., 2015, p. 295). At the schools, like in this paper, rather than addressing the structural conditions, or creating an environment more conducive to well-being, wellness amounted to responsabilizing individuals to cope with a sick system. The coping strategies offered often seemed unrealistic on top of the expectations of medical education, with or without experience of disability.

Although students characterized wellness and related concerns as important for all medical students, they asserted that proactive and inclusive wellness-oriented activities were

indispensable to their functioning as disabled medical students. These included activities such as therapy, exercise, the ability to cook certain foods, and the ability to spend time with family and friends. One student described the indispensable nature of exercise to their everyday functioning:

*Medication helps wonderfully, but exercise is, at least for me, what shows the biggest difference. When I'm getting to do high-intensity exercise on a semi-regular basis? Oh, it's a whole world of difference too. So prioritizing self-care that way? It's as if self-care has more of an impact on focus on people with AD/HD. So, it's an extra layer of "take care of yourself" or an extra layer of consequences, or at least immediate consequences that the student has to deal with. (Participant 4, student)*

Many students echoed these higher stakes for not engaging in self-care. Students attempted to find time to hold on to these critical activities. In the context of battling time within the fixed curriculum, however, making time for self-care was even more challenging and often meant choosing between important activities (study time, leadership opportunities, research projects, networking events, recreation). The challenge of misfitting, the inability to be sufficiently malleable to the environment, had compounding effects.

As a result of their observations of and experiences with wellness-oriented rhetoric at their medical schools, students felt the efforts merely paid lip service to the concept of wellness. The perceived lack of attention to deeper structural issues with responsive rather than proactive measures signaled a lack of real commitment to the tenets of wellness. Several students found that despite their school's stated commitment to wellness, even the responsive measures did not align. Some students, for example, reported difficulty accessing mental health services during their clinical rotations, having been told that it was not possible to give students release from clinic for therapy appointments. This was in contrast to other schools that had designed their student mental health services to allow for appointments outside of traditional hours (i.e., after a clinical rotation shift). Even in this arrangement, however, self-care was an additional thing to do after a very long day, rather than something that could fit into the everyday. One student started a peer support group around mental health and wellness and joined forces with another student to create a forum to share lived experiences of depression in training with peers. In the peer support group, students had discussed structural measures that could better their experiences, and they planned to share them with administration. At other schools, students longed for more robust, structured peer support that held space for discussions of mental illness (currently marginalized in peer-support offerings).

Across schools, almost all students wanted structural change to shift conditions towards preservation of student wellbeing. Students' experiences of wellness programming resonate with Meeks, Ramsey, Lyons, Spencer, and Lee's (2019) identification of mixed messages about wellness in residency programs. Meeks, Ramsey, et al. (2019) identified a mismatch

between professed care for physician well-being and the reliance on individual responsibility rather than implementation of structural measures. The demand for individual resilience in the face of environmental conditions reinforced the capability imperative.

In contrast, school officials often expressed pride and excitement over the wellness programs available at their schools, many of which were the results of their own efforts to expand student support services. They almost uniformly expressed deep concern about the crisis of burnout, depression, and suicide in the field and acknowledged that this was a symptom of a larger cultural problem in medicine. To them, however, the wellness activities seemed to represent a shift in the historical cultural silence about wellness. Simply talking about self-care and actively providing tools to aid students felt like a good start to changing the culture in medicine. This quote from a school official represents a common perspective among school officials:

*Well, there is a part of the old guard learning process that is, you know, “I walked up hill both ways in the snow to school and so are you.” That is slowly disappearing, we are changing, you look around here we do things for the students. We are bringing a pony in . . . we have the sleeping pods, we have the relaxation area, we have all kinds of mental health activities, we have sleep study stuff. . . the gym, the yoga, the boot camp . . . So, we don’t just pay lip service, it’s there, the resources are present. (Participant 14, school official)*

When pushed, however, school officials often did acknowledge that the current wellness programming was largely individually-focused and did little to address the structural conditions that harmed trainee and physician well-being. Many noted that these conditions were deeply-rooted in the structures created by the profit-oriented healthcare system, the larger structure of medical training, and the hierarchical structure of medicine. Thus, they deemed them very difficult to change. Furthermore, they noted that as medical schools, they lacked direct control over clinical training environments and so their greatest influence was on the preclinical years and giving students tools to manage in the clinic and on into residency. While many school officials expressed a desire for change, the problem seemed bigger than they could address, if not impossible in the current system. Given the “real-world” conditions, they aimed to support students as best they could. They had hope that interest among organizations such as the AAMC and initiatives such as the National Academy of Medicine’s (NAM) Action Collaborative on Clinician Well-being and Resilience (2019) signaled a larger movement that had potential to not only promote individual wellbeing but build momentum to address the structural conditions. School officials anticipated that such systemic change would take time. Given the current conditions, moreover, the question of disabled students’ capability to endure medical training and practice remained. Many school officials recognized the bind students with disabilities are in, needing space to do things differently in a system that



does not easily allow for it. Without meaningful change, the capability imperative and its demand for malleable students, in command of their wellbeing against all odds, remained.

## **Conclusion**

I have argued that a context-specific manifestation of compulsory-ablebodiedness and able-mindedness (McRuer, 2006)—the capability imperative—underpinned participant experiences and understandings of medicine. The hidden curriculum of medicine, embedded in policies, structures, interpersonal interactions, and cultural representations, illuminated the capability imperative, which is characterized by three motifs: the requirement for selfless superhuman physicians, a purported “real world” of medicine, and expectations for a malleable student. The capability imperative required students to conform and perform in pre-determined ways that frequently rendered students with disabilities misfits (Garland-Thomson, 2011) in medicine.

Superhuman standards were codified in technical standards and enforced through interpersonal interactions and structures that emphasized competition, demonstrating one’s abilities while covering uncertainty or inability, and suppressing any individual need. The “real world,” believed to exist in residency training and practice, expected superhuman abilities while lacking the flexibility to allow for accommodations. Participants who believed these conditions represented reality questioned disabled students’ potential to succeed. This could affect requests for and provision of accommodations in medical school, advice to students regarding the transition to residency, and perpetuate fear regarding the next stage of training. The demand for malleable students prescribed a singular path through medical education. In light of this, students with disabilities found they often misfit the expectations, most prominently in finding themselves battling time. In response, they tried to find ways to fit (or appear to fit): strategically using time differently, utilizing support services or alternate resources to develop skills to better fit expected ways of working, and disengaging from tasks to avoid detection.

The malleable student motif also responsabilized individuals for their wellness, regardless of larger, systemic conditions. Schools offered interventions for self-improvement and the optimization of wellness. Those with disabilities found that activities of self-care were indispensable for their wellness but challenging to uphold under conditions of battling time. School officials argued that wellness programs signified improvements within medical environments. However, students and school officials agreed that existing efforts towards wellness were insufficient to address structural factors that affected learner and physician wellbeing.

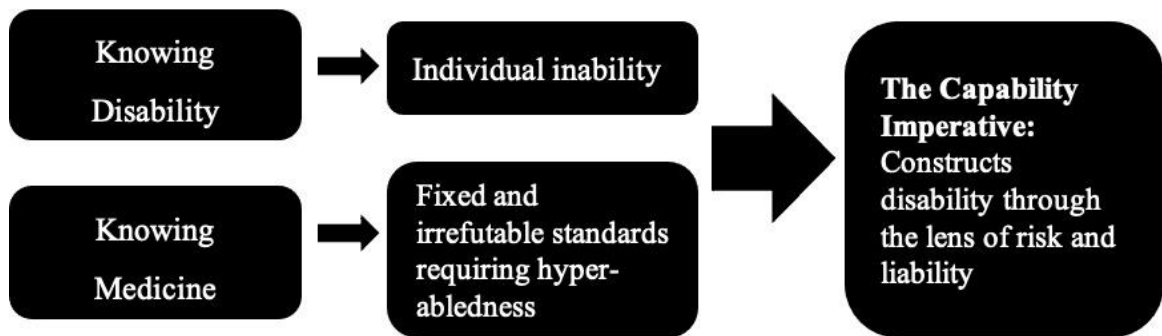
The capability imperative in medicine operated as a cultural logic that demanded certain kinds of behavior from individuals and institutionalized them into structures of medical education, training, and practice. This reinforced and interacted with the ways of knowing disability described in Chapter 4, where I argued that participant actions were undergirded by a dominant understanding of disability as individual inability. In the next chapter, *Negotiating the Capability Imperative*, I bring these two ways of knowing together to illustrate a theory of how inclusion operated at these schools and its implications.

## Chapter 6. Negotiating the Capability Imperative: Precarious Inclusion in Medical Education

### Introduction

In the previous chapters I outlined the two key forces that influenced the inclusion process in medical education for participants: knowing disability and knowing medical education. Through these descriptions, I have established that particular discourses dominated the settings. In terms of knowing disability, the dominant discourse positions disability as individual inability. Concerning knowing medical education, the dominant discourse posits that the standards of medical training require hyper-abledness and are fixed and irrefutable. This discourse effectively embeds *the capability imperative*, under which disability becomes a liability (Figure 6.1 represents these relationships visually).

**Figure 6.1: Tracing dominant discourses**



In this three-part chapter, I theorize that in the context of these discourses students and school officials enacted disability inclusion through a process of *negotiating the capability imperative*.

The first part of the chapter argues that in the presence of the capability imperative existing mechanisms for inclusion present a risk to students' capability. The accommodation process poses a paradox: the promise of beneficial change paired with the possibility of diminished capability. Each student is required to negotiate personal accommodations without systemic change. Change is not guaranteed as accommodations are contestable. Disabled students, therefore, occupy a position of sustained precariousness. As students move through new training environments and encounter novel barriers, their capability is continually questionable.

The second part of the chapter argues that participant actions to negotiate the capability imperative were reflective of their perception of malleability in the social environment and were highly informed by notions of risk. I describe how participants assessed risk and took action in the face of barriers, typified in three ways: *upholding the capability imperative*; *working the capability imperative*; and *resignifying capability*. The first type represents participant actions aimed at fitting students into existing medical education structures and

standards without systemic change. The second includes participant actions to make or seek individualized exceptions to medical education structures in order to allow students to meet existing standards. The third, which has some overlap with the first two types, includes actions taken with the aim to fundamentally change the conditions that create risk in order to invite new possibilities.

Part three of the chapter argues that there are three key implications of negotiating the capability imperative. The first implication is that the process reveals an ableist hegemony that constrains inclusive action. Theories of ableism and compulsory abledness (Campbell, 2001, 2009a, 2017, 2019; McRuer, 2006) and Butler's (1988, 1990, 1991) notion of performativity are used to explicate this argument. Through these lenses, I discuss the opportunities and limitations for greater inclusivity within a system driven by negotiation. The second implication is that individualized inclusion mechanisms are insufficient to disrupt performative acts of hyper-abledness. Critiques of accommodations and other individualized mechanisms of inclusion develop this argument (Dolmage, 2017; Graham & Slee, 2008; Hibbs & Pothier, 2006; Titchkosky, 2011). I discuss how individualized approaches Otherize disabled students while promising their inclusion. The final implication is that meaningful inclusion remains elusive. Despite advancements, the current conditions constrain inclusive possibilities and the promised benefits of diversity to medicine. I engage critiques of legislative mechanisms of inclusion to develop this argument (Mitchell, 2016; Mitchell & Snyder, 2015). Ultimately, I argue that current conditions follow a logic of *inclusionism* (Mitchell & Snyder, 2015)—a logic that demands interrogation and transformation.

## **Part I. Precariousness**

The previous two chapters have laid the context of disability inclusion in medical education. Participant descriptions of their ways of knowing medicine and disability revealed the precarious position of students with disabilities in medical education. As described in Chapter 4, the dominant conceptualization of disability as individual inability made students alert to their potential for stigmatization should they reveal their disability status. For school officials, this understanding raised questions about students' ability to succeed in medicine, supported the use of individual solutions for access, and animated the need to shield disability information from faculty and naturalize accommodation use among students. As described in Chapter 5, the capability imperative in medicine necessitated a hyper-able superhuman, malleable to inflexible conditions in the "real world." Students found themselves frequently misfitting the conditions of medical education. Thus, disability became a potential liability in medical education. Although inclusion mechanisms were available, they were conditional and largely reliant on individual knowledge to unlock their potential. Student experiences of

disability services were highly dependent on how legible their disabilities were to school officials and, for the most part, inclusion was handled responsively.

In these conditions, the inclusion of disabled students in medicine was precarious. Students understood that to reveal disability and ask for change is to mark oneself as different, possibly unable, and not belonging in medicine. To do nothing, however, may ensure their incapability. From the position of school officials, this precariousness was driven by the uncertainty that disabled students could fit the expectations of medical education and that medical training was sufficiently malleable to accommodate needed changes. Alongside this, school officials tasked with disability inclusion understood that differing openness to accommodations among faculty could limit inclusive possibilities. As non-standard accommodations were determined case-by-case, the outcome of each request was uncertain.

### **Continually precarious**

Precariousness was not something students experienced only prior to gaining admission or entering into a process to access accommodations. Even after they accessed some accommodations, students remained on the edge. As they progressed through medical school, they might encounter additional barriers. Each new barrier carried the possibility of foreclosure. A student's capability was a constantly shifting variable that would be re-negotiated, re-assessed, and barrier removal re-adjudicated at each stage of training. Students with highly-legible, readily-apparent disabilities particularly noted this concern. These students understood that their schools had taken a chance on their potential success. Despite positive working relationships with their schools thus far, these students nonetheless understood the fragility of these relationships. They were highly reliant on school officials to support their continual inclusion in medical school and into residency. Furthermore, each of these students described the perception that their experience would have consequences for the future students like them who followed, meaning it was not just their position that was precarious. One student described this feeling:

*I think having [technical standards] makes it more stressful for me. . . Like, knowing that this was something that potentially could have barred people like me from going to medical school . . . You're the "prototype." If the prototype "doesn't work," it's not going to go into further development for subsequent groups of people. (Participant 46, student)*

As this student described, the existence of technical standards against which their capability was continually judged not only created an individualized stressful sense of precarity but also for others. Serving as a "prototype" of possibility raised the stakes to prove that students with disabilities deserved a place in medical school. As discussed in Chapter 5, technical standards

were just one vehicle that communicated expectations that medical students embody the selfless superhuman motif of the capability imperative, able to be and do all things.

### **The accommodations paradox**

In the encompassing presence of the capability imperative, the individual nature of accommodations created a paradox. As described in Chapter 4, recognizing oneself as disabled was a minefield. To achieve access, students needed to claim recognition as disabled, a “spoiled identity” (Goffman, 1963) that brought their capability into question. Requesting accommodations also raised the possibility of unintended, adverse consequences. Dolmage (2017) analogized the accommodations process in universities to a game of battleship, where students launch personal information into a void with uncertain and possibly negative consequences. In this void, students imagined the “worst-case scenario,” wherein they exposed their disability or disabling barriers, thereby violating the capability imperative, only to find that no accommodations were possible, or that approved accommodations disadvantaged them in the environment. Imagining the stigmatizing effect of accommodations was thus a barrier to requesting them. Although schools made some attempts to destigmatize accommodation use, these efforts were not always effective. Students largely operated on their own understandings formed through historical experiences, social networks, and socialization, which tended to reinforce stereotyped understandings of disability as associated with inability and risk to capability.

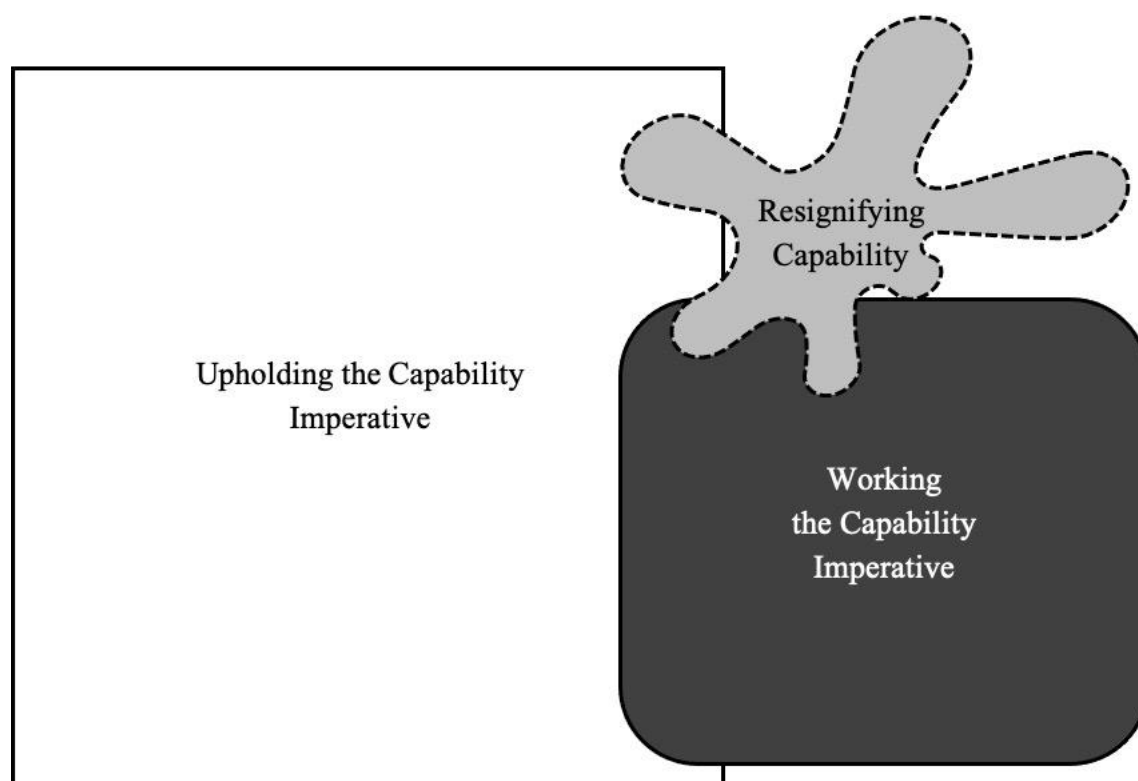
### **The process of negotiation**

Negotiating barriers to inclusion was a continual process for all participants. Recognizing their precarious position, students negotiated the capability imperative with the intention to preserve their capability in the eyes of others. Some students also acted to change conditions for the collective. School officials entered negotiations when they became aware of a barrier to disabled student access. The motives for their negotiations were caught between preserving the integrity of the academic program and the medical profession, their legal responsibility to ensure equal access, and at times inclusive personal or institutional values.

Participants engaged in three kinds of negotiations: *upholding the capability imperative*, *working the capability imperative*, and *resignifying capability*. The first category entails managing without asking for change, assisting students to meet existing requirements without change, or blocking access to environmental change. The second category typically involves engagement with accommodation processes. The third category includes actions that had the potential to disrupt the capability imperative and shift conditions for learners with disabilities. While it may seem as though the first two categories cannot resignify, they do have some potential to do this. Remaining silent, for example, can resignify insofar as an individual

appears capable without the need for change. Figure 6.2 depicts these ways of negotiating. The shapes used represent the level of environmental malleability imagined or insisted by the respective action, with *upholding* representing the most rigid and *resignifying* representing the most malleable. The size of the shape indicates its dominance in the context, with *upholding* the most dominant form of action, followed by *working*, and *resignifying* the least dominant. *Resignifying capability* has a permeable boundary, indicating that actions to *uphold* or *work* the capability imperative may also *resignify* capability. The three shapes overlap, indicating that individuals may act in some ways to *uphold the capability imperative* while also taking action that *works* the capability imperative and/or *resignifies* capability.

**Figure 6.2: Categories of negotiation**



**Image description:** Three overlapping shapes are depicted: a traditional square labeled “upholding the capability imperative,” a square with rounded corners labeled “working the capability imperative,” and an organic, asymmetrical shape with rounded edges labeled “resignifying capability.” The *upholding* square is larger than the other shapes, and the *resignifying* shape is smaller than the other two. The three shapes overlap each other. The *upholding* and *working* shapes have solid boundaries, while *resignifying* has a dotted-line boundary.

## Part II. Negotiating Risk and Resignifying Capability

When faced with disability-related barriers in medical education, participants assessed the risk of seeking change. The precariousness described in the previous section ensured that assessments were oriented towards avoidance of the worst-case scenario: incapability or incompetence. Perceptions of available options and their perceived consequences depended on individual understandings. Each participant’s understanding was influenced by shared

knowledge, subject to legibility, dependent upon social networks, social location, and contingent upon one's perceived power to change things. That is, the scope of possible actions was relationally and socially situated and, therefore, partial (Haraway, 1988; Stoetzler & Yuval-Davis, 2002). Actions informed by the risk assessment ultimately operated within a narrow frame: the available mechanisms to address disability inclusion (i.e., primarily accommodations) and existing social conditions. Three questions illustrate the ways participants approached this assessment:

- Is change necessary? For students, this included an assessment of whether one could manage on their own and whether their performance would suffer without change. This was also informed by a student's understanding of the requirements and settings of medical education. For school officials, this included an assessment of their responsibility to foster change according to legal requirements and institutional missions. This was also influenced by their understanding of the student's disability and the requirements of medical education.
- Is something different possible? This was informed by one's knowledge of disability, rights, access, inclusion mechanisms, and accommodations and their possibilities in the medical education context. This also included an assessment of one's power to facilitate the needed change.
- What will it mean? This entailed querying the possible consequences of asking for or accepting change to one's status and reputation, and in some cases for similar others who follow. For school officials, this also included an assessment of perceived administrative and financial consequences, patient safety, and impact upon academic integrity and the profession.

Having evaluated these questions, participants negotiated the capability imperative through three kinds of action: upholding the capability imperative, working the capability imperative, and resignifying capability.

The following example illustrates the risk assessment process from the perspective of one student. This student was diagnosed with AD/HD early in medical school and had an earlier diagnosis of depression. The student had declined a suggestion to seek AD/HD testing as an undergraduate, noting that at the time the student did not believe they could have the diagnosis. Their achievements, thus far, including attainment of medical school admission without treatment or accommodation, suggested that they could not have AD/HD. The student's knowledge of AD/HD was informed by prior experiences with individuals who did not succeed academically. After struggling academically in their first year, the student sought evaluation for AD/HD, was formally diagnosed, and began taking medication. In pre-clinical years, they used extensive self- and environmental-management to support their learning:



studying in a dark room to achieve focus, managing their physical position in public spaces to avoid distraction, orienting study around their medication schedule, and more. Prior to entering the clinic, the student had disclosed their diagnosis to a mentor, who suggested that, while the student may struggle with some aspects of clerkships, they would be fine. The mentor did not suggest that the student seek accommodations. Now in the clinic, the student struggled with maintaining focus on rounds in noisy hospitals, managing medication effectiveness during long shifts, and completing tasks in the shared workroom. The student's ability to complete patient chart notes and engage in necessary studying was hampered by the environment; that is, they recognized a barrier that posed a risk to their capability. The student identified several options that might help: they could wear noise cancelling headphones or seek formal accommodations to have a separate charting area. But what would this mean? Like many other students who described this risk assessment, the student imagined the "worst-case scenario." The student was concerned that exposing their disability would risk their perceived capability, or that approved accommodations would disadvantage them in the clinical environment. The student explained:

*I really am hesitant to [ask for accommodations]. . . . I don't want to have special needs or something in a team-based setting. That makes me feel like I'm not as good as other people. . . . I guess I sacrifice it [the possibility of access] to not have to deal with those social problems maybe? (Participant 28, student)*

Imagining the stigmatizing effect of accommodations was thus a barrier to requesting them. Furthermore, in a previous rotation, a private room for charting was available. When the student opted to use it, however, they felt disconnected from their clinical team, missing out on spontaneous conversations and opportunities that occurred within the shared space. Using noise-cancelling headphones in a shared space, however, could be perceived as aloof behavior. Han et al. (2015) identified the importance of impression management in clinical learning, where students needed to be seen as available, interested, and engaged in order to earn learning opportunities and positive evaluations. The student did not see suitable options for change based on their understanding of what was possible. At the time of our interview, the student had decided to wait and see how things progressed. They would try to persist in the existing conditions and seek additional options if their performance suffered further.

The preceding example of one student's risk-assessment process demonstrates the tensions at play in negotiating the capability imperative. The individual's understanding of the possibility for beneficial change influenced their decision making about the best course of action. In the following sections, I characterize the types of actions participants took to uphold the capability imperative, work the capability imperative, and resignify capability. I bring

together concepts developed in the previous two chapters to explicate these categories of negotiation. For ease of reading, I do not cross reference each time.

### **Upholding the capability imperative**

Upholding the capability imperative followed the call for a malleable student. When individuals upheld the capability imperative, their actions were precipitated by low expectations for the possibility of change, perceived inability to affect change, and the perception that change would negatively impact the individual or the medical field. Belief that change would erode the final competencies of a medical graduate also supported actions to uphold the capability imperative. What followed this belief was a need, to the greatest degree possible, for the student to fit existing expectations. In the following sections, I discuss student and school-official actions taken to uphold the capability imperative.

#### ***Students making do***

Students upheld the capability imperative by *making do* in existing environments. They raised concerns only when they could not self-manage and this would significantly impede their participation. In general, the aim of these actions was to find ways to fit into existing structures while maintaining academic standing and positive relationships. Upholding the capability imperative, then, reflected a considered decision. This entailed weighing the personal, interpersonal, financial, and administrative impact of requesting change in light of lived and known experiences. On balance, finding ways to meet expectations without requesting accommodations appeared the best solution.

In this and the previous two chapters, I have described students upholding the capability imperative by minimizing their needs and figuring things out informally. The prior illustration of the risk-assessment process exemplified a student upholding the capability imperative. Participant 28 did not seek accommodations in order to fit the requisite role of a capable clinical team member. Many students already accessing accommodations also minimized their needs. Those with the most legible disabilities minimized their needs to maintain a good relationship with their school, even when their current relationship was positive. Students in legible and illegible positions frequently upheld the capability imperative when they believed there was no available or acceptable solution to resolve a disabling barrier. In these cases, students upheld the capability imperative through strategies such as using time double, opting out, and disengaging. They also utilized existing support services such as therapy, learning specialists, and tutors to help them fit existing expectations.

Upholding the capability imperative encompassed strategic acts that entailed extra work on top of the already-challenging condition of battling time. These actions often required background work, at times navigating complex administrative systems, in order to avoid

detection as questionably capable. One student's decision to informally organize accessible parking at a clinical site depicts the catch-22 of upholding the capability imperative:

*I'm trying to shine in my rotation like every other medical student . . . and I am spending a whole day dealing with parking . . . If I had called ahead of time and [asked] "What is the parking going to be like there?" it is like a red flag. "Okay, she is not even here yet, she is not even in residency, and she is already asking for something." . . . I want them to know that they don't have to do anything. But then . . . days happen where I just cry because I'm frustrated that things are hard. (Participant 44, student)*

Student attempts to self-manage often took time and energy away from their academic performance. If they asked for change, however, their capability could be devalued, and they could be labeled demanding or difficult. While frequently acknowledged by students as an unreasonable burden, making do felt necessary given the high stakes of the environment and their precarious status within it.

Some instances of students upholding the capability imperative illustrated Marcus' (2004) assertion that "Disability is not a brave struggle or courage in the face of adversity. Disability is an art—an ingenious way to live" (p. 59). These actions entailed creative problem-solving through disability. While the end result was an attempt to fit expectations, the means were distinct and disability-informed. In one example, the inaccessibility of gross anatomy tables inhibited a student's ability to fully participate in dissections. Believing that an accessible table did not exist, the student carefully prepared for each dissection. This ensured they would be the most knowledgeable group member, able to direct classmates through the process and lead teaching sessions. The student leveraged their strengths, earning their place as a valuable group member. Simultaneously, the student's inability to fully participate in hands-on dissections, a condition that might raise questions of meeting technical standards, was neutralized. This approach also resolved the issue of the inaccessible table unceremoniously, an important factor for the student. This type of action hinted at the potential for upholding the capability imperative to also resignify capability, which I will discuss more fully in a later section. While important to celebrate, like other upholding actions, these creative strategies represented workarounds for unresolved systemic barriers.

Martimianakis and Hafferty (2016) suggested that revealing workarounds can provide fruitful space for critical analysis to drive systemic change. They noted, however, that revealing these strategies may be dangerous as they occur outside the bounds of sanctioned practice. Revealing make-do actions may indeed be dangerous for students, who engage in such activities to avoid detection. Understanding where students are making do, however, is critical to identifying persistent inequities in educational environments. The additional time and labor spent in workarounds, for example, may result in students passing but underperforming and inhibit change in physical or curricular structures that could enable

students' fluid participation. Many school officials were wholly unaware of the workarounds students deployed, often believing that, because students brought some issues to their attention and were not failing, they were ensuring full access for students. Students' deft maneuvers, however, by design concealed significant background work. Like ducks in a pond they appeared to sail along, while below the surface they furiously paddled away.

### *School officials upholding*

School officials upheld the capability imperative by expecting students to fit current environments or aiding them to do so. I have discussed some manifestations of this, such as firewalling, centering the “real world,” maintaining a responsive approach to accommodations, facilitating students' ability to fit (e.g., through learning support, counseling, and wellness services), and limiting accommodations. These actions were generally driven by school-official beliefs about disabled peoples' abilities and the malleability of medical education.

School-official actions that upheld the capability imperative reflected a strict compliance approach to inclusion and prioritized assimilation into the existing medical-education structures. The strict compliance approach interprets legal requirements conservatively, intimating that schools need only enact the letter of the law. Legislation requires that accommodations are “reasonable” and students are “otherwise qualified” for program participation (ADA, 1990; HHS Nondiscrimination, 1977). Furthermore, schools are only obligated to respond to student requests for accommodations. The law does not require proactive systemic change to foster inclusion, although it does not prohibit this (General prohibitions against discrimination, 2016). A strict compliance approach, then, limits the responsibility for program change and suggests that students must fit fundamental expectations of the field of study. Actions that upheld the capability imperative may be legal but demonstrate the limits of adherence to legislation. The law does not recognize that “otherwise qualified” standards may be based on ableist expectations of an ideal student or practitioner (A. Taylor & Shallish, 2019). Thus, organic technical standards, limited accommodations, and “real world” visions may indeed be considered legal but circumscribe a narrow vision of medical practice. The law also does not account for the social barriers to requesting accommodations. When school officials maintained a responsive approach and limited information about accommodations, this followed the logic that inclusion can occur despite the oppressive climate under the capability imperative. This logic, furthermore, assumes that students enter medical education with equivalent and high-level knowledge of disability rights for medical education. Juxtaposed with student perspectives, however, these assumptions did not bear out. When school officials limited information about

accommodations, maintained a responsive approach, and centered the real world, this gave students reason for pause in their requests for accommodations.

While the drive towards assimilation was present in each upholding action, it was most central to practices characterized as firewalling and facilitating fitting. Both types of action recognized current conditions were problematic for students with disabilities, but instead of changing the context, they aimed to change the student. Firewalling practices concealed disability and accommodation use from evaluative faculty and administrators in order to minimize stigmatization. Facilitating fitting recognized the inaccessible conditions of medical education and provided coping strategies to assist students. Students acknowledged that both types of action were useful to their educational journey. Nevertheless, these actions positioned change at the level of the student, who must be molded to fit the expectations of medical education and practice.

School-official actions that upheld the capability imperative were motivated by particular beliefs about disabled people and medical education. A disabled-school official's statement regarding their school's incremental, but insufficient progress towards inclusion encapsulates one motivation to uphold the capability imperative:

*I totally understand there are politics here and you have to navigate between people who still don't—even though we now have plenty of successes, they still don't believe we can do it. (Participant 24, school official)*

Actions to uphold the capability imperative reflected disbelief in disabled people's abilities to be successful physicians, despite longstanding evidence to the contrary. At times, as in the reflection of Participant 24, this persistent disbelief resulted in measured policy change. Upholding the capability imperative was also reflective of disbelief in the medical field's willingness or ability to change. In either case, these conditions maintained and reproduced the hegemony of the capability imperative.

Actions that upheld the capability imperative operated as a disciplinary force, suggesting that hyper-normative expectations were unchangeable. Actions were closely animated by the imperative: students attempted to fit, and school officials created policies, practices, and services that centered hyper-ability. This was the case even when participants acknowledged the damaging effects of those expectations. At the same time, students who fit could maintain their status and avoid Otherizing discourses. Participants were not, however, simply subject to the disciplining force of the capability imperative. Some also actively worked the concept, through attempts to reveal that individual changes to existing conditions could buoy capability.

### **Working the capability imperative**

Working the capability imperative entailed seeking accommodations so students could meet existing requirements differently. Rather than finding ways to fit, actions in this vein assumed that there was some possibility for environmental change. Actors worked the capability imperative when they believed that conditions could change and that other institutional actors would accept such change. Such actions demonstrated belief that the change would not negatively affect the medical graduate's competence. In some cases, however, action followed from need; the student would fail if something did not change or the institution would be liable for not changing. Similar to upholding actions, maintaining one's capable status motivated working the capability imperative. In this section, I discuss student and school-official actions to work the capability imperative.

#### *Students seeking accommodations*

Seeking accommodations was the primary way students worked the capability imperative. In Chapter 4, I discussed factors that influenced students willingness to seek accommodations, including recognition of oneself as disabled (in the legal sense) and belief in the beneficial possibility of accommodations. In other words, when students believed that a solution was possible and reasonable, they were more likely to pursue change. These understandings were moderated by previous use of accommodations, knowledge of disability rights, and shared knowledge from one's social network. Understandings were, therefore, inconsistent between students, reflective of their social location, legibility of their disability, their historical experiences, and their social networks. This had particularly complicated outcomes for students with intersecting marginalized identities, who contended with the colluding forces of racism, ableism, and sexism.

Whether students sought accommodations was dependent on perceived risk. Some accommodations were framed as standard, frequently used, and thus less risky to pursue. Less frequently-used accommodations were deemed non-standard and presented greater risk. Requesting non-standard accommodations occurred when the student knew someone else had achieved similar change or an influential other suggested such change was reasonable. One student's account of their admissions interviews demonstrates the persuasive impact of such information:

*If they were nervous about accommodating me, I could say, "I talked to these five different people. . . at these five schools and this is how they were accommodated." Then people were like, "Oh, I didn't even know that there were other schools doing this." But if I hadn't been able to say that, I don't think they would have been reassured.*

(Participant 10, student)

As this student described, evidence of other schools' practices could legitimize different ways of doing medicine. When students successfully accessed non-standard accommodations, they reformed others' understandings of capability in medical education. This illuminates how working the capability imperative could also resignify capability. There are obvious tensions to this way of shifting capability. Not all students had access to a network of disabled peers or outside mentors, which presented inequities. Furthermore, the relative invisibility of others' accommodations and inconsistent sharing of accommodation possibilities meant that working capability may benefit only one student.

When inclusion practices reflected a collective project centered on possibility this was a productive opening to work the capability imperative that could spark innovation. Many school officials, however, maintained a responsive stance to students' requests. Without a collaborative approach, attempts to work the capability imperative were less successful and often more laborious for students. Furthermore, students' careful assessment of the implications of asking for change produced risk-averse action. This meant that students were more likely to make do than to seek change, meaning that attempts to work the capability imperative might be delayed and academic performance might suffer in the interim. When school officials lessened the burden of seeking accommodations and demonstrated an ethic of care for students, this reduced barriers to working the capability imperative.

### *School officials naturalizing and extending accommodations*

School officials worked the capability imperative in two ways: naturalizing accommodation use and extending accommodation practices. I have described these types of action in detail in Chapter 4. To recap, in the first type of action, school officials advertised disability services to legitimize its use, reduce associated stigmatization, and make students aware that supports were available. Some students validated this practice, noting it provided the opening they needed to speak to someone about the barriers they encountered or anticipated. In the second type, school officials attempted to improve the quality and reach of accommodations. These actions attempted to remove barriers to accessing accommodations and improve their palatability by addressing the perceived risk to seeking or implementing change. Some school officials also pushed against the status quo to extend the kinds of accommodations allowable, often using their knowledge of the law, peer institution practices, and the support of higher-level school leaders. Working the capability imperative pushed forward the possibility for accommodations, most notably in the cases of students with physical disabilities with whom school officials made collaborative, proactive efforts to ensure students' inclusion. Other actions, such as hiring a disability specialist for medical education, extending the reach of accommodations into previously disallowed spaces, and revising technical standards with the

aim to allow more students access to medical education worked the capability imperative at a systemic level.

These actions followed a “spirit of the law” approach to inclusion that broadened institutional responsibility to facilitate inclusion and moved away from the rigid nature of compliance by prioritizing equity goals. These acts, however, were inconsistently applied and remained contested among school officials. When some school officials upheld rigid notions of capability, this could block attempts by others to work the capability imperative or limit their acceptance. For example, when a school extended the reach of accommodations into standardized patient exams, they did so because the deciding committee believed to not do so would be illegal. A cohort of faculty remained unconvinced that doing so was beneficial to the school’s academic integrity. Attempts to work the capability imperative were heightened when a student’s experience was legible to school officials. When school officials believed in a student’s capability and prospective benefit to medicine, the medical apparatus’ flexibility, and the institution’s duty to advance inclusion, working the capability imperative was most likely to occur.

Strategies to work the capability imperative generally did not shift the larger structures that created barriers. Rather, they allowed for some difference in the manner of meeting capability on an individual basis and funneled more individuals into the accommodation process. In some cases, successful attempts to work the capability imperative began to loosen systemic rigidity; the benefits of doing so, however, were largely individual and inconsistent across students.

### **Resignifying capability**

The previous two sections have conceptualized participant actions—upholding and working—produced in the face of the capability imperative that have been highly informed by a sense of risk. In this section I describe the third category of action, *resignifying capability*, which consists of two types. The first, *overt resignifying*, entails actions I have previously characterized as political disclosure, organizing, and implementing UD. Rather than fitting existing expectations or seeking incremental individual change, overt resignifying sought to change conditions for all. In this, these actions are subversive and political. Moreover, they disrupt existing inclusion frameworks and seek systemic change. The second can be referred to as *covert resignifying*. This included actions such as minimizing one’s needs with the explicit goal to preserve opportunities for similar students in the future; making do in ways that leveraged one’s strengths or introduced unique, disability-informed ways of being and doing; revising policy to signal openness to accommodations; and introducing new



accommodations that could become precedent for future students. These actions found subversive potential within existing structures and expectations.

Resignifying acts occurred on micro and macro levels with students and disabled-school officials most likely to enact them. Dissatisfaction with the status quo plus politicization was frequently the impetus for these actions. Politicization occurred when one connected individual experience with larger social problems. At times this developed organically, for example, when some students of color connected their already-politicized understandings of institutional racism to their disability-related experiences. This also occurred when students connected their experiences of misfitting (Garland-Thomson, 2011), or being told they did not fit, to the constructed nature of medical education. For others, this happened through meeting other disabled people and sharing stories. Disabled-school officials often acted out of a sense of duty. Now in positions of greater power, they felt responsible to change conditions for students and peers who followed. Among students, those with individual traits such as a tendency towards activism, being extroverted, and connecting with conceptualizations of disability as valuable were more likely to engage in overt actions. Some students who did not fit these descriptors, however, were empowered by peers' actions to take active roles in overt resignifying actions. Non-disabled school officials were more likely to engage in covert resignifying acts. Their actions were fueled by the responsibility of their role and knowledge of disability rights and inclusive possibilities. Several, however, took overt action within their formal roles to push towards UD.

Taken together, moves to resignify capability offered different possibilities for disabled futures in medicine. They tended to blur the disabled/nondisabled binary characteristic of ableism (Campbell, 2001, 2009a, 2017, 2019), challenged notions of normal and abnormal, and defied disability stereotypes. Drawing on Halberstam's (2011) concept of the queer art of failure, Mitchell and Snyder (2015) suggested that failures to normalize offer "alternative strategies of nonnormative living" (p. 77) that open new ways to move in the world. Resignifying capability, similarly, represented refusals to normalize or push others towards normalization. Even covert resignifying acts achieved different kinds of fitting within existing structures. These actions suggested new ways to be a physician and do medical education, a kind of crip potentiality. Through resignifying, participants problematized the individual inability discourse and challenged the capability imperative.

Embracing the failure to normalize is not without risk. Though it may be liberating in some respects, refusing normalization is not necessarily a desirable nor feasible option for all, as Johnson (2015) suggested. While they persisted with resignifying actions, students with less-readily apparent disabilities wondered about possible harm to their future careers from having a public profile as a disabled person and activist. Furthermore, these actions often

required time, something many students reported having very little of. Similarly, disabled-school officials' resignifying activities were often not rewarded in their academic or professional roles and they were aware that institutional support for disabled faculty and clinicians is fragile (see also, Neal Boylan et al., 2012; Price, Salzer, O'Shea, & Kerschbaum, 2017; Steinberg et al., 2002; Swenor, 2019; Swenor & Meeks, 2019). This made the work of resignifying a luxury, sometimes in competition with the activities of being a medical student, administrator, or academic physician. To engage in resignifying activities was to risk failure and, thus, remained an uphill battle against the normalizing demands of the capability imperative.

### **Part III. Implications of the Grounded Theory**

Having explicated the theory of negotiating the capability imperative in parts one and two of this chapter, this part discusses three implications of the theory. First, I relate the process of negotiation to theories of ableism, compulsory abledness, and performativity to demonstrate that the grounded theory reveals an ableist hegemony at work. The second implication is that available mechanisms for inclusion individualize disability and access, an argument developed through engagement with critiques of accommodation. Finally, negotiating the capability imperative suggests that disability inclusion is incomplete and insufficient, a condition that demands transformation.

#### **Performing and subverting hyper-abledness**

Examining the process of negotiation illustrates how the capability imperative (re)produces a standard of hyper-normal behavior in medical education within the system of ableism. Despite the existence of mechanisms that purport to include students with disabilities in medical education, their engagement with inclusion mechanisms was constrained. Campbell (2009a) explained that "ableism is an epistemology (a knowledge framework) and an ontological modality (a way of being) that frames an individual's identity formation and, thus, becomes the power 'that animates ones emergence' (Butler, 1997, p. 198) through complicity and resistance" (p. 28). The capability imperative represents a local manifestation of ableism in medical education that animated student and school-official actions. Students upheld or worked the capability imperative through actions that attempted to approximate it. They carefully measured their engagement in activities that deviated from normative means to meet those expectations. Participant actions were restricted by the capability imperative, constantly compelled to approximate it in ways that ensured its hegemony.

At the same time, participants called the supremacy of capability imperative into question through actions that deviated from normative expectations. This process is resonant of Butler's (1991) explanation of heterosexual hegemony and performativity. Butler (1991)

argued that norms of heterosexualized genders are simultaneously made hegemonic and revealed as fragile through repeated acts that attempt to achieve the norm and inevitably fail to do so. McRuer (2006) drew the connection between Butler's (1988, 1990, 1991, 1993) theory of performativity and ableism in his development of *compulsory ablebodiedness*. McRuer (2006) problematized the achievability of ability standards, a condition he refers to as "*ability trouble*—meaning not the so-called problem of disability but the inevitable impossibility, even as it is made compulsory, of an able-bodied identity" (p. 10, emphasis added). In the context of medical education, similarly, the capability imperative represents expectations of hyper-ability that are always out of reach. As discussed in Chapter 5, for example, expectations for selfless superhuman physicians are both impossible and compulsory. Students labeled disabled are compelled to reach towards the capability imperative through self-management or legally-informed mechanisms in ways that solidify the capability imperative's hegemony.

While participant actions were limited by the capability imperative, the performative quality of negotiations allowed for the possibility of challenging a rigid notion of capability through acts that upheld or worked the capability imperative and those that resignified capability. Acknowledging the possibility for subversion even in oppressive conditions, Butler (1988) argued that "the stylized repetition of acts through time" (p. 520) allowed for the possibility of transformation. This, she argued, occurred "in the possibility of a different sort of repeating, in the breaking or subversive repetition of that style" (Butler, 1988, p. 520). This type of subversion is often described as *queering* or in queer/disability studies as *cripping*, actions that open innumerable possibilities for inventive interpretations against the norm (Kafer, 2013; McRuer, 2006; Mitchell & Snyder, 2015; Price, 2011; Sandhal, 2003). When participants resignified capability, they created new ways to be and do medicine, beyond the restrictive bounds of the capability imperative. When participants found ways to enact capability through different means, using accommodation or self-adaptation in acts that upheld or worked the capability imperative, they suggested different ways to "do capability" to achieve competence. That is, they revealed capability as a malleable rather than a fixed construct.

Capability may be a malleable construct, but if its permutations are to go beyond momentary actions that benefit individual students, these actions must be, as Butler (1988) suggested, repeated, or otherwise articulated into broader systemic action. Actions that upheld the capability imperative often occurred in the perceived absence of alternatives. Decisions to work the capability imperative often happened only after failure, after sustained arguments for change, or were partial—addressing some but not all barriers. Systematic efforts to make accommodation possibilities transparent did not occur. Students were often unaware of what accommodations and strategies other students used unless they were shared. Similarly, school

officials were not aware of the modifications made at other schools unless they sought this information. Without formalized disabled-student communities, it was only through happenstance or with significant effort that students met other disabled students and shared possible accommodations. Furthermore, systematic efforts to identify and resolve barriers only rarely occurred and were more likely for students with physical disabilities. Efforts towards UD or changed practice across all students were minimal. Thus, responsive or fundamental malleability was rarely built into medical education culture and practice. Disrupting the meaning of capability through resignifying was an uphill battle against the capability imperative's dominance. This suggests the limits to transformative possibilities through the process of negotiation. Unless subversive acts are repeated and systematized, they will not fundamentally shift or break down the capability imperative.

To foster change, the way forward must not simply attempt to address individuals' behavior. Butler explained that "individual acts work to maintain and reproduce systems of oppression" (1988, p. 525) but that acts and social conditions are connected in multidirectional and mediated ways. As a result, Butler (1988) insisted that "transforming hegemonic social conditions" should be the target of change rather than addressing "individual acts. . . spawned by those conditions" (p. 525). To suggest that individual participants are wholly responsible for reproducing the conditions described here would be incorrect. Nor would it be sufficient to suggest that working or resignifying the capability imperative will, alone, transform the ableist conditions of medical education and practice. Much broader transformative action that targets systems is needed to move beyond incremental change and dismantle hegemonic conditions.

### **Individualizing disability and access**

The second theoretical implication of negotiating the capability imperative emphasizes that the mechanisms in place to facilitate inclusion individualize disability and access. Disability was treated as a condition within the person and as the "location of trouble" (Titchkosky, 2011, p. 12) that necessitated change and caused barriers to learning. The primary method of inclusion, the accommodation process, constituted after-the-fact adjustments that cost time, money, and labor, and often visibly marked the person as Other (Dolmage, 2017). The approach required that each individual student seeks recognition as disabled and asks for change to be included in the educational environment.

An individualizing process is limited by the power inequities between students and school officials. Hibbs and Pothier (2006) suggested that, in addition to ignoring the structural and systemic barriers to access, this model assumes an individual agency understanding of power. That is, the model assumes that individuals possess power and this power can be balanced in a negotiation. They argued this ignores the inherently less powerful position of

students put into an adversarial position with their schools to secure access, which inevitably moderates students' willingness to access inclusion mechanisms (Hibbs & Pothier, 2006). Unlike Hibbs and Pothier's (2006) findings, the participating schools did not require students to directly negotiate their accommodations with faculty. As described in Chapter 4, most participating medical schools utilized firewalling to separate faculty from disability documentation and accommodations were negotiated through a disability specialist or school committee. Although many students described a relatively straightforward process to request and access standard accommodations, concerns remained. Students often hesitated to access inclusion mechanisms or minimized the barriers they encountered through self-management in order to approximate the hyper-abledness demanded by the capability imperative, similar to findings by Easterbrook et al. (2015). Even when a disability specialist negotiated accommodations on the student's behalf or when schools employed a proactive collaborative approach to accommodations, the impact of individualizing access persisted. Faculty still evaluated the reasonable nature of accommodations with the disability specialist and often other school leaders were involved in determinations of "non-standard" accommodations. As a result, students perceived the import of appearing easy, good-natured, and not-too-needy to maintain a positive relationship with their schools. Removing the student from direct accommodation negotiations with faculty was insufficient to buffer the power inequities inherent in an individualizing process.

Through individualizing disability and access, systemic change was incidental rather than central to inclusion. The approach centered individual students as the locus of change, due to "their" disability, rather than considering how disabling programs and environments might change in recognition of diverse learners with or without a disability label. Systemic interventions at participating schools were generally in service of improving accommodations, through making them appear safer to access, extending their reach, improving institutional expertise, or better communicating their availability. These arrangements, however, maintained what Campbell (2009a) referred to as a *constitutional divide* (p. 6), essential to upholding ableism. Within ableist systems, a construction of a "normative" person is centered and systems are oriented around them, whereas those labeled "disabled" are always treated as afterthoughts and thus in need of allowances to foster their inclusion (Campbell, 2009a). Dolmage (2017) explained that accommodations often operate as *defeat devices*, meeting the legal standard while masking the ableist systems that remain. Thus, school officials often reported that they believed their school's approach to inclusion was sufficient because they had a clearly-defined accommodation policy and a qualified individual in place to facilitate evaluation and implementation, conditions that met compliance. Accommodations may have assisted students by removing some of the systemic barriers they encountered, but they did not

change the medical education system. Provision of accommodations obscured the exclusionary operations of medical education by arguing that disabled students are present, educated, and graduate and, therefore, included. This avoided engagement with the actual, complicated experiences of students seeking inclusion that are represented in the process of negotiating the capability imperative. Expectations of hyper-normative ways of doing and being remain intact and centered, through explicit policies such as technical standards, course assessments, and physical arrangements, as well as implicit behavioral standards.

Treating disability and access as individual problems heightened the risk of Othering through processes of inclusion. Accommodations offer only individual retrofits (Dolmage, 2017), special changes for those who prove their disability status and overcome perceptions that such a change will diminish the quality of medical education. Through this process, students were invited to approximate the established norm (Mitchell & Snyder, 2015). Each request for change (re)inscribed the student's status of Other and left the student's capability up for question. Graham and Slee (2008) explained that this type of Othering system results in "an illusory interiority due to the adoption of discourses and practices that are both normative and confer exteriority" (p. 289). That is, accommodations promise to include, but the very need to be "included" and the use of a process that requires biocertification (Samuels, 2014), use of individual fixes, and maintenance of the capability imperative signals disabled students' continued marginalization. Because of this marginalizing effect, the individualization of disability and access heightened the risk of seeking equitable access to medical education.

A tension in this critique of individualizing systems is the heterogeneity among experiences of disability. The responsive approach recognizes students' individuality in that it does not assume that all disabled students are the same and honors students' agency to identify the barriers that are significant to them. One student, for example, suggested that she would not like her school to simply assume that they know what she needs based on her category of disability or diagnosis. Similarly, a school official questioned the possible alternatives to a responsive approach because disabled students are so different from each other. Indeed, this argument underpins the use of accommodations as the tool to ensure access in employment and education settings under the ADA, rather than provisions for general proactive access improvements, as is required for places of public accommodation (Crossley, 2004). Although recognition of disabled peoples' heterogeneity is essential (Bulk et al., 2020), this argument absolves programs from systemic change. Reliance on individualizing processes suggests an assumption that there are no similarities among disabled students and between disabled and non-disabled students. The individualizing process assumes that only some students, those who are labeled disabled, are anomalous and require change rather than recognizing that all people benefit from built-in flexibility and customization (Titchkosky, 2011). Within a system

premised upon UD (introduced in Chapter 2), for example, a school would assume their learners have a broad spectrum of embodiments, learning preferences, and backgrounds, and would implement systemic flexibility, revise and innovate iteratively, and respond to individuality (Dolmage, 2005, 2017). Under the capability imperative, not fitting has consequences that make an individualizing approach a risky Otherizing process. Although accounting and allowing for individual difference is necessary, any changes in response to the problem of individualization will also need to attack the roots of the capability imperative.

### **Reconsidering inclusion**

In light of the previous two implications, the final implication is that disabled students' inclusion in medical education is, as yet, incomplete and in need of transformation. The promise of U.S. disability-rights legislation is to facilitate disabled people's equal access to educational opportunities. Central to these laws are the principles of non-discrimination on the basis of disability and the provision of reasonable accommodations. In this sense, the law reflects an equity approach, recognizing that to achieve equal access and address discrimination, affirmative change is required (Crossley, 2004). The requirement for reasonable accommodations also acknowledges that existing social environments are largely inaccessible to disabled people. Or, as Eichhorn (2002) suggested, the legislation "assumes that the world is always, already, a hostile environment for people with disabilities because it is fraught with socially-constructed obstacles" (p. 618). The affirmative requirement to address discrimination, however, is responsive. These individual fixes situate disabled people as exceptional rather than expected members of society. Furthermore, reliance on accommodations as the sole mechanism for change reflects a belief that the very cultural forces the legislation seeks to ameliorate will not impede an individual's ability to make use of them. Instead, the legal mechanisms seem to suggest that the existence and exercise of rights provisions will reform sociocultural views on disability inclusion.

Certainly, disability rights legislation has advanced access to medical education for disabled people (Bagenstos, 2016; Meeks, Case, et al., 2019; Meeks & Jain, 2018). Recent litigation advanced by disabled students under these laws have reaffirmed their right to equal access, challenging how schools have historically determined limiting factors such as fundamental alteration and undue burden (see, e.g., *Argenyi v. Creighton University*, 2013; *Featherstone v. Pacific Northwest University of Health Sciences*, 2014; *Palmer College of Chiropractic v. Davenport Civil Rights Commission*, 2014). While these advancements have increased access to accommodations, negotiating the capability imperative demonstrates the persistence of educational environments that assume and reproduce hyper-normative bodyminds.

Although the formal curriculum (Hafferty & Gauferg, 2013) of the participating medical schools suggested that disability-inclusion mechanisms were available, the hidden, informal, and null curricula (Hafferty & Gauferg, 2013) taught students to find ways to fit into existing structures unless absolutely necessary. The discourses of diversity and inclusion as well as those of disability were in conflict with the capability imperative. This was evident through the process of negotiating the capability imperative, where participants attempted to first approximate hyper-abledness rather than seek change through inclusion mechanisms. Furthermore, the ongoing attention to improving accommodations to the exclusion of systemic change maintains the conditions of risk and precariousness that underpin the need for negotiations. Addressing the capability imperative is essential to achieve meaningful inclusion for disabled students in medical education.

The promise of disability as a form of diversity in medicine was also constrained under the capability imperative. Expanding student diversity is said to enrich the field by including those with different ontological and epistemological standpoints (Iezzoni, 2016; Nivet, 2015). Students, however, remained caught between societal ideas of disability as inability, reinforced in their medical school environs, and their own understandings of their disability experiences as sometimes valuable and highly contextual, affected by the environment. This created internal dissonance, a kind of double consciousness (Du Bois, 1903/1994, Garland-Thomson, 2011) between disability under the ableist gaze and more complex conceptions borne of experience.

Most students had little exposure to emancipatory frameworks of disability that recast it in more complex ways (e.g., Linton, 1998), and those who did have such exposure did not see these understandings animated in the medical school environment. As a result, some distanced themselves from disability to avoid stigmatization. This distancing could subvert development of a positive disability identity (Forber-Pratt, Lyew, Meuller, & Samples, 2017) and hamper integration of their unique disability-related standpoint or sitpoint (Garland-Thomson, 2005) with their burgeoning professional identity (Battalova et al., 2020; Stergiopoulos et al., 2018). Inattention to these factors potentially limits the benefit disability epistemology could bring to students' medical practice and to near-peer learning (Fergus et al., 2018). While some students described acting against the capability imperative to disclose their disabilities in political ways, or to assert the value of their disabilities, these were relatively grassroots efforts that were not widely supported by school officials.

The conditions described here follow a logic of *inclusionism*, where disabled bodyminds are integrated and tolerated in minor ways that obscure their ongoing exclusion within neoliberal academic environments (Mitchell & Snyder, 2015). Mitchell and Snyder (2015) suggested that the legal parameters, focused on accommodations, assist in the maintenance of



this approach. As they explained, “accommodation[s provide] some bodies with levels of already integrable differences into normative frameworks that [do] not significantly disrupt environments suited to a narrow range of abilities” (Mitchell & Snyder, 2015, p. 44). Indeed, the existing legal frameworks only require programs to provide reasonable accommodations that do not fundamentally alter their academic standards or create undue financial or administrative burden. This allows for surface-level change without disrupting the ableist roots of medical education or contending with the “messy materiality” (Mitchell, 2016, p. 10) of all bodyminds, disabled or otherwise. Schools can claim to value diversity, treating it as capital that advances their own status, but only minimally change their practices in response (Ahmed, 2012; Mitchell, 2016). The maintenance of a false binary between physician and patient in the capability imperative aided avoidance of fundamental change. The expectation of superhuman perfection and a student who can fit these expectations locates the problem of misfitting with the student rather than the structure and culture of medical education. Within the logic of inclusionism, the schools have met their responsibilities under the law, offering mechanisms to access accommodations, and in fact have graduated students with disabilities, which adds to their diversity credibility. An examination of the negotiations that students and school officials undertook, however, illuminates the deeply-rooted immutability of the capability imperative that belies the enduring incompleteness of the inclusion project. Negotiations were laden with inconsistencies across individuals resulting from differences in situated, shared, and assumed knowledge that tended to overly disadvantage already marginalized students and those whose experiences of disability were less legible to school officials. Furthermore, even in the best of circumstances, students made do as a result of the capability imperative’s predominance over their actions. These findings suggest the limits of current processes, centered around accommodations and overshadowed by the capability imperative, to achieve meaningful inclusion for students with disabilities.

Transformation will require reconsideration of how medical education can enable all students’ capabilities in medical education. In a sense, this would shift the focus from how to fit students into existing structures to designing structures that account for and value difference. Kafer (2013) argued for a politics of *crip futurity* wherein we must imagine disability and disabled peoples’ lived presents and possible futures differently, beyond limited understandings of disability and possibility. To do so, she says we must “challenge the rhetoric of naturalness and inevitability that currently dominate” (p. 3) perceptions of societal barriers to inclusion. In this way of thinking, she continues, we must assert that decisions about the futures of disability and disabled people are political (Kafer, 2013). Thus, the barriers disabled medical students experience with regard to the capability imperative must not be interpreted as a natural or inevitable consequence of their disabled state or the realities of the medical field.

Rather, barriers must be seen as the consequence of decision-making that has not fully considered or prioritized inclusion of disabled people in the structuring of medical education. To cripple the future of medical education, then, system-wide transformation is needed. Such a transformation would start from a place of valuing disability as a valid embodiment, assuming that disabled people have the potential to become physicians, and recognizing that they may bring necessary situated knowledge to the field of medicine.

## **Conclusion**

Medical schools are premised upon a flawed, dichotomous cultural logic. The physician is positioned as a healthy, intelligent, and supremely able healer; the disabled person receives care, is unable, and unwell. This dichotomy sets up the problem of the capability imperative: To move fluidly through medical school and proceed to a medical career, students must perform hyper-abledness. Disability, then, poses a risk to fulfilling this role, creating a threat to students' career trajectories. In this chapter I have formulated a grounded theory of disability inclusion in medical education. Through analysis of the experiences of disabled students and school officials at four medical schools, I developed an understanding that inclusion was not a discrete process unto itself, but always compromised because it entailed negotiating the capability imperative.

The negotiation began with a risk assessment: What might be the consequences to asking for or making change? Under the capability imperative, the least amount of deviation from normative processes is desirable. To achieve capability, however, change was sometimes required. Despite barriers, participants sometimes upheld the capability imperative by maintaining or approximating existing expectations without change, or worked the capability imperative, by seeking or making change to allow students to meet expectations in different ways.

In the process of negotiating the capability imperative, participants also resignified the notion of capability. This occurred through upholding and working actions that suggested capability could be achieved in different ways. Notwithstanding the risk it involved, participants also took overt action to seek collective change. These actions refused the capability imperative to suggest that disabled people had a place in medicine and that existing structures should change to include them. Collectively, resignifying actions challenged the supremacy of the capability imperative but were largely grassroots efforts that did not translate to systemic change.

Negotiating the capability imperative as a means to achieve inclusion is insufficient. The capability imperative functions as the gravity against which inclusion occurs. This ensures that beneficial change is incremental. Indeed, change was most often individual and the benefit of

resignifying acts were not leveraged systemically. This also ensures that students who are multiply marginalized will have greater difficulty accessing change.

These dilemmas and negotiations can be attributed to ableist discourses (Campbell, 2001, 2009a, 2017, 2019) that saturate medical school culture. Rather than reimagining medical education in a manner that anticipates diverse students' needs, current structural arrangements include disabled students only to the extent that they can continue to approximate the capability imperative. This analysis suggests that improvements to accommodations processes at the level of the institution will be of limited value unless the underlying culture of ableism within medical education is addressed. To realize the promise of inclusion, a transformative approach that seeks to dismantle the capability imperative is necessary.

## Chapter 7. Transformative Practice: Designing From Disability

*What hopeful imagination might inform the struggle for a better future and assist one to act as if a vision of that which is not yet has already begun to emerge?*  
(Simon, 1992, p. 4)

*In imagining more accessible futures, I am yearning for an elsewhere— and, perhaps, an “elsewhen”—in which disability is understood otherwise: as political, as valuable, as integral.* (Kafer, 2013, p. 3)

### Introduction

The previous three chapters presented a grounded theory of negotiating the capability imperative. I argued that these negotiations were highly individualized and informed by risk that followed from dominant understandings of disability and medicine. Actions that resisted the capability imperative were important interventions but did not wholly destabilize the center. In the previous chapter, I concluded that disability inclusion was incomplete and insufficient insofar as it failed to systemically contest ableism. At the participating schools, inclusion practices centered on finding ways to fit students into existing medical education structures rather than shifting the context towards inclusion.

In this chapter I employ Kafer’s (2013) politics of crip futurity. I imagine a possible future where disabled medical professionals are considered natural and inevitable. To develop this transformative vision, I began with a provocation: what would medical education look like if it started from the assumption that disabled people make excellent physicians? In response, I imagine a desirably disabled future for medical education, one that celebrates unique ways of being in and knowing the world that come with it and, therefore, necessarily makes space for variety beyond an ableist binary (McRuer & Wilkerson, 2003). This future “does not rely on a normalizing impulse” (Kafer, 2013, p. 23). Rather than individualized, incremental change, the culture, structure, and content of medical education are the key sites of change. The transformation, then, dismantles conceptions of a singular, “standard” learner in recognition of—and, indeed, with an affinity for—human variation.

The chapter begins with a foundation for transformation that imagines a broadly-inclusive medical education community. This section engages UD and usability theory to lay the groundwork. The next section reconceives four traditional markers of capability: productivity, time, pluripotency, and independence. The final section explores ways to foster

disability epistemology in professional identity formation through reorientation of pedagogy and the formal curriculum, and by building community and mentoring networks. In each section of this chapter, I depict the current problem and then explore lines of thought towards a new future. I hesitate to jump to solutions, as transformation must be a collective effort informed by “those most impacted” (Sins Invalid, 2019, p. 23) by the current paradigm. Rather than providing prescriptive approaches that are all too often inflexible, decontextualized, and silencing of multiple voices, this chapter offers a number of conceptual anchors and signposts to help guide effective practice and policy development in the specific environments that medical education occurs.

Participants offered immediate practice recommendations and some were exemplified by the participating institutions. In large part, these practices sought to make accommodation practices more visible, transparent, accepted, and consistent within the existing educational paradigm. Formal practice recommendations that align with these findings, however, are already available (Blacklock, 2016, 2017; Brown-Weissman & Carli, 2016; Jauregui et al., 2020; Kezar et al, 2019; Laird-Metke, 2016; May, 2017; Meeks et al., in press; Meeks & Jain, 2016, 2018; Meeks & Murray, 2019; Meeks & Neal-Boylan, 2020; Mehta & Clifford, 2017). Moreover, these represent incremental practice improvements that may contest powerful discourses but remain constrained by the capability imperative and do not sufficiently attack its ableist roots (as discussed in Chapter 6). They represent “tinkering around the edges” (Meyer, 1997, p. 80) rather than transformation. With a desire to move beyond the existing paradigm, I do not focus on incremental practice recommendations in this chapter.

Medical education is not a static enterprise. Rarely, however, is a disabled learner considered, let alone centered, in revitalization efforts. In this chapter, I try to dream differently, free of the question, “Is it possible?” This question cements current circumstances to limit dreaming. By articulating a transformative vision, I follow the crip theory assertion that a broadly accessible world, in opposition to neoliberal pressures, is possible (McRuer, 2006). I declare this possibility and assert the importance of disabled learners in the future of medical education. My hope is that this declaration generates friction between current practice and a possible future to encourage discomfort with the status quo and accelerate change.

## **Universal Design as a Foundation for Transformation**

I have spoken about UD in previous chapters, most prominently chapters 2 and 4. I want to return to the concept here as a launching pad to think about transformation. To briefly recap, UD, as originally conceived, is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaption or specialized design” (Center for Universal Design, 1997). Although the concept was originally developed in

relation to the material environment, it has since been extended to other areas, such as instructional and program design (Burgstahler, 2012; McGuire, Scott, & Shaw, 2006). The intent of UD is to plan proactively rather than retrofitting for inclusion. Instead of a one-time procedural exercise, critiques emphasize the need for UD to operate as an active practice that is iterative, pays holistic attention to environments, policy, and practice, and remains committed to a critical-disability studies politic (Dolmage, 2005, 2017; Hamraie, 2016, 2017).

To describe the universal-design approach in Burgstahler's (2015) terms, it would begin by "defin[ing]the universe. . . the overall population (e.g. the users of the service). . . [and their] diverse characteristics" (p. 1). In other words, UD invites an interrogation of the assumptions concerning the types of bodyminds that will and need to be present in an environment. In the context of medical education and the medical field, greater diversity is necessary to fully meet patient-care demands. Attention to healthcare inequities is also critical to build a workforce uniquely equipped and committed to addressing these persistent problems. As such, UD would encourage a medical profession that is intentionally inclusive of students and faculty with all types of disabilities and, more broadly, those who are Black, Latinx, indigenous, queer, transgender, parents, women, first-generation to college, undocumented, caregivers, from refugee backgrounds, low socio-economic backgrounds, and a variety of religious backgrounds. Importantly, those who live at the intersections of multiple forms of difference are considered expected community members. This reconfiguration aligns with Linton's (1998) call for theories "that conceptualize disabled and nondisabled people as integral, complementary parts of a whole universe" (p. 129). Recognizing the interlocking nature of systems of oppression, in particular the co-constitutive nature of ableism, white supremacy, heteropatriarchy, colonialism, and capitalism, transformation is conceived of with intersectionality and cross-movement concerns in mind (Annamma et al., 2013; Sins Invalid, 2019; Withers, 2012; Withers et al., 2019). This starting place fundamentally shifts medical education to a new plane; a foundation of assumed and valued difference necessitates novel ways of working. Students escape a need to negotiate their capability in medical education and instead are afforded the assumption of capability in medical education.

Of course, the diversification movement in medical education has already noted some groups' underrepresentation and some schools have developed pipeline initiatives to bring underrepresented communities into medicine and support programs for matriculated students (Raffoul, Bartlett-Esquillant, & Roberts, 2019; Tekian, Jalovecky, & Hruska, 2001; Yang & Richardson, 2013). The persistent marginalization of these "diverse" students suggests a more fundamental reorientation of medical education is needed—beyond getting students in and adding on programs to support them while there (Ackerman-Barger, et al., 2020; Phelan, et al., 2019; Razack et al., 2014; Razack, Risør, Hodges & Steinert, 2019; Teherani, Hauer,

Fernandez, King, & Lucey, 2018; see also, Chapter 4). Pipeline programs and support systems beyond accommodations for students with disabilities are, furthermore, relatively non-existent. Although some disabled students of color may benefit from existing pipeline programs, they are not oriented towards disability-related concerns. Here, I am thinking beyond add-on measures like pipeline programs and support programs, though these may remain necessary and perhaps need reconfiguration and expansion (Freeman, Landry, Trevino, Grande, & Shea, 2016). Instead, the shared fabric of medical education, for all students, should shift.

From this expanded notion of who is assumed to be present and needed in medical education, this diverse community is involved in conceptualization, ongoing evaluation, and iterative review and adjustment of the way things work (Burgstahler, 2015; Dolmage 2005). Examining the exclusionary features of existing medical education structures is one place to start. Identifying places where students require accommodations illuminates some of these sites at which to reimagine design. As I have discussed across Chapters 4-6, however, self-management of barriers is prevalent. To gain a fuller picture of existing barriers, a transformative process needs to understand how students work around current structures. Beyond this, a transformative process seeks to understand who does not make it into medical education and why. Such an exploration identifies barriers to admission in terms of pre-medical preparation, exclusionary admissions processes, and what bodyminds are considered excludable within current practices and why. Through this multi-layered exploration, the aim is to identify exclusionary features and barriers, already-known solutions, and then seek to reconceive of medical education as deliberately inclusive of diverse bodyminds. This reconfigures disabled students' ways of being, learning, and doing from deficits into resources that inform how the program is organized.

Starting from a baseline of intentional inclusion that proactively takes diverse bodyminds into account significantly reduces the need for individual accommodations. Through an iterative approach, achieving inclusion is seen as a point on the horizon rather than a destination. Programs must remain alert, always looking for ways to improve and evolve. In the following sections, I conceive of transformations to multiple aspects of medical education identified as problematic to disability access in Chapters 4-6. This discussion expands upon my initial exploration of a transformative approach to disability inclusion (Jain, 2020a) and joins other “cripping” projects that counter ableism through asserting disability's productive possibility in places it is otherwise absent or marginalized (Connor & Gabel, 2013; Steinborn & Nusbaum, 2019; Thorneycroft & Asquith, 2019).

## **Reconceiving Capability**

A transformation of medical education, and the field of medicine more broadly, requires that cultural understandings of the capable physician are reframed. This necessitates alternative constructs of time, productivity, pluripotency, and independence. In the present paradigm, notions of capability are intimately connected to these constructs. Productivity, time, and independence are linked to the motifs of the selfless superhuman physician and the “real world” of medicine discussed in Chapter 4. The expectation for undifferentiated graduates, able to enter any specialty upon graduation, suggests that graduates must have the potential to independently execute all aspects of a physician role. Assessments of disabled students’ capabilities, however, remain skewed by low expectations. This means that disabled peoples’ capabilities are often implicitly under-estimated, while physician’s capabilities are over-estimated.

On top of these conceptual challenges, the ground from which assessments are made is a healthcare system often characterized by long work hours, profit motives, alienation from meaning and purpose, and insurmountable administrative tasks (Dyrbye & Shanafelt, 2016; Liao, 2020; Shanafelt, Dyrbye, & West, 2017; Waitzkin, 2018). The system does not seem to work for many, with these conditions recognized as primarily responsible for high levels of trainee and practitioner burnout, depression, and suicidality (Dzau et al., 2018). This transformation imagines alternative starting points to reconceive capability for all medical students and physicians. I take Mitchell and Snyder’s (2015) vision of a disability-based model of social production as a guide:

The interdependency of intense singularities working for common goals (the politics of atypicality)—rather than the obverse, which is the functioning logic of capitalism: intense singularities suppressed by incoherent goals of marketplaces and imposed by companies upon those who produce products and profits from which they do not adequately benefit (p. 222).

This model assumes individuals will have many different ways of contributing to collective goals. By taking this approach, in the case of medicine, the wellbeing of patients, families, physicians, and other healthcare workers is prioritized. This necessarily dismantles systems that prioritize industry profits.

### **Reconceptualizing productivity**

The construct of productivity underlies many concerns about disabled students in medical education. This arises from the central aim of most medical schools, to produce professionals prepared to meet workforce demands. Furthermore, medical training is multi-staged, with students moving from undergraduate to graduate medical education. This means that trainees potentially move through several different sites with differing expectations. I have already



argued, in Chapter 5, that the “real world” concept is flawed in that demands vary across specialties and the availability of accommodations must be taken into account. Here, I take this argument beyond current conditions. Even with accommodations, students described a constant state of *battling time*, always catching up and trying to fit in to rigid systems of expectations. To transform this, a (re)configuration is needed wherein productivity is not the central marker of value and productivity itself is not uniform. Such a system, that de-centers market-driven conceptions of productivity, starts by thinking deeply about what patients need, and what kinds of physicians and workplace arrangements benefit those patients and workers rather than conceiving of physicians as cogs in a capitalist healthcare machine.

Designing from disability reconceives traditional notions of productivity. In this alternate conception, differing ways of being and knowing the world are ascribed value and are translated into inclusive training and workplace policies. As Sins Invalid (2019) asserted, “we resist conforming to ‘normative’ levels of productivity in a capitalist culture, and our labor is often invisible to a system that defines labor by able-bodied, white supremacist, gender normative standards” (p. 24). Rethinking productivity allows other aspects, beyond the amount of work completed, to mark a capable and valuable doctor. This could look like a move from a quantitative, volumetric output standard to a qualitative measure. For example, a physician who is unable to see 25 patients in a day, but whose ability to provide nuanced primary care for teens with autism far exceeds that of other physicians, would be seen as highly productive and adding significant value to a medical practice. This reconfiguration of productivity and value takes into consideration physician capabilities, desires, and patient needs.

This kind of radical departure from current expectations has manifold benefits. These measures benefit not just disabled patients, trainees, and physicians but also those who are parents, caregivers, and those with familial duties. For example, a more fluid conception of physician productivity allows for variability in appointment lengths for patients. In the current system, standardized 15-minute appointments plague some disabled patients with differing needs for sharing and receiving information. Re-orienting productivity expectations for all imbues greater flexibility (and less stigma) for those who require or desire to balance their professional time with familial roles. Reconception of productivity also benefits those who wish to otherwise de-center their profession as their sole life focus through pursuit of other interests, allowing for people in the profession to be more than their job (ten Cate, 2014). This is not, however, a suggestion that the same outsized expectations are “balanced” with greater flexibility to also do other things by coming in early or working late into the night (Abaza & Nelson, 2018). Rather, this shift moves towards a more humane workplace for all that assumes

human variation and thus differential “output.” A broad revision of productivity for all—not just disabled people or women—is required to truly shift the culture.

In this transformation, productivity becomes a more fluid construct, dependent on an individual’s abilities and desires rather than set expectations. Interconnected with ideas of crippling time, differentiation, and UD, the end point of medical education is not cookie-cutter physicians, a range of shapes are expected. A more fluid conception of productivity opens opportunities for trainees and professionals to do medicine differently rather than needing to fit into pre-existing molds.

### **Crippling time**

A shift in understanding productivity requires a shift in the configuration of time. Normative conceptions of time create ongoing concerns for many students with disabilities. In Chapter 5, I articulated this through an in vivo concept, *battling time*, that characterized the ongoing and myriad challenges students experienced against normative time structures in medical education. The disability-studies concept of *crip time* presents a lens to consider medical education transformation that accounts for disabled peoples’ ways of moving through the world. Crip time is borne of disabled peoples’ situated knowledge of temporality built through experiences of pain, differing forms of cognition, hospitalization and diagnosis time, communicating with sign language and through interpreters and assistive technology, negotiating ableist barriers, and navigating medical and social systems (Kafer, 2013; Price, 2011; Samuels, 2017; Zola, 1993). It is not just a need for more time, but an exploded concept of time that is flexibly managed, negotiated, and experienced (Kafer, 2013; Price, 2011; Samuels, 2017; Wood, 2017a).

Crippling time in medical education requires a foundation of flexibility, with attention to the ability to move through the curriculum at differing speeds. As it currently exists, medical education is underpinned by a “one-way fits all” logic, wherein students must move through training along a singular path in relatively lock step. Crip time would allow students to move at differing speeds and in differing ways. This approach does not assume what students will need and acknowledges that students may have conflicting and variable needs across their program. This might look like the option to decelerate all aspects of the curriculum, to account for differing levels of concentration, learning speed, stamina, sleep and medication schedules, medical appointments, and outside obligations (e.g., caregiving, other familial and community roles, employment) that are not exclusive to disability-related need. This arrangement offers, for example, the ability to take fewer classes at a time, the ability to lengthen rotations to support learning, to shorten days, and the ability to modulate patient load in clinical rotations. Alternate forms of participation are available, that allow students to participate remotely or

asynchronously during periods when travel to the classroom is not possible. Crippling time might also look like the opportunity to accelerate curriculum when a student is able to do so. As discussed in Chapter 5, movements towards time-variable medical education align with such an approach, insofar as the approach dispenses with the idea of a normative learner who achieves competency in a standardized manner (Lucey et al., 2018). Taking Hodges' (2010) warning into account, however, a concerted effort is necessary to ensure time variability is not a tacit route only to accelerated timelines.

Of course, in medical practice time is not just a matter of the physician or medical student's needs but also those of the patient that include essentially time-bound procedures (e.g., drawing blood, inserting an endotracheal tube, performing CPR). Crippling time must take these time restrictions and patient safety into account but requires careful consideration to avoid overreliance on tradition that limits flexibility. Extending flexibility by design to all students acknowledges ability diversity (Gabel, 2002) and other forms of diversity, rather than enforcing a dis/abled binary wherein only disabled people move through the world and learn at different speeds and rhythms.

### **Beyond pluripotency**

A transformative approach (re)considers the undifferentiated graduate and, in turn, technical standards. As discussed in Chapters 2 and 5, technical standards outline the non-academic criteria for admission, promotion, and graduation. These standards are generally built upon the expectation for undifferentiated graduates, prepared to enter any specialty upon graduation, and set standards for physical, sensory, and behavioral abilities. Even in the current structure of medical education, however, the undifferentiated expectation is a fallacy as all students will have varying levels of individual abilities and interests that make them suited for some but not all specialties (DeLisa & Thomas, 2005; DeLisa & Lindenthal, 2012). Licensing exam scores, for better or for worse, also define all students' potential to enter many specialties (Prober, Kolars, First, & Melnick, 2016). Although the idea of an undifferentiated graduate is well-intentioned, to ensure students have a broad knowledge of and exposure to medicine, it is not in line with residency selection and physician practice (Bagenstos, 2016; Reichgott, 1996). This philosophy leads to the potential exclusion of disabled students, especially those who may have the physical and sensory abilities to do some but not all aspects of medicine directly without the use of an intermediary (Argenyi, 2016; Reichgott, 1996, 1998). Furthermore, technical standards create ongoing pressure for students with disabilities, constantly aware they are excludable if they face a required task that cannot be accommodated.

A transformative approach to medical training dispenses with the undifferentiated graduate standard, with acknowledgment that people with diverse disabilities can be

successful in a variety of medical specialties. Reconsideration of technical standards, and whether they continue to serve medicine's aims, starts with deep consideration of what is truly essential to the physician role.

- What makes a physician a physician?
- What tasks must they be capable of doing and why?
  - Is this true across all or just some specialties and settings?
- Could students be exposed to all areas of medicine, through coursework and clinical observation, but not expected to execute all tasks?
- How much direct clinical observation is needed at the undergraduate phase if a student has no intention of entering, for example, very physically demanding specialties like surgery or obstetrics?
- Could an ethic of interdependence in a clinical setting allow for sharing tasks?
- Is it sufficient for a physician to know the process, logic, and rationale for a procedure but not be able to do the procedure, and in what settings?

This type of deep consideration might identify a more focused list of essential qualities or dispense with technical standards altogether. Rather than a global policy that discourages and polices students, perhaps an evolving and customized analysis in relation to defined course and rotations competencies is more effective and inclusive. Course competencies ought also to be subject to the aforementioned analysis. Following Argenyi (2016), this analysis of the physician role must include disabled people, disability experts, legal scholars, and ethicists as meaningful decision-making partners to challenge implicit biases (Schwarz & Zetkovic, 2019).

A transformative approach to medical training assumes specialization and the potential for accommodations at later stages of training. This opens routes for early specialization or alternative participation in clinical rotations. For example, as one participating student with a physical disability suggested, could observation of surgery films be a permissible alternative to requiring a student to observe hours-long surgeries in person? The student argued that such films give a student a better view of the surgery than is available when observing in a crowded operating room, and do not force students who have no intention of pursuing surgery to endure the physical fatigue inherent to in-person observations. Determining possible suitable alternatives necessitates sustained consideration of the purpose of broad participation in all rotations.

At the same time, with expanded flexibility and alternatives medical schools must lean further into developing accessibility for full participation. The availability of alternatives should not foreclose the possibility of a student, for example, with a physical disability who desires a fully accessible, in-person surgical rotation. To this end, the transformation offers an explosion of possibilities for participation, with all students able to select the route that best

matches their learning and career goals in consultation with informed advisors. This requires not just fitting students in to where they already fit, but a collective project centered on possibility that asks: how could this happen? What could it look like? What might be the positives and drawbacks of taking this approach? This approach moves beyond forcing a student to fit (or excluding them) for the purpose of pluripotency.

With movement away from pluripotency and towards differentiation, new spaces open that broaden imagined communities of medical education and practice. As ten Cate (2014) suggested in his consideration of the 21<sup>st</sup>-century physician, assuming specialization shifts the trajectory of training as students move more quickly into focused learning. Assumed specialization signals movement away from a requirement for broad exposure to things students do not fully retain nor ever do again (ten Cate, 2014). This shift necessitates changes to the structure of licensing and residency training. In a transformative approach, the turn toward differentiation creates new possibilities for disabled students taken into consideration from the outset.

### **Toward interdependence**

The idea of the independent, autonomous physician is historical and continues to be deeply embedded in emerging training practices such as competency-based medical education. These models of training are oriented towards progressive independence in clinical procedures (Kennedy, Regehr, Baker, & Lingard, 2005). This goal of independence then drives trainee behavior. The quest or requirement to demonstrate readiness for independence sometimes manifests in ways that present risks to patient safety (Kennedy, Regehr, Baker, & Lingard, 2009a, 2009b). The centrality of independence persists despite movement away from solo practice, specialization, and increasing recognition of interdependence among trainees, supervisors, and healthcare teams (Sebok-Seyer et al., 2018). Moving beyond pluripotency, as described in the previous section, is a departure from conceptions of independence. Further embracing interdependence in the physician role advances disability inclusion and yields benefits for trainee and practitioner well-being.

Viewing the physician role as interdependent fosters an ethos of cooperation. In this way of working, all rely on others, not only disabled people. In some sense, this already happens in practice, however, the principle must be centered, particularly in training. Similar to the findings discussed in Chapter 5, several studies of medical students and residents have emphasized the cultural pressure trainees feel to act as if they are all-knowing and able to persevere in difficult situations and in the face of exhaustion in order to be seen as capable or credible (Beagan, 2001a; Grant et al., 2019; Han et al., 2015; Haas & Shaffir, 1987; Kennedy et al., 2009a; T. Taylor et al., 2019). Centralizing interdependence as a way of being and doing

medicine fosters a culture where cooperation and imperfection among all clinicians, particularly those most senior, is assumed, highly visible, and help-seeking is encouraged (Abaza & Nelson, 2018; Peters, Horn, & Gishen, 2018). Development of trainees' *discernment* or knowing one's limits, and relying on this aspect of self-regulation, is critical to successful interdependence. Discernment is already a dimension of trustworthiness measurements in the emergent area of *entrustable professional activities* (EPAs; Lomis et al., 2017). Further exploration of and reliance on discernment is beneficial to an interdependent orientation. This allows for the possibility that all practitioners are capable of most tasks, great at some, and not capable of others. Interdependence becomes a normalized reality, with responsibility shared between all rather than excluding some from practice.

Key to an interdependent culture is the ability for trainees and practitioners alike to practice vulnerability with each other. In this way of working, vulnerability is treated as an asset in an ethic of mutual care. Rather than competition, where individual accomplishments are valorized, cooperation is prized. Healthcare outcomes reflect a group effort rather than an individual's success. This benefits physician and trainee well-being, as vulnerability allows individuals to show weakness, revealing when they are uncertain or in need of support. This also encourages care for each other, through shared responsibility according to each person's ability with collective, excellent patient care the ultimate goal. A recent exploration of *educational safety*, the "subjective state of feeling freed from a sense of judgement by others such that learners can authentically and wholeheartedly concentrate on engaging with a learning task without a perceived need to self-monitor their projected image" (Tsuei, Lee, Ho, Regehr, & Nimmon, 2019, p. S32) provides initial insight into what this kind of educational environment might look like. This study of a medical school peer mentoring program found that supportive environments with nonjudgmental, unassessed, longitudinal relationships built these safe environments, which allowed students to let their performative guard down, unlike other learning environments (Tsuei, et al., 2019). With an underlying ethos of vulnerability as strength, educational safety has the potential to be leveraged beyond classroom spaces.

For disabled physicians, this kind of vulnerability and mutual care provides scaffolding to foster what Mingus (2011, 2017) referred to as *access intimacy*, "that elusive, hard to describe feeling when someone else 'gets' your access needs" (2011, para. 4). Mingus (2017) suggested access intimacy is a tool of liberation rather than logistically-focused surface-level inclusion or equality. Access intimacy recognizes access as relational and "calls on non-disabled people to inhabit [disabled people's] worlds" (Mingus, 2017, para. 19). This kind of access is only possible when we recognize that all humans are always already interdependent, relying on each other in myriad ways, and disabled people are not uniquely dependent (Mingus, 2017). A space where all participants are vulnerable with and reliant on each other

supports access that is not purely logistical and is instead a collective act. When access is not individualized and vulnerability is not judged, sharing one's needs with others becomes expected rather than risky, and resolving access concerns becomes a collective effort. Because all kinds of needs are recognized as collective, disability access is not seen as an individual problem but an aspect of the collective work that all desire to move through together. Challenges become opportunities to evolve and innovate group practice. Institutions might make resources available for teams to enhance their ability to work collectively. In this new context, conditions reflect an interdependent ethos, necessitating teams that work together regularly, able to develop strong, trusting, interdependent relationships (Holmboe, Ginsburg, & Bernabeo, 2011).

This section explored four aspects of capability that currently frame medical training and practice. I identified ways to rethink these aspects by starting from disabled lives. In recognition of the normative standards that center quantitative measures of productivity, a shift is needed that centers physician and patient needs and outcomes. This drives a new, qualitative assessment of what a physician can offer. Design from the perspective of crip time encourages flexible options to move through medical training that honors variety in speeds of learning and moving through the world. Likewise, a shift towards differentiation aligns with the specialist orientation of the medical workforce and allows for flexibility in modes of learning, levels of exposure, and focused training. Finally, assuming that physicians are interdependent professionals shifts expectations from individual mastery towards a recognition of vulnerability, partiality, mutual care, and shared responsibility. With these aspects in mind, I transition to a reconsideration of professional identity formation that fosters disability epistemology.

### **Fostering Disability Epistemology in Professional Identity Formation**

In order to realize a transformative approach, one must consider *disability epistemologies* (Garland-Thomson, 2017; Scully, 2008)—the ways of knowing the world developed through living with disability—as a resource to be cultivated in the project of professional identity formation. The theory of negotiating the capability imperative, presented in Chapters 4-6, describes a medical-education context that discouraged public identification with disability through implicit or explicit encouragement to cover (Yoshino, 2006) or remain silent about one's experience of disability. Although some students engaged their disability identities in educational and clinical settings, they did so in spite of repressive educational conditions with an understanding of possible risk. These findings align with recent studies that found disabled students had minimal opportunities to apply their lived experience in education and practice

and were uncertain how to do so within professional bounds (Battalova et al., 2020; Stergiopoulos et al., 2018).

The duty to cover or erase difference runs counter to the rhetoric of diversity in medical education, which extols the benefit of bringing a variety of people, particularly those who experience systemic marginalization, into the medical profession (Boursicot & Roberts, 2009; Cohen, 2004; Cohen et al., 2002; DeLisa & Lindenthal, 2012; Nivet, 2011, 2015; Ray & Brown, 2015). Diverse physicians, scholars argue, will benefit patients, peers, the educational experience, and the profession as a whole (Iezzoni, 2016; Nivet, 2011, 2015; Meeks, Herzer, & Jain, 2018; Meeks, Poulos, & Swenor, 2020; Young et al., 2012). Although the potential of these benefits is great, the enduring requirement to constrain one's difference raises questions about whether medical education has sufficiently engaged diversity in the educational process.

Some have likened medical education to a neutralizing process that works against beneficial difference (Beagan, 2000; Tsai, 2018), or treats students as “blank slates” thereby flattening, silencing, and erasing difference (Fergus et al., 2018). Exploring the construct of professional identity formation, Frost and Regehr (2013) identified conflicting discourses of standardization and diversity in medical education literature. They argued this discursive conflict creates discord for students when forming their professional identities, but is rarely explored in research. Professional identity formation literature, for example, has largely ignored the role of students' sociocultural identities, leading to a hegemonic perspective of a neutral learner that centers upper-middle class white men (Volpe, Hopkins, Haidet, Wolpaw, & Adams, 2019). This vision of a “neutral” learner dominates educational practice.

Similar to the aforementioned findings about disability, the few studies that engaged sociocultural factors<sup>14</sup> found that underrepresented trainees experienced difficulties in professional identity formation due to feelings of alienation from their professional and home cultures (Volpe et al., 2019). Certainly, not all students will respond alike, and aspects of standpoint epistemologies (Haraway, 1988) will persist in resistance to repressive conditions (Frost & Regehr, 2013), as demonstrated through acts of political disclosure and organizing described in Chapter 4. These findings suggest that simply including different kinds of students will not yield the intended benefits without shifts in educational approaches as well as attention to the formal and hidden curriculum.

I want to be clear that disabled students, and those who occupy other marginalized locations, have no duty to “claim” disability (Linton, 1998), politicize their experiences, ascribe to pride movements, or become disability justice advocates. They have no duty to

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<sup>14</sup> Notably, these 10 studies focused primarily on gender (7/10), while the remaining three focused on racialized and ethnic minority students, and one also examined class and sexual minority students. None explored disability and only one explored intersectional experiences.



pursue practice that serves marginalized communities (Michalec, Martimianakis, Tilburt, & Hafferty, 2017). Rather, my concern is that in the current conditions, these possibilities are actively discouraged or repressed while narratives that figure disability as individual inability or tragedy are perpetuated. This presents a particularly hostile environment for disabled students and underprepares them, and their non-disabled colleagues, to provide affirming medical care for patients with disabilities. In the following sections, I discuss transformative possibilities through curriculum and associated pedagogy, as well as community development and mentoring.

### **Curriculum and pedagogy beyond the curative imaginary**

Participating students reported that formal curricula about disability was overwhelmingly biomedically-focused, with rare reference to sociocultural models. Many participating students did not develop new understandings of disability through medical education. Those who were already familiar with disability studies and disability rights did not find these ideas alive in medical education. This recalls Mitchell and Snyder's (2015) assertion that "disabled people's social marginalization occurs in tandem with their neglect in educational materials" (p. 74), a condition that Nusbaum and Steinborn (2019) have theorized as *ontological erasure*, "the active erasing of certain body-minds from 'being' in the educational landscape" (p. 24). In response to such erasure, Nusbaum and Steinborn (2019) argue a "visibilizing" project is necessary.

A transformative approach to the formal curriculum embeds critical disability studies theory throughout training. At its heart, the curriculum identifies ableism as a structuring force in society that is interlocked with other forms of marginalization, most prominently racism (Annamma et al., 2013; Erevelles & Minear, 2010). To achieve this, the curriculum is imbricated, woven together in a holistic approach to anti-racist practice, queering and decolonizing medicine, and other critical projects to dismantle co-constitutive marginalization and resist siloed work (Waitoller & King Thorius, 2016). The curriculum seeks to counter what Kafer (2013) calls the *curative imaginary*, "an understanding of disability that not only *expects* and *assumes* intervention but also cannot imagine or comprehend anything other than intervention" (p. 27, original emphasis). This vision requires a fundamental shift from normalizing agendas that assert what is "normal" and "natural" in human bodies (Clare, 2017; Mitchell 2016). Such a curriculum instead emphasizes disability as socially constructed, political, and relational and lead students to critically "reinterpret their own experiences and taken-for-granted attitudes and practices" (Campbell, 2009b, p. 230). In addition to self-examination, the aim is for students to critically examine social conditions in the medical profession and practice, and act towards change.

This kind of curriculum would offer the opportunity for *all* students to understand disability differently and connect them to a broader social struggle. Through this learning, students develop a sociological imagination about disability, connecting personal troubles to public issues (Mills, 1959). This aligns with Garland-Thomson's (2017) vision for a disability cultural competency program that "build[s] an affect of pride and positive identity in people experiencing disability and in patients in waiting" (p. 332) and fosters "learning how to flourish as a person with disabilities, not just living as a disabled person trying to become nondisabled" (p. 335). This ethos is essential for disability epistemologies to flourish in medicine and broadly benefits all students who will soon treat, love, or be disabled people, if not already.

This transformative approach builds on existing suggestions to improve medical curricula about disability (Alliance for Disability in Health Care Education [ADHCE], 2019; Ankam et al., 2019; Bowen, Havercamp, Bowen & Nye, 2020; Campbell, 2009b; Iezzoni & Long-Bellil, 2012; Kirschner & Curry, 2009; Lynch, Last, Dodd, Stancila, & Linehan, 2018; Sarmiento, Miller, Chang, Zazove, & Kumagai, 2016; Symons, Morely, McGuigan, & Akl, 2014). An alternate vision for curriculum aims to address healthcare inequities for disabled people and associated curricular absences (Agaronnik et al., 2019a, 2019b; Carel & Kidd, 2017; Seidel & Crowe, 2017; Shakespeare & Kleine, 2013; WHO, 2011; Yee et al., 2018). Moreover, this vision pushes back on the common argument that no time is available in the curriculum for additional content (see, e.g., findings from Seidel & Crowe, 2017) with the assertion that disabled peoples' experiences of healthcare inequities comprise a deadly crisis that requires urgent, systemic attention. The propagation of alternative visions of disability and for disabled people throughout the curriculum, when combined with practical skills, shifts thinking about disability on multiple levels and, in turn, medical practice.

Critical pedagogy that incorporates disability studies theory into praxis pairs well with a transformative curricular project (Chinn, 2016; Dolmage, 2005, 2017; Gabel, 2002; Garland-Thomson, 2017; Goodley, 2007; Knoll, 2009; Waitoller & King Thorius, 2016). This type of critical pedagogical approach incorporates UD with practices attuned to developing students' critical consciousness (Freire, 1968/2000; Halman, Baker, & Ng, 2017; Kumagai & Lypton, 2009). Medical-education scholars who have applied Freire's (1968/2000) pedagogical theory explain that it involves "the development of an orientation—a critical consciousness—which places medicine in a social, cultural, and historical context and which is coupled with an active recognition of societal problems and a search for appropriate solutions" (Kumagai & Lypton, 2009, p. 782). In the context of disability, this necessarily includes development of students' understanding of medicine's complicity in eugenics histories including institutionalization and its contemporary echoes, structural and societal barriers that influence disabled peoples' health

and experiences of healthcare, and the curative imaginary. This requires illumination of healthcare barriers from disabled peoples' perspectives (see, for example, Disability Rights Education and Defense Fund, 2011). Rather than examining disability solely as biomedical pathology in need of cure and intervention, students learn about the ways constructions of disability have been used as tools of violence and how medicine profits from this violence (Clare, 2017; Dolmage, 2017; Kafer, 2013; Kudlick, 2013; Mingus, 2015). Moreover, students critically consider the tensions between care and cure, paying particular attention to what drives the necessity for "cure," such as ideas of defectiveness or imagined futures that medical interventions intend to free people from (Clare, 2017; Kafer, 2013). This would help to illuminate how ableism can operate in medical practice and the ways medicine can be wielded as a tool of liberation and oppression (Clare, 2017).

This pedagogical approach uses the creation of cognitive disequilibrium and dialogue as central techniques within a non-hierarchical learning environment (Freire, 1968/2000; Halman, et al., 2017; Kumagai & Lypson, 2009). Importantly, exploration of social conditions is combined with an emphasis on action (Sharma, Pinto, & Kumagai, 2018). Competency-based approaches for disability curricula offer concrete learning outcomes (ADHCE, 2019; Ankam et al., 2019; Kirschner & Curry, 2009), however, this can risk simplifying what is a complex process of "continuous critical refinement and fostering of a type of thinking and knowing. . . of self, others, and the world" (Kumagai & Lypson, 2009, p. 783). Unlearning ableism will be an ongoing process that will challenge traditional approaches and values that saturate the medical environment and wider society.

### **Community and mentoring**

In addition to formal curriculum about disability that incorporates critical pedagogy, a transformative approach resources community-building and mentoring. Dyrbye, Lipscomb, and Thibault (2020) named fostering social relationships as one structural measure needed to promote learner well-being, stating that programs should "intentionally promote and build relationships among learners and between learners and faculty and remove barriers to meaningful human connections in the learning environment" (p. 676). They note structured mentorship programs as one element of this endeavor. As described in Chapter 4, some participating students wanted spaces to share experiences, strategies, and build community with other students with disabilities. Organizing, when it occurred, happened in spite of active discouragement and lack of attention to the need for it among school officials. Mentoring was also inconsistent, with many students unable to locate disabled mentors, and non-disabled mentors largely unequipped to discuss disability-related concerns. Those students who did find disabled mentors or befriended disabled students described these relationships as essential to

their development. Disabled peers created spaces of basic understanding of everyday ableism that provided respite from stigma and shared strategies for navigating training. Mentors identified possible accommodations and provided needed advice.

Within a transformative approach, medical schools create space for and resource disability community development. Attending to this kind of space as a taken-for-granted benefit, rather than something students need to fight for, signals that organizing is positive and that gathering as a community is not stigmatized. Students have space to share experiences, celebrate disability cultures, and organize for change within and outside of their medical school. Community spaces, ideally, benefit students' positive disability-identity development and professional-identity formation (Forber-Pratt & Zape, 2017).

Mentoring is also resourced in a transformative approach. One approach to mentoring that may be beneficial for all medical students, and indeed all medical faculty, is *critical mentoring*, a “practice that challenges deficit-based notions of protégés, halts the force of protégé adaptation to dominant ideology, and engages in liberatory processes that trigger critical consciousness and an ongoing and joint struggle for transformation” (Weiston-Serdan, 2017, p.1). Critical mentoring challenges those approaches that encourage normalization in order to fit in and get ahead. Instead, it fosters collaboration between mentors and mentees to challenge oppressive structures (Weiston-Serdan, 2017). While Weiston-Serdan's (2017) approach is built on critical race theory, further development of a critical mentoring approach infused with critical disability theory, other critical theories such as queer theory, and intersectional theories such as DisCrit (Annamma et al., 2013) is possible and would be beneficial. Building an approach that considers disability aids the joint need for practical mentoring and collective system transformation. Within this approach, schools foster networks of diverse disabled physicians to serve as mentors and compensate their labor. Existing conditions for disabled medical faculty and practitioners are mixed, with significant barriers still in play (Neal-Boylan et al., 2012; Steinberg et al., 2002; Swenor & Meeks, 2019). Reflecting the core of the transformative project, a stance of desire and value towards disability, medical schools actively recruit disabled faculty, ensure their full access to the workplace, and recognize the diversity-related labor that inevitably accompanies their position.

## **Conclusion**

This chapter has deployed Kafer's (2013) politics of crip futurity to imagine a transformation of medical education that starts from an assumption that disabled people make excellent physicians. From this starting point, I have imagined various ways of conceptualizing and doing that shift the structures and underlying thinking that drives medical education. These

transformations aim to dismantle the capability imperative and broaden the understanding of capability in medicine through structural change. This transformative approach has examined ideas of productivity, time, pluripotency, and independence. Then, through considering the formal curriculum, pedagogy, and community support structures, I suggested changes in these areas that move towards an approach to education that fosters difference rather than neutralization in the process of socialization. This transformation has focused primarily on medical education, however, as the previous chapters have shown, medical schools are just one space and moment of medical training. A transformation necessitates broad application of these ideas across all phases of training and medical practice.

This new way of educating requires strong, creative, solution-focused support for all learners to consider their strengths, interests, and possibilities to engage in various professional environments. This transformation signals a possibility that entirely reimagines medical education, building from a starting point of inclusion through UD. This approach likely invokes initial discomfort, as principles of fairness tend to assume sameness rather than differentiation in practice. Furthermore, a total re-imagination of program structures may feel challenging, given outside pressures that privilege adherence to conformity. The potential for transformation hinges on a new ethos, one that fosters cooperation, interdependence, and collective benefit rather than individual success, assumptions of independence, and competition as driving principles. A radically new image of medical education and practice, one that centers justice while ensuring high standards of patient care, is necessary.<sup>15</sup>

The transformative project outlined in this chapter has focused on disability. At various points, ways to consider intersectionality and cross-movement transformation were also discussed. One example of cross-movement transformation was to consider the needs of parents and caregivers in tandem with those of disabled people (and disabled parents) when reconceptualizing productivity. These ideas converge with broader concerns in medicine. This exploration, however, represents only an initial discussion that suggests further points of departure. Despite stated commitments to diversify medical education (Cohen et al., 2002; Nivet, 2011, 2015), numerous projects have demonstrated the distance yet to be traveled to realize the promise of these commitments beyond the disability-focused concerns discussed here (Ackerman-Barger et al., 2020; Bleakley, 2013; Mansh et al., 2015; Phelan et al, 2019; Razack et al., 2019; Robertson, 2017; Teherani et al., 2018; Tsai, Ucik, Baldwin, Hasslinger, & George, 2016). A cross-movement transformation that employs UD to re-think medical education from a foundation of valued difference is required.

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<sup>15</sup> A version of this paragraph appears in Jain (2020a, pp. 9-10).

## Chapter 8. Looking Back and Moving Forward: Expanding the Narrative and Reaching for Transformation

### Four Research Recollections

*I am at the University of British Columbia on a visiting scholarship. We are comparing the experiences of students who accessed accommodations from my study with those of similar students in their Canadian study. The U.S. students do not have the same issues as the Canadians do when accessing accommodations; the U.S. logistics are much smoother. But similarities in student accounts of stigma cross the two contexts. Initially, I want to focus on the logistics, that is the finding, right? But Tal<sup>16</sup> pushes me. The persistent stigma is also important.*

*I am lying in bed, thinking about my data. I am searching for examples of structural action towards inclusion. An image of a tree comes to mind: They are pruning, the roots are undisturbed. Any structural solutions are focused on improving accommodations, not necessarily changing fundamental conditions. The next morning, I write in a memo “The culture seems to be shifting in small ways, but is wholly insufficient in the context of the bigger picture.”*

*I am in the Valley of Shit.<sup>17</sup> My mind, usually whirring with endless thoughts about my research, has gone completely quiet. We are housesitting in Devonport and I take a book to the beach. If I cannot think and I cannot write, maybe a book I have been meaning to read will wake something up. The book is Alison Kafer’s “Feminist, queer, crip” (2013). A door opens.*

*I have developed chronic insomnia leading up to a keynote about my research. I am worried about how a call for transformation will be received by disability service professionals and health science administrators. I fear they will think I have lost touch with the day-to-day work of inclusion. Jan and Jay encourage me to be bold, to articulate a reimagined future not just a reformed one. I conclude the talk with a reference to Kafer’s (2013) crip futurity. The talk goes well; my fears are unrealized. I head deeper into a journey to envision transformation.*

### Enduring Tensions

I began this thesis with snapshots from my professional life, working as a disability service provider with graduate health science students. I begin the final chapter with four snapshots of

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<sup>16</sup> Professor Tal Jarus, my host and mentor at UBC.

<sup>17</sup> Mewburn (2012) explains, “The Valley of Shit is that period of your PhD, however brief, when you lose perspective and therefore confidence and belief in yourself” (n.p.). In my experience, the Valley, however long and painful, is often followed by a period of significant growth.

my evolution through the research process. When I began, I had concerns about whether the available mechanisms for inclusion were sufficient, but I believed in their potential. Carefully leveraging legal principles, reforming institutional structures, improving accommodations, and individual education would address gaps in knowledge and get us closer to meaningful disability inclusion. I had observed powerful change at institutions through progressive realization of inclusive aims.

Looking back, I recognize my perspective was limited. I knew my experiences were anecdotal and further research was needed, but the immobility of larger systems had circumscribed my vision of inclusion. On the other side of this research project, I find it impossible to dismiss the limits of accommodations-focused inclusion in the hope of incremental change. A magic moment when incremental progress is realized will not come soon enough through the current mechanisms. Reform is insufficient, a reckoning with the capability imperative is necessary.

As significant as the rupture in my thinking has been, I admit to continued uncertainty when I consider the chasm between current conditions and a goal of transformation. The need for change is so dire and yet calling for transformation feels like a dangerous idea. Incremental change already feels radical and difficult. The insistence on transformation might reinforce ideas that disabled people are unsuited for the medical profession. Certainly, this is not true as disabled people already graduate from medical school, successfully, and work in the field. Yet, the qualitative experiences of these individuals demonstrate that ableism persists. While the need for a medical workforce that aligns with patient populations is desperately necessary, the full potential of diversification cannot be realized without transformation of existing systems, culture, and practice. Disabled people cannot be made responsible to fix the ableist system they are brought into and systems will not fix themselves in response to the mere presence of disabled people. Disabled peoples' perspectives and leadership is, of course, essential, as is increased representation, but the task also requires non-disabled people to commit not just to equity, but justice. As the scholar and activist Angela Davis proclaimed:

The assumption is that all we need is more diversity. . . but it must be combined with justice. . . Diversity without changing the structure, without calling for structural transformation, simply brings those who were previously excluded into a process that continues to be as racist, as misogynist [here I would add: as ableist] as it was before. (UVA Engineering, 2018, 53:50)

Without structural transformation, a requirement to assimilate will persist, with only incremental change possible. I fear this will never be enough to achieve the broader changes needed in medical care and in the medical profession. Despite my reservations, a collective effort towards transformation that seeks justice across multiple axes of difference is the way I can see to achieve a future where disabled people truly thrive as physicians and as patients.

Having discussed my own evolution in thinking and the tensions that remain, in the remainder of this chapter I reflect on the research undertaken and the core arguments made. I suggest the ways this thesis contributes to knowledge and discuss its limits with an eye to future research directions. I close the chapter—and the thesis—with a final reflection.

## **Core Arguments**

This thesis has centered on an exploration of the question: how is disability inclusion enacted in medical education? This research links to issues of ableism in medical education and practice. The findings that followed from the research have consequences for students with disabilities, the medical profession, and justice for disabled people. The study relied on a constructivist grounded theory methodology (Charmaz, 2014) that involved 52 semi-structured interviews, unobtrusive observations of space, and analysis of policy documents carried out at four U.S. medical schools. A total of 46 individuals participated in the research, of which 19 were students with disabilities and 27 were school officials (administrators, faculty, and staff).

Four core arguments were advanced, which can be summarized as follows. First, people operated with four conceptions of disability: individual inability, contextually produced, valuable difference, and a legal category entitled to rights. These conceptions of disability intertwined with *legibility* to influence recognition and possibilities for inclusion. Of the four discourses of disability, the understanding of disability as individual inability was hegemonic, it influenced all actions associated with inclusion.

Alongside constructs of disability, conceptions of medicine and the ideal medical practitioner were underpinned by a cultural logic, *the capability imperative*. This consisted of three motifs, the *selfless superhuman* physician, a “*real world*” of medicine, and the *malleable student*. The capability imperative represents a local manifestation of compulsory able-bodiedness and able-mindedness (McRuer, 2006) that further animated participant actions.

These ways of knowing disability and medicine interwove to impact how inclusion was enacted. That is, inclusion was enacted through a process of negotiating the capability imperative, wherein participants acted to *uphold the capability imperative*, *work the capability*, and *resignify capability*. The latter, in some instances, overlapped the previous two categories of action and tended to challenge the capability imperative. Here, the core argument is that inclusion ultimately followed Mitchell and Snyder’s (2015) logic of *inclusionism*. Schools allowed for disabled students’ participation in medical education to the degree that they could meet existing expectations without fundamentally shifting the underlying ableist structures, aided primarily by contestable, individual accommodations.

This is not to say resistance did not happen. We saw in chapter 4 that resistance does occur, through *political disclosure*, organizing, and select UD efforts. In chapter 6 these



resistant acts joined others in the category of resignifying capability. These acts were informed by subjugated discourses of disability as valuable, borne of context, and entitled to rights, as well as actors' deep sense of frustration. Although important to acknowledge, these resistant acts were not able to dislodge the hegemonic view of disability and the capability imperative. These actions were generally not organized, they emerged from the margins, were often discouraged, and were not ultimately structured into the way things work. This is not to critique those who attempted to resignify capability or minimize their efforts, nor demonize those who attempted to fit conditions through upholding or working the capability imperative. Rather, as Butler (1998) noted, the task is to join these efforts to transform hegemonic social conditions.

Finally, grounded in principles of UD and following a politics of crip futurity (Kafer, 2013), I suggested routes to systemic transformation that start with the premise that disabled people are valued in medical education. This begins by reconceptualizing who is needed in medicine and continues by redesigning education and practice accordingly. The core argument is that the capability imperative can and must be dismantled, with notions of capability reconceptualized. To exemplify this, I offered routes towards reconceptualization of traditional notions of productivity, time, pluripotency, and independence. To reform notions of disability towards an ethos of value, disability epistemology is fostered in professional identity formation through curriculum, pedagogy, community-building, and critical mentoring.

## **Contributions to Knowledge**

This thesis makes contributions to knowledge in three areas: the mechanisms for inclusion in medical and higher education; theories of ableism, crip theory, and crip futurity; and the medical profession and medical education.

A key contribution is to the scholarly discourse on mechanisms for inclusion in higher and medical education. As discussed in Chapter 2, there is a large scholarly discourse on the effectiveness of accommodations, as well as accommodation-oriented practice. This thesis joins existing critiques of accommodations and other individualizing approaches for disability inclusion (see, for example, Dolmage, 2017; Hobbs & Pothier, 2006; Krebs, 2019), extending them into the realm of medical education. Practice guidance in medical education is almost entirely focused on ways to implement and improve accommodations (see, for example, Meeks & Jain, 2016). Notably, even in disability-inclusion research that has found similar inequities to those raised in Chapters 4 and 5, existing studies have not problematized accommodations (Bulk et al., 2017, 2020; Easterbrook et al., 2015, 2019; Kim, 2015; Meeks & Jain, 2018; Newlands et al., 2015; Stergiopoulos et al., 2018). By raising questions about the reliance on accommodations to achieve inclusion, the thesis brings a new perspective into

the discourse of disability inclusion in medical education. In this critique, I do not mean to suggest that accommodations are obsolete, but rather that greater attention to its limits is needed. Accommodations may advance individual access, but they do not disarm the capability imperative.

Through the articulation of a transformative approach in Chapter 7, the research contributes to the UD discourse, which, to my knowledge, is heretofore limited in the medical education context. By imagining UD on a systemic level, this extends the use of the concept, which has often focused on singular spaces such as the built environment (e.g., a building or an object), the digital environment (e.g., a website), or the instructional environment (e.g., curriculum and pedagogy of a course). This follows Burgstahler's (2012) application of UD to all aspects of postsecondary environments and adopts the critical UD ethos advocated by Hamraie (2012, 2013, 2016, 2017) and Dolmage (2017). Because professional education programs are total educational systems closely linked to the professional realm, the systemic application of UD represents a necessary approach to disrupt the capability imperative: examination and reorientation of the total system towards inclusion rather than piecemeal attention to singular elements of the educational environment.

This thesis also offers contributions to theories of ableism and crip theory. I have differentiated between realist and constructivist epistemologies and ontologies of disability, and discussed the various social arrangements that follow from each frame. The findings of this research have called the realist framing of disability into question but have also explored the limits of a social or minority-model approach. This adds to existing critiques of the normalizing tendencies of the social and minority models (Withers, 2012) and of the approach embodied in the ADA and ADAAA, which reinscribes an individualizing, medicalized approach to disability (Donogue, 2003). I have engaged theories in ableism (Campbell, 2001, 2009a, 2017, 2019; Dolmage, 2017), crip theory (McRuer, 2006), and allied theory of a political-relational model of disability (Kafer, 2013) to explore the conditions that uphold the false dis/ability binary and work to dissolve them. My concept, the *capability imperative* adds to the discourse of ableism and crip theory, and in particular academic ableism (Dolmage, 2017), to illustrate the maintenance of hyper-ableism in spaces with high performance requirements and with public responsibilities attached. Furthermore, my transformative exploration in Chapter 7 represents a new application of Kafer's (2013) politics of crip futurity in the context of medical education.

Finally, this thesis contributes to knowledge about the medical profession and medical education. The research raises questions about the structure and purpose of medical education. In particular, can we continue to operate with a training model that aims to calibrate workers to an existing machine? This adds to the existing scholarly discourse on diversity and well-

being in medical education (Ackerman-Barger et al., 2020; Dyrbye et al., 2020; Nivet, 2015). I suggest that education systems plan for diversity from the beginning, creating training environments that are intentionally inclusive by design. This requires allowance for variety in ways of being and doing as well as actively seeking ways for diversity to flourish in the process of education. Aligned with critical conceptions of access and UD (Dolmage, 2017; Hamraie, 2012, 2013, 2016, 2017), this shift prioritizes a justice-oriented mission, rather than compliance, cost-savings, neutralized post-disability narratives of “eliminating disability,” or depoliticized notions of the universal. This challenges the imposition of programming that seeks to standardize learners and mechanize the professions in ways that are anti-human. For example, in Chapter 7, I discussed alternatives to notions of productivity that shift from prescriptive, quantitative outcomes to qualitative measures in order to measure a capable and valuable practitioner differently. This positioning aligns with existing work in medical education calling for engagement of difference in professional identity formation (Fergus et al., 2018; Frost & Regehr, 2013; Volpe et al., 2019), those calling for change to medical education curriculum and pedagogy to foster critical reflexivity (Kumagai & Lypson, 2009; Tsai et al., 2016), and calls for structural change to foster learner and practitioner well-being (Dyrbye et al., 2020).

## **Limits and Future Directions**

There are at least four limits to this thesis, which suggest directions for future research.

*Wider examination of medical school practices:* This thesis explored the circumstances at four medical schools that met certain indicators suggesting they may be more advanced in their inclusion practices. Future studies should seek to understand institutional conditions at other types of schools. As demonstrated in this thesis, however, simply meeting certain indicators did not yield wholly positive conditions for students. Further interrogation of the tentative indicators of advanced inclusion used in this study (discussed in Chapter 3) may be beneficial to refine them or reject their importance.

*International comparative work:* The U.S. context of this study brings particularities, such as the structure and culture of medical education, and legal framework for disability rights. In the U.S. framework, for example, fairly strong legal precedents provide sticks to drive compliance. Exploration of inclusion in other national contexts would be valuable to understand whether concepts developed in this thesis hold, show nuanced differences, or illustrate other positives and challenges. Existing research in Australia (Shrewsbury et al., 2018), the UK (Newlands et al., 2015; Shrewsbury, 2018; Tso, 2017), and Canada (Bulk et al., 2017, 2020; Easterbrook, 2015, 2019; Kim, 2015; Stergiopoulos et al., 2018) suggests resonance with the findings of this thesis in international contexts, but cross-national research

and deep exploration would aid this examination. Particularly beneficial would be exploration of possibilities and arrangements in international contexts that may benefit inclusion outside of a U.S.-oriented compliance framework and associated practices.

*Understanding the extent and reach of the capability imperative:* The capability imperative, I argued in Chapter 6, is a context-specific manifestation of ableism and compulsory abledness in medical education. The concept may, however, have resonance in other spaces, including more broadly in health science education and in other professional education contexts. Further exploration of disability-inclusion experiences in other disciplines with public accountability, such as law, teacher education, psychology, and social work would benefit an understanding of how pervasive the construct is throughout other professional educational spaces and into the world of professional practice.

Perhaps most importantly, the capability imperative as an agent of ableism is an underlying logic that impacts everyone. Students with disabilities are an obvious group highly impacted by ableism. If the capability imperative is, indeed, a hegemonic and unreachable standard, like other conditions such as hegemonic masculinity, its effects will be widespread. In Chapter 5, I noted that students linked their experiences, which I have characterized as illustrative of the capability imperative, to the crisis of burnout, poor mental health, and suicidality in medicine. This suggests a broader effect, beyond disability, of this cultural logic. Research that explores the capability imperative from the perspectives of all medical students and medical professionals would bring the concept into clearer view and expand understandings of its implications and adverse effects. This could further aid efforts towards its dissolution.

*Building the foundations under possibility-focused imagining:* Finally, the ideas I put forth in Chapter 7, Transformative Practice, are speculative, a necessary step to imagine a better world. The moves I have suggested, as well as possible ways beyond those ideas, warrant further philosophical consideration and debate. Of course, in my view, philosophical debate entails the notion of praxis. That is to say, the meaning imputed to concepts is replete with implications for practice. My hope is that the speculative future I have imagined provides fruit for continued contestation—even if others judge the fruit not ready for picking, or worse, already rotten.

## **Final Reflection**

In an interview for this thesis, a student recalled Chimamanda Ngozi Adichie's 2009 TED talk, "The Danger of a Single Story." Adichie's (2009) talk described the need for multiple, overlapping stories to broaden our understanding of others. The student invoked Adichie's (2009) concept to crystalize her frustration with the way her medical school's curriculum

represented Black and brown people, mostly from a singular position of deficit and dismal medical statistics. She also recalled the limited stories told in her classes about disability, until one day a story aligned with her own experiences. An instructor noted that very smart adults can be diagnosed with AD/HD late in life when they hit a wall in their immense coping resources. The story at once felt like a spark of recognition, the power of a new story, but its danger was also discernible. What did this singular story of AD/HD signal to her peers about those who had been diagnosed earlier in life? Would this story suggest that those with earlier diagnoses were not smart? After all, the diagnosis was said to hinge on hitting a wall, intimating that they long lacked coping mechanisms. There were so many more stories of AD/HD waiting to be told, needing to be told to characterize the complex picture for her burgeoning physician peers, and to honor the stories of her friends. Adiche (2009) explained the role of power in the single story:

It is impossible to talk about the single story without talking about power. There is a word, an Igbo word, that I think about whenever I think about the power structures of the world, and it is “nkali.” It’s a noun that loosely translates to “to be greater than another.” Like our economic and political worlds, stories too are defined by the principle of nkali: How they are told, who tells them, when they’re told, how many stories are told, are really dependent on power. (9:33)

The student’s experiences with the single story tell a story about power, about what is known, whose stories are foregrounded, and from what lens and whose viewpoint.

Adichie’s (2009) concept of the single story aligns with the throughline of this thesis. The stories of disabled people in medicine are limited, as are the discourses that dominate understandings of disability and disabled peoples’ experiences. The mechanisms for inclusion discussed and implemented are also narrow. The paucity of stories about disabled people in medicine limits our inclusive imagination, about what disability can mean and what is possible. We need more stories, told from different perspectives, that engage with and call out multiple axes of power, and bring in a variety of theories of disability and inclusion.

In this thesis, I have attempted to tell new stories from different perspectives, and engage theory in new ways, however partial and incomplete this endeavor has been. As a temporarily non-disabled person, I have attempted to interrogate my own practices and complicity with the system of ableism in the course of this research. In the Introduction, I reflected on my internal conflict as a person who held positions of power and authority, and my attempts to shift ableist systems from the inside. I have questioned whether the mechanisms I have advocated for are sufficient and have become convinced that my work has thus far been insufficient. New ideas, new ways, and new energy toward system transformation are necessary.

At the same time, this thesis again tells a single, albeit collective, story from a specific viewpoint. In our discussion, the student longed for a statement to accompany stories that risked fulfilling stereotypes, to signal the author's meta-understanding of the single-story dilemma for the reader. So, this is my statement: This thesis is but one story, please do not take this to represent all stories, there are many more to be told from different angles and in different ways. I add this story to the collection with the hope that it brings a new lens to disability inclusion in medical education and that the collection of stories we tell, our ways of knowing, continues to expand and transform our ways of doing.

# Appendix A. Semi-Structured Interview Guides

## I. Students

### Background

1. What led you to pursue medical training?
2. How did you decide which medical schools to apply to?
3. What influenced your decision to attend this medical school?

### Access and accommodations

1. Tell me about your experiences as a medical student with a disability so far. Are there events that stick out in your mind?

**Follow up:** Can you describe [event]? How have they affected your medical school journey? How did you respond to [event/experience]?

#### Key time periods to explore:

- Admissions process
  - Orientation
  - 1st two years (experiences in classroom and labs)
  - Clinical years (transition)
2. Can you describe your experiences accessing accommodations in medical school?  
**Follow up:** What are your thoughts and feelings about these experiences? How have you managed challenges that have arisen?

#### Areas to explore:

- Use of formal channels
  - Finding out about services
  - Process to access accommodations (registration, implementation)
  - Experiences with disability services
  - Experiences with faculty
  - Accommodations in clinical settings
3. Are there other aspects of the university experience that stand out?  
**Follow up:** Can you describe [aspect]? How has this affected your experience as a student? How did you respond to [event/experience]?
- #### Areas to explore:
- University housing
  - Physical environment
  - Libraries
  - Classroom access
  - Student life (clubs and activities)
  - Online materials (course management system, lecture capture)
4. How have you navigated disability-related barriers you have experienced in medical school?

**Follow up:** Can you describe barriers? What or who has been helpful in this process?

#### Areas to explore:

- Curricular
- Attitudinal
- Programmatic

- Physical
- Policy

### **Disclosure**

1. Can you tell me about how you navigate disclosing your disability in medical school

#### **Areas to explore:**

- How did you learn when and how to disclose?
- What drives your decision to disclose or not?
- Differ by audience? (peers, faculty, supervisors, patients)
- What support or advice have you received?

### **Campus Climate**

1. How would you characterize the climate of your medical school towards students with disabilities?

#### **Follow up:**

- How do you “know” the climate (signs, signifiers, experiences)?
- How does this affect you as a student?
- Is there anything you have done to affect the climate related to disability?
- If negative climate: What would change/improve this?
- How do you compare this to the climate for other diverse communities on campus?

2. Please tell me about your sense of belonging at medical school.

#### **Follow up:**

- How do you know/characterize whether you belong?
- If applicable: What kinds of things would improve your sense of belonging?
- If applicable: How do you navigate that feeling of not belonging?

3. Can you describe a safe space where you feel you can be “out” about your disability, fully express all aspects of your identity?

**Follow up:** What about at medical school – do you have a safe space and what does it look like?

4. Can you tell me about how disability is discussed in your classes and in the clinic?

#### **Follow up:**

- Thoughts and feelings about experiences
- Ideas about what could be done differently

### **Supports and Challenges**

1. Who has been most helpful to you while in medical school? How have they been helpful?

#### **Areas to explore:**

- Faculty
- Mentors
- Online community
- Peers
- Family

2. What other supportive factors have been present? How have they been supportive?

#### **Areas to explore:**

- Formal university programs or services
- Online resources



- Student groups
- Informal resources

3. What have you found to be most challenging about being a medical student with a disability? Why? How have you navigated this challenge?

### **Closing questions**

1. In a perfect world, tell me what would positively impact your experience as a student with disability in medical school.
2. What do you think are the most important ways to navigate medical school as a disabled student? How did you discover them?
3. What advice would you give a person with disability interested in going to medical school?
4. Is there something else I should know to understand your experience as a medical student with a disability better?
5. Is there a question you wish I had asked? Is there anything you would like to ask me?

## **II. Disability Service Providers**

### **Role**

1. Can you tell me about your role at the university?
  - Follow up:** How did you come to do this work? What other roles do you hold at the medical school?
2. How do you conceptualize your role as a DSP within the larger medical school community?

### **Accessibility and accommodations**

1. Tell me about the work you do to create an accessible medical school environment for students with disabilities
2. Can you tell me how you go about determining accommodations for students at the medical school

#### **Areas to explore:**

- Interactive process
  - Clinical accommodations process
  - Who is included
  - Role of student
  - Deference to faculty
  - Role of disability documentation, licensing requirements
3. What initiatives to improve access, beyond accommodations, are in place at your medical school?

**Follow up:** How did they come about? What have they achieved? If none – what has prevented pursuing this work? What would you like to see?

#### **Areas to explore:**

- Community building
- Campus committees
- Curriculum

### **Policies and Procedures**

1. Can you share how you go about developing policies and procedures for disability services?

**Follow up:** How did you develop this process?

**Areas to explore:**

- Who is involved?
  - How frequently
  - What is taken into consideration?
2. How are you involved in medical school policy creation or revision?  
**Follow up:** Describe what you have been involved in. How did you come to be included?

**Challenges and Successes**

1. How do you navigate the challenges you face in your role as a DSP?  
**Follow up:** What are the sources of these challenges? Who/what is helpful in resolving them? What gets in the way of resolving challenges?
2. What kinds of concerns do you hear from the students you work with?  
**Follow up:** Describe the concerns. What are the sources? What have you been able to do to support students? What have you done in response to student concerns?

**Areas to explore:**

- Physical
  - Curricular
  - Clinic
  - Interpersonal/Attitudinal
  - Digital access
3. Similarly, what concerns and challenges do you hear from faculty regarding students with disabilities?  
**Follow up:** Describe the concerns. What are the sources? What have you been able to do to support faculty? What have you done in response to faculty concerns?

**Campus Climate**

1. How would you characterize the climate of your medical school towards students with disabilities?  
**Follow up:**
  - How do you “know” the climate (signs, signifiers, experiences)?
  - How does this affect your work as a DSP?
  - Is there anything you have done to affect the climate related to disability?
  - If negative climate: What would change/improve this?
  - How do you compare this to the climate for other diverse communities on campus?

**Closing Questions**

1. In a perfect world, what would you do to improve the medical school experience for students with disabilities?
2. What do you think your medical school does very well in creating an accessible environment for students with disabilities?  
**Follow up:** Do you recall how that came about? Why do you think it works so well?
3. What work have you done as a DSP that you are most proud of?
4. What do you think are the most important ways DSPs can create welcoming medical school environments for students with disabilities?
5. How did you discover these techniques?
6. Is there something else you think I should know to understand your work as a DSP better?
7. Is there a question you wish I had asked?
8. Is there anything you would like to ask me?

### III. Faculty and Administrators

#### Background

1. Can you tell me about your experiences at the medical school working with students with disabilities?

**Follow up:** Are there events that stick out in your mind? Can you describe [event]? How have they affected your approach to working with medical students with disabilities? How did you respond to [event/experience]?

#### Areas to explore:

- Mentoring
- Determining accommodations
- Implementing accommodations
- Structural/policy
- Disciplinary
- Training
- Formal or informal roles

2. What role do you have in supporting medical students with disabilities?

**Follow up:** How did that role develop?

3. What concerns do you have regarding students with disabilities in medicine?

**Follow up:** Describe the concerns. What do you think are the sources? What have you done to address these concerns?

#### Access and Accommodations

1. In thinking about students with disabilities, what role do you have in creating an accessible medical school environment for this community?

**Follow up:** Can you tell me about the work you have done in that role? What drove you to take up that role?

2. What policies/procedures regarding disability and accommodations work well? What doesn't?

**Follow up:** Why are they working/not working well? How have you worked with students and other university staff to address these policies or procedures?

3. What support have you received from the school in understanding your obligations to students with disabilities?

**Follow up:** How has this affected your work with students? What additional support do you feel is needed?

## **Challenges/Successes**

1. What challenges do you see in the way your medical school currently operates with regard to students with disabilities?

**Follow up:** What do you think could be done to improve disability support at your school? What steps have you taken to address these challenges?

2. What challenges do you experience working with students with disabilities?

**Follow up:** What is the source of these challenges? What have you done to address these challenges? What more is needed?

### **Areas to explore:**

- Physical
- Curricular
- Clinic
- Interpersonal/Attitudinal
- Digital access

3. What concerns do you hear from students with disabilities?

**Follow up:** What is the source of these concerns? What have you done to address these concerns? What more is needed?

4. What do you think your medical school does very well in creating an accessible medical school environment?

**Follow up:** Do you recall how that came about? Why do you think it works so well?

5. What do you think your medical school does very well in supporting medical school students with disabilities?

## **Campus Climate**

1. How would you characterize the climate of your medical school towards students with disabilities?

### **Follow up:**

- How do you “know” the climate (signs, signifiers, experiences)?
- How does this affect you as a student?
- Is there anything you have done to affect the climate related to disability?
- If negative climate: What would change/improve this?
- How do you compare this to the climate for other diverse communities on campus?

## **Closing questions**

1. In a perfect world, what would you do to make medical schools more accessible to students with disabilities?

2. What do you think are the most important ways faculty/administrators can create welcoming medical school environments for students with disabilities? How did you discover these techniques?

3. Is there something else about your experiences you want me to know?

4. Is there a question you wish I had asked?
5. Is there anything you would like to ask me?

## **Appendix B. Institutional Recruitment Materials**

### **Recruitment Email**

Dear [NAME OF MEDICAL SCHOOL DEAN/CHANCELLOR],

My name is Neera Jain. I am a doctoral candidate at the University of Auckland, Faculty of Education and Social Work, School of Curriculum and Pedagogy.

I am writing to request approval to conduct a research study at your medical school. The focus of the study is to learn more about how medical schools are creating accessible environments for students with disabilities, and to explore the issues, challenges, and best practices involved in this process. With approval, I would recruit medical students, faculty, and staff of your institution for interviews.

[NAME OF UNIVERSITY] is of particular interest as a site for this research because I have identified promising practices regarding inclusion of students with disabilities at your medical school.

Attached please find a Participant Information Sheet that provides greater detail about the study, and an Institutional Consent Form for your consideration.

This project has been approved by the University of Auckland IRB. No participating institutions will be named in research, and multiple institutions will be included to further mask identities.

I would welcome the opportunity to speak to you regarding this project, and answer any questions you might have.

Thank you in advance for your time and consideration.

Best,

Neera Jain

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, Reference: 018365

### **Attachment to email: Sample questions**

#### **Sample questions (Students):**

- Tell me about your experiences as a medical student with a disability so far. Are there events that stick out in your mind?
- Please describe your experiences accessing accommodations in medical school.
- How have you navigated disability-related barriers you have experienced in medical school?
- How would you characterize the climate of your medical school towards students with disabilities?

- Please tell me about your sense of belonging at medical school.
- Who has been most helpful to you while in medical school? How have they been helpful?
- What have you found to be most challenging about being a medical student with a disability? How have you navigated this challenge?

**Sample questions (Faculty and Administration):**

- Tell me about the work you do to create an accessible medical school environment for students with disabilities
- Can you share how you go about developing policies and procedures for disability services?
- How do you navigate the challenges you face in your role?
- What kinds of concerns do you hear from students with disabilities?
- How would you characterize the climate of your medical school towards students with disabilities?
- In a perfect world, what would you do to improve the medical school experience for students with disabilities?

# Participant Information Sheet: Institutional Leader



**EDUCATION AND  
SOCIAL WORK**

School of Curriculum and Pedagogy  
Private Bag 92601  
Auckland 1135, New Zealand

## Participant Information Sheet – Dean/Chancellor

4/13/17

Project title: **A culture of access? The medical school social environment for students with disabilities**

My name is Neera Jain. I am a doctoral candidate at the University of Auckland, Faculty of Education and Social Work, School of Curriculum and Pedagogy, supervised by Professor Janet Gaffney and Dr. Jay Marlowe.

I am writing to you to inform you of a research study that I would like to conduct and ask if you would consider allowing me to interview medical students, faculty, and staff of your institution. The focus of the study is to learn more about how medical schools are creating accessible environments for students with disabilities, and to explore the issues, challenges, and best practices involved in this process.

### **Why is this study being done?**

I expect that the results of this project will help to inform the creation of more accessible and welcoming medical school experiences for students with disabilities. I believe that the perspectives of medical students with disabilities, medical school faculty and staff will help to inform an understanding of the current climate for medical students with disabilities, and how to enhance medical school (and by extension other professional training) environments nationally.

### **What would be involved?**

This study involves a short online questionnaire and interviews. I am writing to ask if you would consider providing consent to conduct this research with employees and students with disabilities from your institution to do the following:

1. Complete a short online questionnaire (10 minutes or less)
2. Individual interview (1-2 hours)

Participating university staff and students will be asked share information in interviews regarding the medical school's provision of equal access to students with disabilities. However, the information will be focused on institutional processes and challenges more globally. Furthermore, no participating institution will be named in research, and multiple institutions will be involved in order to mask the identity of institutions in the final report.

*Students:* Broadly, students will be asked about their experiences accessing the university and obtaining accommodations, the campus climate, supports and challenges.

*Faculty/Administrators:* Broadly, faculty and administrators will be asked about their experiences with accessibility and accommodations for students with disabilities including policies and procedures, successes and challenges. They will also be asked about their perception of the campus climate for students with disabilities.

The interviews will be audio recorded. Only my supervisors (Dr. Janet Gaffney and Dr. Jay Marlowe), a professional transcriber, and I will have access to these audio recordings. The professional transcriber will have signed a confidentiality agreement. After the research is conducted, participants will have four weeks in which they can decide to remove their participation in the study.

### **Institutional Consent**

PAGE 1 of 3



Before I recruit any participants from your institution, I request that you as the Dean/Chancellor of this medical school/university sign a consent form providing assurance that any student or staff member's participation or non-participation in this study will not affect their professional relationship with you or compromise their standing with the university.

### **Recruitment of participants**

If you agree for this study to take place, I would request that the school send an advertisement to all medical students and medical school faculty regarding the study. I will contact several key administrators (e.g., medical school disability services provider, medical school dean of students, and the equal opportunity/affirmative action officer) directly to invite them to participate. Interested parties would be directed to contact me directly to participate. You would not have any knowledge of who chose to participate or not in order to protect participant confidentiality.

### **What risks are expected for participants?**

In the unlikely event that a participant was to become distressed, they would be advised to seek assistance through the university's Employee Assistance Program (employees) or the student counseling center (students). It is important to note that participants can decline to answer any questions and can leave the interview at any point.

All participants will be provided institutional and external channels to discuss perceived concerns with university practices or treatment. Faculty and staff will be directed to contact the campus legal counsel for advisement. As researcher, I will not provide advisement to participants regarding the experiences and practices shared in their interview.

### **Will participants be compensated?**

Participants will not be provided any compensation for their participation in this study. However, any costs for disability-related accommodations needed to participate (e.g., sign language interpreters, CART) will be covered.

### **Will information about participants be kept confidential?**

Information from this study will be kept in a secure location on my computer and accessible only to my supervisors and myself. Participant and institution names will not be used in any subsequent publications or presentations. However, I cannot guarantee total confidentiality. Participant information may be given out if required by law.

The information from this study will be safely stored and locked by Dr. Janet Gaffney in a filing cabinet or a secure computer at the University of Auckland for six years. After this time, this information will be destroyed.

### **Reporting of the study**

The information from this study will be published in my doctoral thesis, and may be published in a report or academic journal articles. Specific universities and participant identities will not be disclosed.

I will make a public presentation about the study at the University of Auckland once it has been completed. Again, specific universities and participants will not be identified in this presentation or in any subsequent reports or presentations.

### **Your rights and choice**

It is your right and choice to take part or not consent to this research. If you have any questions about this study, please use the contact details below:

Student Researcher	Supervisor
Neera Jain Email: <a href="mailto:njai104@aucklanduni.ac.nz">njai104@aucklanduni.ac.nz</a>	Dr. Janet Gaffney University of Auckland Faculty of Education Private Bag 92 601 Phone: +64 9 6238899 ext 48323 Email: <a href="mailto:janet.gaffney@auckland.ac.nz">janet.gaffney@auckland.ac.nz</a>
Head of School	Local Contact
Dr. Helen Hedges University of Auckland Faculty of Education Private Bag 92 601 Phone: +64 9 373 7999 Email: <a href="mailto:h.hedges@auckland.ac.nz">h.hedges@auckland.ac.nz</a>	TBD

### More about the researcher

I am also a consultant to the University of California, San Francisco Student Disability Services office, though I do not provide services to the UCSF School of Medicine. I am a board member of the Coalition for Disability Access in Health Science and Medical Education. I conduct this research in my role as a doctoral student at the University of Auckland.

### Thank you

Thank you for taking time to read this Participant Information Sheet. If you have further questions please let me know. I am also happy to send you a consent form if you are willing for medical students, faculty, and administrators from your university to participate in an interview. The best way to reach me is by email: [njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz)

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone +64 9 3737599 ext. 83711. Email: [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz).

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, Reference: 018365

## Consent Form: Institutional Leader



**EDUCATION AND  
SOCIAL WORK**

School of Curriculum and Pedagogy  
Private Bag 92601  
Auckland 1135, New Zealand

### CONSENT FORM (DEAN/CHANCELLOR)

THIS FORM WILL BE STORED SAFELY FOR SIX YEARS

Project title: **A culture of access? The medical school social environment for students with disabilities**

Student Researcher: Neera Jain, Doctoral Candidate ([njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz))

Supervisor: Professor Janet Gaffney ([j.gaffney@auckland.ac.nz](mailto:j.gaffney@auckland.ac.nz))

If you agree to provide consent for employees and students of your institution to participate in the research project as described in the Participant Information Sheet, please complete this form.

I \_\_\_\_\_ (your name)

Hereby provide consent for you to conduct interviews with students and employees from NAME OF SCHOOL as requested in the research project mentioned in this form by signing below.

I acknowledge that I have read the information provided in the Participant Information Sheet and acknowledge the following:

- I understand it is my choice to consent or not consent to this study with respect to recruiting participants who are students and employees of the university I work for.
- As Dean/President/Chancellor of this Medical School/University, I agree that anyone's participation or non-participation in this study will not affect their relationship with me or the university they work for or study at.
- I understand that University staff will not have direct knowledge of who participated or did not participate in this study.
- I know who to speak to if I am concerned or would like to ask questions about this study as outlined in the Participant Information Sheet.
- Although absolute confidentiality cannot be guaranteed, I understand that participants and universities will not be identified by name and that other identifying information will be changed in any presentations or publications. I understand that information will be shared if required by law.
- I acknowledge that interviews will be audio recorded and transcribed.
- I understand that the information from this study will be safely stored and locked by Dr. Janet Gaffney in a filing cabinet or secure computer at the University of Auckland for six years. After this time, the information will be destroyed.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON:  
December 15, 2016 for 3 years, **Reference: 018365**

## **Appendix C. Recruitment Emails to Individual Participants**

### **Student Recruitment Email**

Dear Students,

Are you a student with a disability studying medicine? Are you interested in sharing your experiences in medical school?

You are invited to participate in a research study called: **A culture of access? The medical school social environment for students with disabilities.**

My name is Neera Jain and I am a non-disabled doctoral student at the University of Auckland, Faculty of Education and Social Work.

I am looking to learn more about the medical school environment for students with disabilities. The study will explore the issues, challenges, and successful practices involved in creating an accessible social environment. All experiences of disability (learning, psychological, physical, sensory, chronic health, and AD/HD) will be included in this research.

The study will include the perspectives of students with disabilities, disability services providers, faculty, and administrators, and will examine the policies, physical and digital environments created by schools.

Participants will be asked to:

1. Complete a short online questionnaire (10 minutes or less)
2. Complete a 1-2 hour in-depth interview with the researcher at your convenience.

Interviews will take place via Skype, phone, or in person depending on your preference and availability.

Your school has provided assurance that participation in this study will not affect your relationship with the university. They will not be informed if you decide to participate, nor will they have access to the information you share with me. Your identity, and the identity of your medical school will not be revealed in any resulting reports or publications.

I hope that the information collected as part of this research study will help to develop a better understanding of the current environment for medical students with disabilities, and what might be done to improve it. This study will be used to develop my doctoral thesis, as well as for scholarly publications and trainings, and a goal is to create suggestions for policy improvements at medical schools.

Your participation in research is voluntary.

#### **More about the researcher:**

I am the Policy Advisor to the Coalition for Disability Access in Health Science and Medical Education. I have worked in disability rights organizations and in United States universities

with health science students with disabilities for over 10 years. I am dedicated to advancing understanding and support for individuals with disabilities studying medicine.

If you are interested in participating in this study, please contact me at [njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz). Attached please find a Participant Information Sheet with detailed information about the study and a consent form for your review.

Thank you for your time and consideration.

Best,

Neera Jain

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, Reference: 018365

### **Faculty Recruitment Email**

Dear [Name of Medical School] Faculty,

Have you had experiences working with medical students with disabilities?

My name is Neera Jain and I am a non-disabled doctoral student at the University of Auckland, Faculty of Education and Social Work.

You are invited to participate in a research study called: **A culture of access? The medical school social environment for students with disabilities.**

I am looking to learn more about the medical school environment for students with disabilities. The study will explore the issues, challenges, and successful practices involved in creating an accessible social environment.

The study will include the perspectives of students with disabilities, disability services providers, faculty, and administrators. In addition, it will examine the policies, physical and digital environments created by schools.

Participants will be asked to:

1. Complete a short online questionnaire (10 minutes or less)
2. Complete a 1-2 hour in-depth interview with the researcher at your convenience.

Interviews will take place via Skype, phone, or in person depending on your preference and availability.

Your employer has provided assurance that participation in this study will not affect your relationship with the university. They will not be informed if you decide to participate, nor will they have access to the information you share with me. Your identity, and the identity of your institution will not be revealed in any resulting reports or publications.

I hope that the information collected as part of this research study will help to develop a better understanding of current environment for medical students with disabilities, and what might be done to improve it.

This study will be used to develop my doctoral thesis, as well as for scholarly publications and trainings. I hope that the study will result in suggestions for policy improvements at medical schools.

Your participation in research is voluntary.

### **More about the researcher**

I am the Policy Advisor to the Coalition for Disability Access in Health Science and Medical Education. I have worked in disability rights organizations and in United States universities with graduate health science students with disabilities for over 10 years. I am dedicated to advancing understanding and support for individuals with disabilities studying medicine.

### **If you are interested in participating in this study, please contact me at**

[njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz). Attached please find a Participant Information Sheet with detailed information about the study and a Consent Form for your consideration.

Thank you for your time and consideration.

Best,

Neera Jain

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, Reference: 018365

### **Administrator Direct Recruitment Email**

Dear [Name of Administrator],

My name is Neera Jain and I am a non-disabled doctoral student at the University of Auckland, Faculty of Education and Social Work.

I am contacting you regarding your role as [name of role] at [name of medical school], to invite you to participate in a research study called: **A culture of access? The medical school social environment for students with disabilities.**

I am looking to learn more about the medical school environment for students with disabilities. The study will explore the issues, challenges, and successful practices involved in creating an accessible social environment. Given your key role in working with students with disabilities and affecting the university environment, I hope you will consider participating in the study.

The study will include the perspectives of students with disabilities, disability services providers, faculty, and administrators. In addition, it will examine the policies, physical and digital environments created by schools.

Participants will be asked to:

Complete a short online questionnaire (10 minutes or less)

Complete a 1-2 hour in-depth interview with the researcher at your convenience. Interviews will take place via Skype, phone, or in person depending on your preference and availability.

Your employer has provided assurance that participation in this study will not affect your relationship with the university. They will not be informed if you decide to participate, nor will they have access to the information you share with me. Your identity, and the identity of your institution will not be revealed in any resulting reports or publications.

I hope that the information collected as part of this research study will help to develop a better understanding of current environment for medical students with disabilities, and what might be done to improve it.

This study will be used to develop my doctoral thesis, as well as for scholarly publications and trainings. I hope that the study will result in suggestions for policy improvements at medical schools.

Your participation in research is voluntary.

#### **More about the researcher**

I am the Policy Advisor to the Coalition for Disability Access in Health Science and Medical Education. I have worked in disability rights organizations and in United States universities with graduate health science students with disabilities for over 10 years. I am dedicated to advancing understanding and support for individuals with disabilities studying medicine.

**If you are interested in participating in this study, please contact me at**

[njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz). Attached please find a Participant Information Sheet with detailed information about the study and a Consent Form for your consideration.

Thank you for your time and consideration.

Best,

Neera Jain

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, Reference: 018365

#### **Faculty and Administrator Direct Snowball Recruitment Email**

Dear [Name of Faculty/Administrator],

My name is Neera Jain and I am a doctoral student at the University of Auckland, Faculty of Education and Social Work.

**I am contacting you because you were named as an especially supportive [faculty member/administrator] by a participant in the research study: A culture of access? The medical school social environment for students with disabilities.**

**I would like to invite you to participate in this study and share your experiences and perspective.**

In this study I am looking to learn more about the medical school environment for students with disabilities. The study will explore the issues, challenges, and successful practices involved in creating an accessible social environment. Given your key role in working with students with disabilities and affecting the university environment, I hope you will consider participating in the study.

The study will include the perspectives of students with disabilities, disability services providers, faculty, and administrators. In addition, it will examine the policies, physical and digital environments created by schools.

Participants will be asked to:

Complete a short online questionnaire (10 minutes or less)

Complete a 1-2 hour in-depth interview with the researcher at your convenience. Interviews will take place via Skype, phone, or in person depending on your preference and availability. Your employer has provided assurance that participation in this study will not affect your relationship with the university. They will not be informed if you decide to participate, nor will they have access to the information you share with me. Your identity, and the identity of your institution will not be revealed in any resulting reports or publications.

I hope that the information collected as part of this research study will help to develop a better understanding of current environment for medical students with disabilities, and what might be done to improve it.

This study will be used to develop my doctoral thesis, as well as for scholarly publications and trainings. I hope that the study will result in suggestions for policy improvements at medical schools.

Your participation in research is voluntary.

**More about the researcher**

I am the Policy Advisor to the Coalition for Disability Access in Health Science and Medical Education. I have worked in disability rights organizations and in United States universities with graduate health science students with disabilities for over 10 years. I do not have lived experience of disability, however, I am dedicated to advancing understanding and support for individuals with disabilities studying medicine.

**If you are interested in participating in this study, please contact me at**

[njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz). Attached please find a Participant Information Sheet with detailed information about the study and a Consent Form for your consideration.

Thank you for your time and consideration.

Best,



Neera Jain

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS  
COMMITTEE ON: December 15, 2016 for 3 years, Reference: 018365

## **Appendix D. Participant Information and Consent Forms**

# Sample School Official Information Sheet



**EDUCATION AND  
SOCIAL WORK**

School of Curriculum and Pedagogy  
Private Bag 92601  
Auckland 1135, New Zealand

## Participant Information Sheet – Faculty & Administrators

Date: \_\_\_\_\_

Project title: **A culture of access? The social environment of medical schools for students with disabilities**

My name is Neera Jain, and I am a doctoral candidate at the University of Auckland Faculty of Education and Social Work, School of Curriculum and Pedagogy, supervised by Professor Janet Gaffney and Dr. Jay Marlowe.

I am writing to you, a medical school [administrator or faculty], to inform you of a research study that I am conducting and ask if you would consider participating. The focus of the study is to learn more about how medical schools are creating accessible environments for students with disabilities, and to explore the issues, challenges, and best practices involved in this process. The study will include the perspectives of medical students with disabilities, disability services providers, faculty, and administrators, and will examine the policies, physical and digital environments created by schools.

### **Why is this study being done?**

I expect that the results of this project will help to inform the creation of more accessible and welcoming medical school experiences for students with disabilities. I believe that there is much to be learned from the perspectives of administrators working in the medical school context that can help to inform how to improve the climate for medical students with disabilities, and the wider context of professional training for health professionals.

### **What would be involved?**

If you choose to participate, you would be asked to:

1. Complete a short electronic questionnaire to provide basic background information about yourself (time commitment: 10 minutes or less).
2. Engage with me in a 1-2 hour interview about your experiences in medical school in person, by phone, or by videoconference (e.g., Skype).

In the interview, you will be asked about your experiences ensuring accessibility and providing accommodations for students with disabilities including policies and procedures, successes and challenges. You will also be asked about the campus climate for students with disabilities.

The interviews will be audio recorded. Only my supervisors (Dr. Janet Gaffney and Dr. Jay Marlowe), a professional transcriber, and I will have access to these audio recordings. You may ask for the audio recorder to be turned off at any point. It is also your right to decline to answer any questions and leave the interview at any time.

After the research is conducted, you can elect to receive an audio recording of the interview, a written transcript, and a summary of my analysis of your interview. You will have up to four weeks to make any changes or withdraw your participation and data from the study once it is sent to you. After this four-week period, the information cannot be removed from the study.

### **Will information about participants be kept confidential?**

Your Dean/Chancellor has already provided an assurance that your participation or non-participation in this study will not affect your relationship or employment with the University. Your employer will not be informed if you choose to participate, and they will

not have access to your data. The interviews can be organized in a private location that is suitable for you.

Information from this study will be kept in a secure location on University of Auckland servers and accessible only to my supervisors and myself. A professional transcriber, who has signed a confidentiality agreement, may transcribe your interview. Participant and institution names will not be used in any subsequent publications or presentations. However, I cannot guarantee total confidentiality. Participant information may be given out if required by law.

At the completion of the study, the information will be safely stored and locked by Janet Gaffney in a filing cabinet or on a secure computer at the University of Auckland for six years. After this time, this information will be destroyed.

### **What risks are expected for participants?**

If anything we talk about during the interview makes you feel upset or distressed, I would be advising you to seek support through your Employee Assistance Program. It is important to note that you can decline to answer any questions and can leave the interview at any time.

If you would like to discuss any concerns about the processes at your university related to disability accesses, you are directed to speak to your campus counsel or your local Office for Civil Rights [insert information for local office].

### **Will I be compensated?**

You will not be provided any compensation for your participation in this study. However, any costs for accommodations to allow you to participate (e.g., sign language interpreters, CART) will be covered.

### **Reporting of the study**

I will make a public presentation at the University of Auckland about the study once it has been completed—specific universities and participants will not be identified in this presentation or in any subsequent reports. The information from this study may also be published in a report, at conferences, or in journal articles. Again, specific universities and participant identities will not be disclosed.

### **More about the researcher**

I am a board member of the Coalition for Disability Access in Health Science and Medical Education. I conduct this research in my role as a doctoral student at the University of Auckland.

### **Your rights and choice**

It is your right and choice to take part or not consent to this research. If you have any questions about this study, please use the contact details below:

Student Researcher	Supervisor
Neera Jain Email: <a href="mailto:njai104@aucklanduni.ac.nz">njai104@aucklanduni.ac.nz</a>	Dr. Janet Gaffney University of Auckland Faculty of Education Private Bag 92 601 Phone: +64 9 6238899 ext 48323 Email: <a href="mailto:janet.gaffney@auckland.ac.nz">janet.gaffney@auckland.ac.nz</a>
Head of School	Local Contact
Dr. Helen Hedges University of Auckland Faculty of Education Private Bag 92 601 Phone: +64 9 373 7999 Email: <a href="mailto:h.hedges@auckland.ac.nz">h.hedges@auckland.ac.nz</a>	TBD

**If you have further questions or would like to participate:**

If you have further questions please let me know. I am also happy to send you a consent form if you are willing to consider participation in an interview. The best way to reach me is by email: [njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz)

Before the interview begins, I will discuss the project with you to make sure that you understand the study and ask you to sign a consent form.

Thank you for taking time to read this Participant Information Sheet. For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone +64 9 3737599 ext. 83711. Email: [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz).

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, **Reference: 018365**

# Sample School Official Consent Form



**EDUCATION AND  
SOCIAL WORK**

School of Curriculum and Pedagogy  
Private Bag 92601  
Auckland 1135, New Zealand

## CONSENT FORM (ADMINISTRATORS & FACULTY)

THIS FORM WILL BE STORED SAFELY FOR SIX YEARS

Project title: **A culture of access? The medical school social environment for students with disabilities**

Student Researcher: Neera Jain, Doctoral Candidate ([njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz))

Supervisor: Professor Janet Gaffney ([j.gaffney@auckland.ac.nz](mailto:j.gaffney@auckland.ac.nz))

If you agree to participate in the research project as described in the Participant Information Sheet, please complete this form. It will be discussed with you by Neera Jain before the interview begins.

I \_\_\_\_\_ (your name) hereby consent to participate as requested in the research project mentioned above. I have read the information provided in the Participant Information Sheet. I have had this study explained to me and I acknowledge the following:

- I understand that it is my choice to participate or not participate in this study.
- I know who to speak to if I am concerned or would like to ask questions about this study.
- Although absolute confidentiality cannot be guaranteed, I understand that I will not be identified by name and that other identifying information will be changed in any presentations or publications. I understand that my information may be shared if required by law.
- I have had enough time to think about whether or not I want to take part in this study.
- I acknowledge that the interview will be audio recorded and transcribed.
- I understand that I can choose not to answer any questions and it is my right to leave the interview at any time.
- I understand that I can receive a copy of my interview transcript and audio recording, and a summary of the analysis of my interview.
- I know that I will have four weeks to make any changes to my transcript or to remove my participation from this project after the date that I receive my transcript.
- I have been informed who to talk to if I need support in relation to participating in this project.
- I understand that my employer has assured that my participation or non-participation in this study will not affect my relationship with the University or my employer.
- I understand that the information from this study will be safely stored and locked by Dr. Janet Gaffney in a filing cabinet at the University of Auckland for six years. After this time, this information will be destroyed.

I would like to receive a copy of the interview audio file	Yes	No
I would like to receive a copy of my transcript	Yes	No
I would like to receive a summary of the interview analysis	Yes	No

If yes, please provide email address for correspondence: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON:  
December 15, 2016 for 3 years, **Reference: 018365**

☐

# Sample Student Information Sheet



## EDUCATION AND SOCIAL WORK

School of Curriculum and Pedagogy  
Private Bag 92601  
Auckland 1135, New Zealand

### Participant Information Sheet - Student

Date: \_\_\_\_\_

Project title: **A culture of access? The medical school social environment for students with disabilities**

My name is Neera Jain, and I am a doctoral candidate at the University of Auckland Faculty of Education and Social Work, School of Curriculum and Pedagogy, supervised by Professor Janet Gaffney and Dr. Jay Marlowe.

I am writing to you, a medical student with a disability, to inform you of a research study that I am conducting and ask if you would consider participating. The focus of the study is to learn more about the medical school environment for students with disabilities, and to explore the issues, challenges, and successful practices involved in creating an accessible social environment. The study will include the perspectives of students, disability services providers, faculty, and administrators, and will examine the policies, physical and digital environments created by schools.

#### **Why is this study being done?**

I expect that the results of this project will help to inform the creation of more accessible and welcoming medical school experiences for students with disabilities. I believe that the lived experiences of students with disabilities can help to inform administrators and faculty how to more effectively improve the climate for medical students with disabilities, and in the wider context of professional training for health professionals.

#### **What would be involved?**

If you choose to participate, you would be asked to:

- Complete a short online questionnaire to provide basic background information about yourself (time commitment: 10 minutes or less)
- Engage with me in a 1-2 hour interview about your experiences in medical school in person, by phone, or by Skype.

You will be asked about your experiences accessing the university and obtaining accommodations, the campus climate, supports and challenges.

The interviews will be audio recorded. Only my supervisors (Dr. Janet Gaffney and Dr. Jay Marlowe), a professional transcriber, and I will have access to these audio recordings. You may ask for the audio recorder to be turned off at any point. It is also your right to decline to answer any questions and leave the interview at any time.

After the research is conducted, you can elect to receive an audio recording of the interview, a written transcript, and a summary of my analysis of your interview. You will have up to four weeks to make any changes or withdraw your participation and data from the study once it is sent to you. After this four-week period, the information cannot be removed from the study.

#### **Institutional consent**

Your school has already provided assurance that your participation or non-participation in this study will not affect your standing at the school. Your school will not be informed if you choose to participate, and they will not have access to your data. The interviews can be organized in a private location that is suitable for you.

**Will my information be kept confidential?**

Information from this study will be kept in a secure location on University of Auckland servers and accessible only to my supervisors and myself. A professional transcriber, who has signed a confidentiality agreement, may transcribe your interview. Participant and institution names will not be used in any subsequent publications or presentations. However, I cannot guarantee total confidentiality. Participant information may be given out if required by law.

The information from this study will be safely stored and locked by Dr. Janet Gaffney in a filing cabinet or a secure computer at the University of Auckland for six years. After this time, this information will be destroyed.

**What risks are expected?**

If anything we talk about during the interview makes you feel upset or distressed, I would be advising you to seek support at your University’s counseling center. It is important to note that you can decline to answer any questions and can leave the interview at any time.

If you would like to report any concerns related to disability services or perceived discrimination at your university, you can do so as follows:

<b>University Process</b>	<b>Office for Civil Rights</b>
[Insert link to university grievance procedures]	[Insert information for local Office for Civil Rights]

**Will I be compensated?**

You will not be provided any compensation for your participation in this study. However, any costs for accommodations to allow you to participate (e.g., sign language interpreters, CART) will be covered.

**Reporting of the study**

I will make a public presentation about the study once it has been completed—specific universities and participants will not be identified in this presentation or in any subsequent reports. The information from this study may also be published in a report, at conferences, or in journal articles. Again, specific universities and participant identities will not be disclosed.

**More about the researcher**

I am a board member of the Coalition for Disability Access in Health Science and Medical Education. I conduct this research in my role as a doctoral student at the University of Auckland.

**Your rights and choice**

It is your right and choice to take part or not consent to this research. If you have any questions about this study, please use the contact details below:



<b>Student Researcher</b> Neera Jain Email: <a href="mailto:njai104@aucklanduni.ac.nz">njai104@aucklanduni.ac.nz</a>	<b>Supervisor</b> Dr. Janet Gaffney University of Auckland Faculty of Education Private Bag 92 601 Phone: +64 9 6238899 ext 48323 Email: <a href="mailto:janet.gaffney@auckland.ac.nz">janet.gaffney@auckland.ac.nz</a>
<b>Head of School</b> Dr. Helen Hedges University of Auckland Faculty of Education Private Bag 92 601 Phone: +64 9 373 7999 Email: <a href="mailto:h.hedges@auckland.ac.nz">h.hedges@auckland.ac.nz</a>	<b>Local Contact</b> TBD

**If you have further questions or would like to participate:**

If you have further questions please let me know. I am also happy to send you a consent form if you are willing to consider participation in an interview. The best way to reach me is by email: [njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz)

Before the interview begins, I will discuss the project with you to make sure that you understand the study and ask you to sign a consent form. Thank you for taking time to read this Participant Information Sheet.

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone +64 9 3737599 ext. 83711. Email: [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz).

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON: December 15, 2016 for 3 years, **Reference: 018365**

# Sample Student Consent Form



**EDUCATION AND  
SOCIAL WORK**

School of Curriculum and Pedagogy  
Private Bag 92601  
Auckland 1135, New Zealand

## CONSENT FORM (STUDENTS)

THIS FORM WILL BE STORED SAFELY FOR SIX YEARS

Project title: **A culture of access? The medical school social environment for students with disabilities**

Student Researcher: Neera Jain, Doctoral Candidate ([njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz))

Supervisor: Professor Janet Gaffney ([j.gaffney@auckland.ac.nz](mailto:j.gaffney@auckland.ac.nz))

If you agree to participate in the research project as described in the Participant Information Sheet, please complete this form. Neera Jain will be discuss it with you before the interview begins.

I \_\_\_\_\_ (your name) hereby consent to participate as requested in the research project mentioned above. I have read the information provided in the Participant Information Sheet. I have had this study explained to me and I acknowledge the following:

- I understand that it is my choice to participate or not participate in this study.
- I know who to speak to if I am concerned or would like to ask questions about this study.
- Although absolute confidentiality cannot be guaranteed, I understand that I will not be identified by name and that other identifying information will be changed in any presentations or publications. I understand that information may be shared if required by law.
- I have had enough time to think about whether or not I want to take part in this study.
- I acknowledge that the interview will be audio recorded and transcribed.
- I understand that I can choose not to answer any questions and it is my right to leave the interview at any time.
- I understand that I can receive a copy of my interview transcript and audio recording, and a summary of the analysis of my interview.
- I know that I will have four weeks to make any changes to my transcript or to remove my participation from this project after the date that I receive my transcript.
- I have been informed who to talk to if I need support in relation to participating in this project.
- I understand that my school has assured that my participation or non-participation in this study will not affect my relationship or academic standing with the school.
- I understand that the information from this study will be safely stored and locked by Dr. Janet Gaffney in a filing cabinet at the University of Auckland for six years. After this time, this information will be destroyed.

I would like to receive a copy of the interview audio file	Yes	No
I would like to receive a copy of my transcript	Yes	No
I would like to receive a summary of the interview analysis	Yes	No

If yes, please provide your email address for correspondence: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON:  
December 15, 2016 for 3 years, **Reference: 018365**

## Appendix E. Demographic Questionnaire

### Students<sup>18</sup>

All questions are voluntary. You may skip any questions you are not comfortable answering.

1. Name (text box)
2. Email (text box)
3. Phone number (text box)
4. Gender (text box)
5. Ethnicity (text box)
6. Date of birth
7. Undergraduate institution (text box)
8. Undergraduate Degree (text box)
9. Did you complete a post baccalaureate program: yes/no (branching)
  - a. If yes, where? (text box)
10. Medical school attending (text box)
11. Year matriculated (text box)
12. Current year in medical school: 1/2/3/4/Other (SPECIFY – text box)
13. How old were you when you started medical school? (text box)
14. Are you in a combined degree program? MD/PhD MD/MPH Other (SPECIFY)
15. Do you have any other graduate degrees (e.g., MBA, MA, MS)? (text box)
16. Have you used accommodations in any of the following? (K-12, college, employment)
17. Do you use accommodations at medical school?
18. Do you identify as a member of any of the following groups – check all that apply:  
(LGBTQI; Underrepresented in Medicine—URM; First Generation to attend college—  
First Gen; Refugee; Veteran Immigrant; Other intersecting identities – text box)?
19. Disability categories (check as many as apply): AD/HD, learning disability,  
psychological disability, deaf or hard of hearing, visual disability, physical/mobility  
disability, chronic health condition, other (specify)
20. Describe your disability in 2-3 sentences (text box)
21. When were you first diagnosed with a disability (age/grade)? (Text box)
22. Will you require any accommodations to participate in this study? Y/N (branching)
  - a. If yes: Please let me know what accommodations you will require (Text box)

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<sup>18</sup> Student and school-official questionnaires were administered via Qualtrics

23. Is there something you would like me to know in advance of your interview? (TEXT BOX)

24. Interviews will be held in person, via Skype or by telephone depending on your availability and preferred method of contact.

Please rank your preferred method of interview with 1 indicating your first choice:

Skype

In Person

Telephone

Thank you for completing this questionnaire, and for your interest in this study. If we have not done so yet, I will be in touch in the next 2 weeks to schedule our interview. If you have any questions, please contact me at [njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz)

### **School Officials**

**All questions are voluntary. You may skip any questions you are not comfortable answering.**

1. Name (text box)
2. Email (text box)
3. Phone number (text box)
4. Gender (text box)
5. Ethnicity (text box)
6. Medical school employed at (text box)
7. Role – check all that apply (Disability Services Provider; Faculty Member—text box to specify department; Administrator—text box specify title)
8. Number of years in this role (text box)
9. Do you identify as a member of any of the following groups – check all that apply (Person with a disability, LGBTQI, Underrepresented in Medicine—URM, First Generation to attend college—first gen, Refugee, Veteran, Immigrant, Other intersecting identities – specify text box)?
10. Will you require any disability-related accommodations to participate in this study? Y/N (branching)
  - a. If yes: Please let me know what accommodations you will require: (Text box)
11. Is there something you would like me to know in advance of your interview? (Text box)
12. Interviews will be held in person, via Skype or by telephone depending on your availability and preferred method of contact.

Please rank your preferred method of interview with 1 indicating your first choice:

Skype

In Person

Telephone

Thank you for completing this questionnaire, and for your interest in this study. If we have not done so yet, I will be in touch in the next 2 weeks to schedule our interview. If you have any questions, please contact me at [njai104@aucklanduni.ac.nz](mailto:njai104@aucklanduni.ac.nz)

# Appendix F. Ethics Approval Letters

## Initial Approval

**Office of the Vice-Chancellor**  
Finance, Ehtics and Compliance



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand

Level 10, 49 Symonds Street  
Telephone: 64 9 373 7599  
Extension: 87830 / 83761  
Facsimile: 64 9 373 7432

### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

15-Dec-2016

#### MEMORANDUM TO:

Prof Janet Gaffney  
Curriculum & Pedagogy

#### **Re: Application for Ethics Approval (Our Ref. 018365): Approved with comment**

The Committee considered your application for ethics approval for your project entitled **A culture of access? The medical school social environment for students with disabilities** .

Ethics approval was given for a period of three years with the following comment(s):

1. PIS – Dean

Please rephrase the following:

Before I recruit any participants from your institution, I request that you as the Dean/Chancellor of this medical school/university sign a consent form providing assurance that any student or staff member's participation in this study will not affect their professional relationship with you or compromise their standing with the university.

To:

Before I recruit any participants from your institution, I request that you as the Dean/Chancellor of this medical school/university sign a consent form providing assurance that any student or staff member's participation or non-participation in this study will not affect their professional relationship with you or compromise their standing with the university.

The expiry date for this approval is 15-Dec-2019.

If the project changes significantly you are required to resubmit a new application to UAHPEC for further consideration.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. Contact should be made through the UAHPEC Ethics Administrators at [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz) in the first instance.

All communication with the UAHPEC regarding this application should include this reference number: **018365**.

*(This is a computer generated letter. No signature required.)*

Secretary  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Curriculum & Pedagogy  
Neera Jain  
Assoc Prof Jay Marlowe

**Additional information:**

1. Should you need to make any changes to the project, write to the Committee giving full details including revised documentation.
2. Should you require an extension, write to the Committee before the expiry date giving full details along with revised documentation. An extension can be granted for up to three years, after which time you must make a new application.
3. At the end of three years, or if the project is completed before the expiry, you are requested to advise the Committee of its completion.
4. Do not forget to fill in the 'approval wording' on the Participant Information Sheets and Consent Forms, giving the dates of approval and the reference number, before you send them out to your participants.
5. Send a copy of this approval letter to the Awards Team at the, Research Office if you have obtained funding other than from UniServices. For UniServices contract, send a copy of the approval letter to: Contract Manager, UniServices.
6. Please note that the Committee may from time to time conduct audits of approved projects to ensure that the research has been carried out according to the approval that was given.

# Amendment 1

Office of the Vice-Chancellor  
Finance, Ethics and Compliance



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand

Level 10, 49 Symonds Street  
Telephone: 64 9 373 7599  
Extension: 87830 / 83761  
Facsimile: 64 9 373 7432

## UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

24-Feb-2017

### MEMORANDUM TO:

Prof Janet Gaffney  
Curriculum and Pedagogy

### Re: Request for change of Ethics Approval Ethics Approval (Our Ref. 018365): Amendments Approved

The Committee considered your request for change for your project entitled **A culture of access? The medical school social environment for students with disabilities** and approval was granted for the following amendments on 24-Feb-2017.

The Committee approved the following amendments:

1. To include the email communication used to contact an institutional leader.

The expiry date for this approval is 15-Dec-2019.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

The Chair and the members of the Committee would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz) in the first instance.

Please quote reference number: **018365** on all communication with the UAHPEC regarding this application.

*(This is a computer generated letter. No signature required.)*

UAHPEC Administrators  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Curriculum and Pedagogy  
Prof Janet Gaffney  
Neera Jain  
Assoc Prof Jay Marlowe



## Amendment 2

Office of the Vice-Chancellor  
Finance, Ethics and Compliance



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
  
Level 10, 49 Symonds Street  
Telephone: 64 9 373 7599  
Extension: 87830 / 83761  
Facsimile: 64 9 373 7432

### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

31-Mar-2017

#### MEMORANDUM TO:

Prof Janet Gaffney  
Curriculum and Pedagogy

#### Re: Request for change of Ethics Approval Ethics Approval (Our Ref. 018365): Amendments Approved

The Committee considered your request for change for your project entitled **A culture of access? The medical school social environment for students with disabilities** and approval was granted for the following amendments on 31-Mar-2017.

The Committee approved the following amendments:

To customize Participant Information Sheets (PIS) and Consent Forms (CF) for obtaining consent at one university.

The expiry date for this approval is 15-Dec-2019.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

The Chair and the members of the Committee would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz) in the first instance.

Please quote reference number: **018365** on all communication with the UAHPEC regarding this application.

*(This is a computer generated letter. No signature required.)*

UAHPEC Administrators  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Curriculum and Pedagogy  
Prof Janet Gaffney  
Neera Jain  
Assoc Prof Jay Marlowe

## Amendment 3

Office of the Vice-Chancellor  
Finance, Ethics and Compliance



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand

Level 10, 49 Symonds Street  
Telephone: 64 9 373 7599  
Extension: 87830 / 83761  
Facsimile: 64 9 373 7432

### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

19-May-2017

#### MEMORANDUM TO:

Prof Janet Gaffney  
Curriculum and Pedagogy

#### **Re: Request for change of Ethics Approval Ethics Approval (Our Ref. 018365): Amendments Approved**

The Committee considered your request for change for your project entitled **A culture of access? The medical school social environment for students with disabilities** and approval was granted for the following amendments on 19-May-2017.

The Committee approved the following amendments:

1. To customize Participant Information Sheets (PIS) and Consent Forms (CF) for obtaining consent at one university.

The expiry date for this approval is 15-Dec-2019.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

The Chair and the members of the Committee would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz) in the first instance.

Please quote reference number: **018365** on all communication with the UAHPEC regarding this application.

*(This is a computer generated letter. No signature required.)*

UAHPEC Administrators  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Curriculum and Pedagogy  
Prof Janet Gaffney  
Neera Jain  
Assoc Prof Jay Marlowe

## Amendment 4

Office of the Vice-Chancellor  
Finance, Ethics and Compliance



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### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

08-Jun-2017

#### MEMORANDUM TO:

Prof Janet Gaffney  
Curriculum and Pedagogy

#### **Re: Request for change of Ethics Approval Ethics Approval (Our Ref. 018365): Amendments Approved**

The Committee considered your request for change for your project entitled **A culture of access? The medical school social environment for students with disabilities** and approval was granted for the following amendments on 08-Jun-2017.

The Committee approved the following amendments:

1. To directly recruit key faculty and administrators whom other participants identify as playing an important role in their experience.

The expiry date for this approval is 15-Dec-2019.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

The Chair and the members of the Committee would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz) in the first instance.

Please quote reference number: **018365** on all communication with the UAHPEC regarding this application.

*(This is a computer generated letter. No signature required.)*

UAHPEC Administrators  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Curriculum and Pedagogy  
Prof Janet Gaffney  
Neera Jain  
Assoc Prof Jay Marlowe

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