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Centering the Perspectives of Medical Students With Disabilities: Perceived Challenges and How Students Navigate Them at One Allopathic Medical School

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# UNIVERSITY OF CALIFORNIA

Los Angeles

Centering the Perspectives of

Medical Students With Disabilities:

Perceived Challenges and How Students Navigate Them at One Allopathic Medical School

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Education

by

Sue Jean Nahm

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#### ABSTRACT OF THE DISSERTATION

## Centering the Perspectives of

## Medical Students With Disabilities:

Perceived Challenges and How Students Navigate Them at One Allopathic Medical School

by

## Sue Jean Nahm

#### Doctor of Education

University of California, Los Angeles, 2024

Professor Christina A. Christie, Co-Chair

Professor Kristen Lee Rohanna, Co-Chair

Students with disabilities in college and beyond face numerous barriers to seeking out and receiving supportive services or disclosing that they have a disability. Research indicates that they are vulnerable to stigma, lack of support, and discrimination resulting in inequities in educational outcomes. Less is known about the challenges medical students with disabilities face and the ways they navigate these challenges. This descriptive, mixed-methods study highlighted the perspectives of medical students at one allopathic medical school to identify the types of the disabilities reported, the challenges medical students with disabilities experienced, and how they navigated their challenges. A survey was conducted of 204 medical students to identify the types of disabilities students report, and a Chi-squared analysis examined the association between

disability status and the types of challenges students experienced in three dimensions: academic, institutional, and personal/inter-personal. Interviews with 18 students who reported a disability provided richer insight into the nature of the challenges that students experienced and ways they navigated these challenges. Drawing on the social model of disability framework, this study builds on earlier studies of medical students with disabilities and revealed a higher percentage of psychological and chronic health disabilities relative to other types of disabilities. Study findings also indicated that some academic and personal challenges may disproportionately impact students with disabilities relative to their non-disabled counterparts. Notably, students with disabilities pointed to systemic and institutional factors as key sources of their challenges. They described navigating challenges in a variety of ways, including by engaging in trial and error, drawing boundaries to prioritize self-care, and by relying on informal supports such as close friends, family members, and trusted mentors. This study highlights the dynamic nature of disability and recommends student-centered approaches when designing and implementing supportive resources and services.

The dissertation of Sue Jean Nahm is approved.

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### **DEDICATION**

I dedicate this dissertation to my husband whose unwavering support and belief in me made this possible. Your kindness, patience, and devotion ministered to me in ways that I cannot put into words.

I also dedicate this dissertation to my family. My parents have shaped who I am today. I am deeply indebted to their sacrifices and their influence on my life. My father's endless optimism and intellectual curiosity spurred my own intellectual pursuits. My mother's relentless work ethic and her sacrificial love kept our family grounded. My loving sister, Millie, has provided a precious companionship that only a sister can provide.

I am grateful for the journey that God has laid out for my life, as circuitous and unpredictable as it has been. I am in awe of God's never-ending grace and mercy to me through Jesus Christ. Though I am weak, He is strong.

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I owe much gratitude to my colleagues and mentors at the David Geffen School of Medicine; in particular, Dr. Lee Miller, Dr. Iljie Fitzgerald, and Brandon Susselman, for supporting my professional development, and for encouraging me in big and small ways. I am continually inspired by your ability to navigate the many challenges of the medical education landscape with such wisdom, grace, and humor. Thank you to the Rose Foundation for your generous support during the second year of my program. I also want to thank my colleagues at USC, UC Davis, and UC Riverside, and Disability Resource Provider, Grace Clifford, for taking

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#### CHAPTER ONE

## INTRODUCTION

"If they are truly public, then our institutions should be run with a deep knowledge of the motives, aspirations, cognitive capacity, and inner and outer barriers of the full range of the people they serve."

- Mike Rose, Why School?<sup>1</sup>

"We continually ask, 'Whose stories are privileged in educational contexts, and whose stories are distorted and silenced?"

– Daniel Solorzano & Tara Yosso<sup>2</sup>

The number of individuals reported to be living with a disability in the United States has increased dramatically as a proportion of the overall population over the past several decades. The Centers for Disease Control and Prevention (CDC) has estimated that more than one in four individuals have some type of disability (CDC, 2023)<sup>3</sup>. These same individuals face numerous barriers to accessing quality healthcare, education, and economic opportunities. People with disabilities are less likely to receive a college degree and are more likely to be unemployed than their non-disabled counterparts (CDC, 2023; Herbert et al., 2014; Huber et al., 2016; National Center for Education Statistics, 2017). There has nevertheless been a notable increase in the number of students with disabilities pursuing college and advanced professional degrees over the past several decades, in part, as a result of federal legislation that have facilitated increased access and supportive resources for students with disabilities (Herbert et al., 2014; National Council on Disability, 2003).

<sup>&</sup>lt;sup>1</sup> Rose, M. (2014). Why school? Reclaiming education for all of us (pp. 175-180). NY: The New Press. pp. 194-195.

<sup>&</sup>lt;sup>2</sup> Solórzano, D. & Yosso, T. (2002b). "Critical Race Methodology: Counter-Storytelling as an Analytical Framework for Education Research." *Qualitative Inquiry*, 8(1), 23–44. https://doi.org/10.1177/107780040200800103

<sup>&</sup>lt;sup>3</sup> See also: <a href="https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html">https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html</a>

Despite improved access to higher education, inequities in educational outcomes for students with disabilities in secondary education and higher education persist and have been well-documented (Berg et al., 2017; Herbert et al., 2014; Marshak et al., 2010). Less wellresearched or understood are the unique challenges of students with disabilities in graduate programs, and the ways in which they navigate these various challenges as graduate students. In medical education, there is limited research to-date about the unique experiences and challenges students with disabilities encounter during their training from the perspective of students themselves. Existing research indicates that medical students face numerous barriers, both institutional and personal, as well as social and cultural; this prevents many from seeking supportive services or even disclosing they have a disability due to concerns about discrimination and internalized stigma (Haque et al., 2021). Recently, this research has expanded to include the rates and prevalence of medical students with disabilities as well as the services and supports available to them (Meeks et al., 2018; Meeks et al., 2019; Meeks et al., 2021; Pereira-Lima et al., 2023). Much of this literature depicts students as vulnerable to stigma, lacking support, or even experiencing discrimination on the part of faculty and fellow students. The research, however, often overlooks how students navigate these challenges.

This study focused on the experiences of students with disabilities at one allopathic medical school to better understand the challenges students say they face and the ways they navigate and address these challenges. In doing so, this study draws on the social model of disability; the social model depicts perceptions and barriers of disability as constructed in relation to society which must be addressed by examining how institutions, society, and legal practices serve to exclude and marginalize individuals on the basis of these perceptions (Berghs et al., 2019; Donlon, 2016; Oliver, 2004; Oliver, 2014; Pothier & Devlin, 2006).

This research was designed to address a gap in the existing literature on students with disabilities by centering the unique experiences of medical students, one which depicts students as active agents rather than passive recipients of support. This study was also meant to contribute to increased understanding among educators, administrators, and policymakers about the types of disabilities reported and the perspectives of this understudied but growing population of students with regard to the challenges they experience and the ways they navigate them. The expectation is that insights gleaned from this study will help inform programming and resources designed to address the needs of students with disabilities in medical education with implications for students in other professional programs.

## **Statement of the Problem**

Many existing studies focus on challenges students with disabilities face at the undergraduate level, including discriminatory practices, lack of supportive resources, lack of belonging, which have been found to impact students' willingness to disclose they have a disability and seek out support (Herbert, et al., 2014; Marshak, et al., 2010; Trammel & Hathaway, 2007). In college and graduate school, students must disclose they have a disability in order to receive supportive resources, and there are a number of complex factors that impact a student's decision to disclose (Wolanin & Steele, 2004). Students' willingness to seek support for their disability has been associated with both personal factors, such as students' attitudes and perceptions and levels of engagement (DaDeppo, 2009; Hartmann-Hall, et al., 2002; Hill, et al., 1996), and institutional factors, such as faculty knowledge and practices and the quality of campus disability services (Marshak et al., 2010; Rao, 2004; Vogel, et al., 2006). In general, graduate students face a variety of unique circumstances vis-à-vis their institutions given the degree of autonomy and responsibility placed on them to disclose and seek out supportive

services. While much emphasis has been placed on examining the barriers and challenges to persistence students with disabilities face in higher education, there are few studies about medical students with disabilities and what they perceive as challenges, as well as ways in which they navigate and respond to them.

This study investigated the perceived challenges and barriers of students with disabilities at one allopathic medical school, as well as their experiences navigating these challenges. More research is needed to understand the experiences of students with disabilities in professional and graduate programs, an area that has been the focus of limited research to-date (Marzolf et al., 2022; Meeks et al., 2021).

## **Background**

# Disparities in Educational Outcomes

A growing number of individuals with disabilities have begun enrolling in postsecondary schools, reflecting the rise in the general population of individuals with disabilities. Between 1987–2003 alone, there was a 32% increase in enrollment among students with disabilities (National Council on Disability, 2003, as cited in Hong et al., 2007). Despite improved access and enrollment in postsecondary education for students with disabilities in the past several decades, disparities in educational outcomes persist. While increasing numbers of individuals with disabilities have begun to enroll in postsecondary education, only 23% of undergraduates who reported a disability in 2012 when they entered college graduated with a bachelor's degree by 2017, compared to 38% of students without disabilities. In addition, among individuals in the United States 25 years of age or older reporting a disability, 18% held a bachelor's degree or higher in 2019, compared to 36% of the population not reporting a disability (Postsecondary National Policy Institute, 2022).

Limited data available on students with disabilities in medical school also reveal disparities in educational outcomes. According to a study of medical students who graduated and matched into residency programs in 2018 and 2019 across 11 U.S. medical schools, students with disabilities were less likely to graduate on time, scored lower on their USMLE licensing exams, and were less likely to match into residency programs on their first attempt compared to their counterparts. These findings were particularly significant for students who reported cognitive/learning disabilities compared to those with physical/sensory disabilities (Meeks et al., 2022).

## Research on Medical Students With Disabilities and a Focus on Technical Solutions

Research and awareness about medical students with disabilities is expanding as the result of efforts by a small but growing team of researchers specializing in disability support services for health professionals. Of note, Meeks, working with a team of researchers, conducted a survey of institution administrators of allopathic medical schools in the United States and found that 4.6% of the medical school population were reported to have a disability in 2019 based on a survey of school administrators. They noted that 7.6% of graduating medical students anonymously self-reported they identified as having a disability on a national Graduate Questionnaire (GQ) by the American Association of American Colleges (AAMC) during the same period. This has led some researchers to note a significant disclosure gap when comparing the number of students receiving accommodations and reporting a disability to school administrators, and those willing to disclose their disability status on an anonymous questionnaire (Meeks et al., 2021). This disclosure gap has found to persist as recent data by the AAMC reported 10.9% of graduating students reporting a disability in 2023, compared to 5.9%

<sup>&</sup>lt;sup>4</sup> These researchers founded the Coalition on Disability Access in Health Science Education and the Association on Higher Education and Disability, see: <a href="https://www.coalitiondahse.org/">https://www.coalitiondahse.org/</a> and <a href="https://www.ahead.org/home">https://www.ahead.org/home</a>.

of medical students receiving accommodations, as reported in a follow-up survey of disability resource providers (Pereira-Lima et al., 2023).

Indeed, some scholars studying medical students with disabilities have focused on disclosure as a central problem and barrier for students with disabilities and point to institutional barriers as the likely culprits: that is, students with disabilities are less likely to disclose or seek support when there is not a designated disability resource provider, or when the designated disability resource staff member is in a position to evaluate the student. Students may also be less incentivized to seek accommodations when a disability resource provider lacks specialized knowledge about clinical accommodations. Scholars have also indicated that policies and technical standards must be well aligned with relevant disability or case law and reflect the unique needs of students both in terms of assessments and their clinical education for students with disabilities to receive the appropriate support (Meeks & Jain, 2018). That is, the lack of a supportive structure for disclosure, as well as the lack of a designated disability professional who is knowledgeable about the medical curriculum can pose as significant barriers to students who might otherwise disclose they have a disability and seek out support.

Researchers who have applied some of the same findings on students with disabilities in higher education to medical students point to both physical/environmental and attitudinal and behavioral barriers that impact student persistence (Harris Petersen, 2022). For example, students may be disinclined to seek support for their disability due to the stigma of being identified as disabled, fear of bias on the part of peers and faculty, and perceptions that it might negatively impact their career prospects, among other factors, consistent with the experiences of students with disabilities in college (Hong, 2015; Meeks et al., 2020). Much of this research focuses on disclosure and challenges associated with seeking and receiving accommodations but does not

incorporate student-level perspectives when it comes to identifying their challenges as well as their views with respect to how to better support students with disabilities.

The lack of research which centers the perspectives of students with disabilities in medical school reflects a major gap in the literature; one which would be important as the basis for developing supportive resources and evidence-based programming to support students with disabilities. Moreover, researchers acknowledge students (and individuals in general) with disabilities are a heterogeneous group (Bell, 2017; Kohli & Atencio, 2021; Shakespeare, 2017; Wolanin & Steele, 2004). As such, there is a recognized need to include diverse student perspectives, not only regarding the varied nature of their challenges, but also the divergent ways students have navigated and overcome these challenges. The student perspective is also important in informing the types of resources, programming, and supports would be most helpful and relevant.

# **Study Overview**

This study examined students' experiences and the ways in which they navigate challenges related to their disability in medical school. This study reflects findings from a general survey of students with and without disabilities as well as first-hand accounts and narratives about the experiences of students with disabilities at one allopathic medical school in the western United States. The framework provided by the social model of disability yields key insights into students' understanding of their challenges and the ways they navigated them. The findings from this study builds on earlier research on medical students with disabilities and explores the challenges students with disabilities say they face, with implications for developing a more nuanced picture of not only the challenges, but also the ways they address these challenges.

Findings were based on an anonymous survey completed by 204 respondents as well as 18 semi-structured interviews. Students who were interviewed represented students with several types of disabilities at different stages in training. Findings were also based on students from various racial and ethnic backgrounds, to reflect the diverse challenges and needs of different sub-populations of students with disabilities and to represent a diverse range of perspectives and experiences.

## **Research Questions**

Three primary research questions and numerous secondary questions formed the foundation of the research study.

- 1. What are the types of disabilities medical students report?
- 2. What perceived challenges, if any, do students with disabilities say they face in medical school?
  - a. What academic challenges do they say they faced, if any?
  - b. What institutional challenges do they say they faced, if any?
  - c. What personal, social challenges do they say they faced, if any?
  - d. How, if at all, are the types of challenges reported by medical students with disabilities different, if at all, from those reported by medical students without disabilities?
- 3. How do medical students with disabilities describe their experience navigating, addressing or overcoming these challenges?
  - a. To what do students attribute their ability to navigate, address, or overcome these challenges?
  - b. What resources, if any, have they used? And how have they used them?

- c. What strategies, if any, have they implemented?
- d. What actions, if any, have they taken to adjust and adapt to medical school?

# **Study Design**

Building on previous studies of students with disabilities, this study was conducted as a mixed method, sequential study to explore the prevalence and types of disabilities as reported by medical students. In addition to collecting data on the prevalence and types of disabilities at one institution through an anonymized survey, it explored students' perceptions of their own challenges in the domains of academic, institutional, and personal and interpersonal challenges, through semi-structured interviews. The study aimed to collect both systematic, empirical data on the prevalence and types of disabilities students report, as well as qualitative data, centering their voices, perspectives, and lived experiences (Merriam & Tisdell, 2016).

The study was conducted in two stages: the first stage consisted of a survey that was administered to the student body at one allopathic medical school. Students were eligible to participate in the study if they were current medical students at the institution and were at least 18 years of age at the time of the study. In-depth individual interviews were conducted with 18 medical students who volunteered to participate from among survey respondents who identified as having a disability.

## **Study Significance**

Recent studies on medical students have posited numerous barriers that students with disabilities encounter in medical school and focus on institution level factors or the availability of institutional resources (Marzolf et al., 2022; Meeks et al., 2021). These same studies tend to extrapolate from the literature on undergraduate students with disabilities with limited information drawn from the perspectives of students themselves. Thus, there is a need to

understand the actual experiences of medical students with disabilities, their perceived challenges, the nature of these challenges, as well as the ways in which they navigate and overcome or address these challenges.

Exploring medical students' perceptions will provide those who work with medical students, administrators, faculty, and disability resource providers, among others, a better understanding of the unique needs and perceptions of students with disabilities. Much of the existing research on students with disabilities focuses on students in K-12 and college and is grounded in a deficits-based framework where students with disabilities are depicted as passive recipients of support. While the needs of students in graduate school are no less significant given the disparities in educational outcomes that persist in the form of access to professional degrees and employment in the health professions, the ability to persist in the face of such challenges has been understudied and under-appreciated in the existing literature. More work is needed to develop assets-based best practices to support students with disabilities' persistence in medical school and other professional programs.

#### Conclusion

Research on students with disabilities often focuses on the K-16 continuum and the barriers and challenges associated with access to higher education and persistence in college. Less researched is the actual experiences of students with disabilities in medical school (or graduate and professional schools, generally) when it comes to the challenges they encounter and the ways they can persist and thrive in the midst of these challenges. The lack of information and research on this population of students reflects a major gap in the literature – one which would be important as the basis for developing supportive resources and evidence-based programming for this population of students. This study addressed this gap in research and identified ways in

which barriers to persistence can be addressed systematically at graduate and professional programs and institutions for students in medicine with disabilities.

#### **CHAPTER TWO**

#### LITERATURE REVIEW

Over the past several decades, the number of individuals with disabilities who have gained access to higher education in the United States has grown significantly, in part, as the result of legislation and policy initiatives which have helped to remove barriers to entry and enabled students to access a wider range of supportive resources to accommodate their needs (Herbert et al., 2014; Scheef et al., 2020). Despite significant efforts on the part of educators, lawmakers, and institutions to address inequities and improve access to higher education, individuals with disabilities continue to face challenges beyond college and in their professional training and careers (Banks, 2014; Barber, 2012).

The challenges are particularly significant for medical students with disabilities. According to one statistic, individuals with disabilities make up approximately 7.6% of the medical student population in the United States (Meeks et al., 2021),<sup>5</sup> yet they are more likely to face academic difficulty, score lower on their licensing exams, and experience delays to entry into the workforce (Meeks et al., 2022). The challenges medical students with disabilities face during their medical training remains an understudied phenomenon, and little is known about their experience navigating support for their disability and the factors that impact their decision to disclose they have a disability.

This study illuminates the challenges medical students say they face in medical school and highlights the many ways students navigate and address these challenges through an asset-

<sup>&</sup>lt;sup>5</sup> Estimates of prevalence of disability vary based on the survey instruments used for various studies. The study above by Meeks et al., 2021, cites the Association of American Medical Colleges (AAMC) Graduate Questionnaire of 2020, and compares it to a web-based survey of disability resource providers reporting the number of students receiving accommodations in 2019. A follow-up survey of disability resource providers at 56 medical schools indicated 5.9% of students receiving accommodations in 2022 (Pereira-Lima et al., 2023) and the AAMC Graduate Questionnaire reported 10.9% of graduating students reported a disability in 2023.

based lens by sharing their strengths, resilience, and creativity in addressing these challenges. In order to better understand this phenomenon, this chapter opens with a definition of disability, information about the prevalence of students identifying as having a disability in postsecondary and medical education, and what some of the existing research says about the various challenges and barriers individuals with disabilities face when transitioning from secondary to postsecondary institutions. This review then highlights recent research about the unique challenges medical students experience and delineates the growing push to diversify the medical profession and support students with disabilities in the United States. <sup>6</sup> The review then describes the conceptual framework central to this study: the social model of disability (Berghs et al., 2019; Donlon, 2016; Oliver, 2004; Oliver, 2014).

# **Definition of Disability**

The concept and use of the term, "disability" has evolved over time and continues to be contested in the social, legal, and political realms (Devlin & Pother, 2006; Rimmerman, 2013). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), adopted by the General Assembly in 2006, defines those with disabilities as individuals "who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, UNCRPD, 2006, Article 1, para 2). According to the American with Disabilities Act (ADA) of 1990, a disability is defined as "with respect to an individual — (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such an impairment; or (c) being regarded as having such an

<sup>&</sup>lt;sup>6</sup> This study focuses on allopathic or M.D.-granting (rather than osteopathic or D.O.) medical schools accredited by the Liaison Committee on Medical Education in the United States.

impairment" (ADA, Section 3(2), consistent with the definition provided in the Rehabilitation Act of 1973, Section 7(20)). Scholars have also defined individuals with disabilities as "persons whose physical, sensory, cognitive, and/or emotional characteristics differ from the norm to such an extent that they require an individualized education plan and related services and accommodations to fully participate in instructional processes" (Kourea et al., 2021, p. 112 citing Heward at al., 2017).

Indeed, the definition and criteria provided by the ADA and the expansion of the criteria under the ADA Amendment Act of 2008 encompass a broad range of individuals who possess physical disabilities as well as those with cognitive disabilities. Both the ADA and UNCRPD definitions define disability in relation to specific impairment, but the UNCRPD emphasizes how the impairment is defined in relation to the various barriers that exist to prevent individuals from participation on an equal basis with others. Notably, the Individuals with Disabilities Act (IDEA) states that "Disability is a part of the natural human experience and in no way diminishes the right of individuals to participate in or contribute to society," consistent with the framework put forth under the social model of disability (Wolanin & Steele, 2004, p. xv).

Notwithstanding the distinction some disability scholars make between individual impairment and disability (see Oliver, 2004 & 2013; Shakespeare, 2017),<sup>7</sup> most public post-secondary institutions rely on the criteria consistent with the ADA of 1990 and the 2008 Amendment to the ADA to identify individuals with disabilities who are eligible for

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<sup>&</sup>lt;sup>7</sup> The social model of disability is elaborated later in this chapter. Various scholars have critiqued the social model in favor of alternate conceptualizations of disability, but this study relies on the social model, while incorporating contributions from other theoretical traditions, including critical theory and critical disability theory. For a fuller discussion of the critiques of the social model, its origins and the evolution of disability theory, see Meekosha & Shuttleworth, 2017; Shakespeare, 2017.

accommodations. Such disabilities can be physical, sensory, cognitive, or emotional and may include, but are not limited to, learning disabilities, chronic illnesses, as well as acute illnesses.

Even prior to the passage of the ADA, a variety of laws were put in place to protect individuals with disabilities, in the context of the civil rights era of the 1960s, when advocates for disability rights pushed for legislation to advance the rights of individuals with disabilities in the United States. Under Section 504 of the Rehabilitation Act of 1973, institutions that receive federal funds, whether public or private, are prohibited from discriminating against or excluding any "otherwise qualified person," with disabilities from participation in any program or activity receiving federal financial assistance or denying such individuals its benefits (Eckes & Ochoa, 2005). As such, colleges and universities must comply with these standards in all aspects of its services, including recruitment and admissions, the curriculum, housing, and employment assistance. Furthermore, institutions must provide students with disabilities with "reasonable accommodations" in the classroom and where relevant, for testing. Similarly, IDEA of 1975 established the right of children with disabilities to attend public schools and to the greatest extent possible, allow for their integration in the classroom alongside nondisabled children The Act also required such schools to provide a "free, appropriate public education in the least restrictive environment" (as cited by Aron & Loprest, 2012).

The number of individuals attending public schools at the K-12 levels and in higher education rapidly increased in the decades following the passage of these laws even as the number of individuals who identified as having a disability also increased in the United States. Interestingly, among K-12 students, learning disabilities have been counted among the most prevalent of students who receive special education services accounting for 38% of students with

a reported disability in 2009-2010, followed by speech or language impairment at 22% and "other health impairment" at 11% (Aron & Loprest, 2012).

#### Prevalence of Individuals with Disabilities in the United States and in Medical Education

Today, approximately 61 million adults or 26% of the population in the United States live with some type of a disability. Among the general population, the highest reported type of disability is physical mobility (13.7%), while 10.8% of the population reported cognitive related disabilities, followed by hearing (5.9%) and vision (4.6%), among other categories (CDC, "Disability Impact All of Us," 2022; CDC Disability and Health Data System (DHDS), 2018; Okoro et al., 2018).

According to the National Center for Education Statistics (NCES), only 37% of college students with disabilities informed their college they had a disability in 2016 (NCES, 2022)<sup>8</sup>. The NCES reports that 19% of undergraduate students, or 3,755 out of 19,308 students disclosed having a disability between 2015-2016, while approximately 12% or 423 of 3,124 of students in postbaccalaureate programs reported having a disability. Notably, most students with disabilities in postbaccalaureate programs are students of color, approximately 77% between 2015-2016 (NCES, 2018).

Among medical students enrolled in allopathic medical schools in the United States, a study conducted in 2019 estimated a 69% increase in the number of medical students reporting a disability between 2016-2019; approximately 2,600 medical students, or 4.6% of 56,217 students in the study were reported to have a disability. Finally, 6.0% of these students reported some

<sup>9</sup>Note that this figure was based on a web-based survey sent to disability professionals, "from which an institutionally designated disability professional reported complete accommodation data" (p. 2023). Only students

<sup>&</sup>lt;sup>8</sup> Note that the report by the NCES published in April 2022 was based on longitudinal data of surveys conducted of high school students starting in 2009 who entered college by February 2016. Information about college students with disabilities relies on self-reports and schools are not permitted to collect this data from students directly. See also pp. 20-21.

form of a mobility disability or functional impairment while the highest proportion of disabilities were in the form of cognitive (e.g., attention deficit hyperactivity disorder (ADHD), 30.4%), psychological (32.3%), or learning disabilities (18.3%). A total of 18.0% of medical students with disabilities reported having a chronic health disability, 2.3% a visual impairment, and 1.2% were deaf or hard of hearing (Meeks et al., 2019). More recently, the Association of American Medical Colleges (AAMC) Graduate Questionnaire (GQ) reported that the proportion of fourthyear students reporting a disability increased from 7.6% in 2020 when the question was first included on the survey, to 8.3% in 2021 and 10.9% in 2023 (AAMC GQ, 2023). Interestingly, among GQ survey respondents (graduating medical students) in 2023, the highest reported disability was ADHD at 63.0%, followed by chronic health disability at 15.8%, psychological disability, 14.2%, and learning disability, 6.6%. Some studies have noted that students with cognitive, psychological, and learning disabilities, so-called "hidden disabilities" are less likely to disclose than those with physical disabilities (Couzens et al., 2015; Haque, 2018). However, results from both studies indicate that psychological and cognitive disabilities are still higher in relation to other types of disabilities among medical students.

## Disparities in Educational Outcomes for Individuals With Disabilities

The prevalence of secondary students with disabilities has grown over the past several decades, and so too has the number of these students going on to pursue postsecondary education. According to a longitudinal study of students with disabilities in the United States, the number of individuals with disabilities matriculating into some form of postsecondary education within four years of graduating from secondary school increased from 26.3% to 46% between

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receiving formal accommodations were counted in this study and only those professionals who reported having "complete accommodation data" at 87 allopathic medical schools were included. This data is thus likely an underestimate of the actual population of medical students with disabilities.

1990 and 2005 (Newman et al., 2010), and the number of individuals 25 years old or older who reported holding a bachelor's degree or higher increased from 13% in 2010 to 18% in 2019 (Postsecondary National Policy Institute, 2022). Nevertheless, the proportion of individuals with disabilities who enroll in postsecondary education was significantly lower than that of non-disabled students, 46% compared to 63% in 2005 (Newman et al., 2010). In addition, individuals with disabilities who obtained a Bachelor's degree were more likely to have majored in the social sciences and humanities when compared to their non-disabled counterparts during the same time period, and they were less likely to major in science, engineering or math fields (Postsecondary National Policy Institute, 2022). Despite significant increases in the number of individuals with disabilities enrolling in college and graduate programs, in general, individuals with disabilities are far less likely to hold a high school diploma or bachelor's degree than their non-disabled counterparts. They are also more likely to be unemployed (U.S. Bureau of Labor Statistics, 2015) and to earn less than non-disabled individuals upon graduation from college (Herbert et al., 2014; Huber et al., 2016).

# Supports for Students in K-12 vs. Postsecondary Education

In the United States, one of the key challenges individuals encounters is a disparate system of support available to them in K-12 versus post-secondary education. In K-12, students who qualify for support under IDEA are entitled to individualized education plans (IEP) with provisions in place to ensure they receive an education that is on par with their peers in primary and secondary schools. <sup>10</sup> Even for students who do not qualify for an IEP under the IDEA, Section 504 of the Rehabilitation Act of 1973 requires that schools provide students with resources and support that enable them to receive reasonable accommodations (Tamjeed et al.,

<sup>10</sup> The Individual with Disabilities Act (IDEA), mandates that all students, ages 3-21, enrolled in public schools in the United States receive a "free and appropriate" education. (NCES, 2022)

2021). The American with Disabilities Act and subsequent amendments have extended these provisions by broadening the definition of what constitutes a disability and placing the burden on institutions to demonstrate compliance with the provisions in place to protect individuals with disabilities against discrimination (ADA, 1990; ADA Amendments Act, 2008).

Unlike elementary and secondary institutions, higher education institutions as well as postsecondary institutions possess less direct guidance, resources, and support to students with disabilities (Newman & Madaus, 2015; Wolanin & Steele, 2004). The burden often falls on students to disclose they have a disability, advocate for their own accommodations, and request resources and programming to support their learning (Newman & Madaus, 2015). Not surprisingly, there are fewer supportive resources for students in graduate/professional school than there are for students in K-12 and college (Getzel & Thoma, 2008; Herbert et al., 2014; Yssel, 2016). As one researcher put it, students go from "a system of entitlement" to one of "eligibility" when going from high school to postsecondary institutions (Berg, 2017) and many are often depicted as unprepared or lacking the knowledge and skills to self-advocate or navigate the systems and processes they encounter as young adults in college or graduate school (Hong et al., 2007).

# **Higher Education and Support to Students With Disabilities**

A number of empirical studies explain the types of challenges students with disabilities encounter in college in relation to disclosure and seeking support and persistence. Studies have found that not being aware of how to access resources or self-advocate, as well as concerns about the stigma of being labeled as a person with a disability, disincentivize disclosure (Adam & Warner-Griffin, 2022; Getzel & Thoma, 2008). In addition to individuals' personal attributes, including their background, culture, perceptions, and beliefs, individuals' social skills and self-

advocacy skills are found to impact students' ability to seek and receive support for their disability (Brinkerhoff et al., 2002; Hong, 2015). Studies have also emphasized institutional factors such as the presence of disability resources, disability support staff, and faculty who are knowledgeable about disability accommodations as important for outcomes (Marshak et al., 2010; Rao, 2004; Vogel et al., 2006). Consistent with these explanations, campus climate has been cited as a key factor in determining whether students with disabilities persist in college (Wilson, Getzel, & Brown, 2000). The lack of supportive resources and programs is said to create additional barriers for students who might otherwise seek support for their disability. (Wilson et al., 2000).

Other studies indicate that many of the same factors that impact student persistence in college are found to apply to students with disabilities. That is, students who are first-generation, low-income, or non-traditional students who reside at home and attend school part-time are less likely to persist (Herbert at al., 2014). More importantly, students of color are found to be over-represented among the population of students with disabilities, particularly in the K-12 arena, with African Americans being three times as likely to be identified as needing special education services than other students (Aron & Loprest, 2012)<sup>11</sup>. An additional set of studies have attempted to analyze the effectiveness of disability resource offices and interventions or programs as determinative of outcomes for students with disabilities (Herbert et al., 2014).

Despite the wealth of literature on students with disabilities, in higher education, many of these studies are limited in scope and cannot be compared or generalized across institutions

<sup>&</sup>lt;sup>11</sup> The double stigma students of color with disabilities face in high school and college are the subject of a number of studies, and they highlight the importance of understanding intersectional identities since students with disabilities are disproportionately members of other minority groups but are less likely to persist in college or be employed (See, for example: Aron & Loprest, 2012; Banks, 2014; Gatlin & Wilson, 2016; Harry & Klingner, 2006; Pellegrino et al., 2011).

because they use different definitions of disability or focus on one type of disability, such as learning disabilities, or physical versus cognitive disabilities. While some studies do draw on definitions of disability that are in concordance with the ADA and ADAA 2008 definitions, many studies acknowledge that the exact numbers of students with disabilities is difficult to accurately capture given the self-reported nature of the data and the fact that Section 504 and the ADA explicitly do not allow institutions of higher education or graduate programs to gather information on disability status. Indeed, because neither colleges nor medical schools are able to collect data on the prevalence or numbers of students who identify as having a disability upon admission, existing data on the prevalence of disabilities among medical students relies heavily on self-reports by students as well as staff members or disability resource providers at these institutions (Eckes & Ochoa, 2005; Herbert et al., 2014; Hong et al., 2007).

Keeping these limitations in mind, it is nevertheless important to compare the prevalence of types of disability among K-12, college, and medical students across the education continuum and limited data suggests that the type of disability and prevalence varies significantly from K-12, college, and medical school (Meeks et al., 2021; Wolanin & Steele, 2004). Whereas learning disabilities accounts for over 30% of students receiving special education benefits in elementary school, it is estimated that only about 16.7% of medical students with disabilities possess a learning disability among those who have been identified by school officials and are receiving accommodations, whereas attention deficit hyperactivity disorder and psychological disabilities account for 33.5% and 23.7% of reported disabilities among medical students, respectively among those receiving accommodations (Meeks et al., 2020).

The variation in prevalence and type of disability between college and medical school warrants a closer look at how medical students' experiences may be distinct from that of students

in college. As students transition from K-16 to graduate and professional programs, they are no longer minors, but rather, adult learners. Much of the research on students with disabilities focuses on K-16. While some challenges are similar between college students and graduate students, it is important to note the unique experiences of medical students, vis-à-vis their institutions and medical school culture, in particular. More importantly, the social model of disability framework may help to explain why the nature of the challenges students with disabilities face might vary between K-16 and professional and medical schools, i.e., how institutions are configured to restrict entry for some and perhaps create opportunities or an advantage for others. While recent studies on students with disabilities at times depict students as passive agents who merely respond to the institutions they are a part of to access resources, this study illustrated and pointed to the varied ways in which students are able to creatively navigate challenges and thrive.

# Medical School Culture and Unique Challenges to Students With Disabilities

As is clear from research conducted on medical students in the United States (and around the world), physician trainees experience challenges that are distinct from college and other graduate programs (Deepa & Panicker, 2016; Dyrbye et al., 2014; Lane et al., 2020). For one, the sheer volume of information students must learn and the pace at which they must learn poses a significant challenge for many students (Hill et al., 2018). Many describe learning in medical school like "drinking out of a fire hose," when compared to their experience in college (Yurkiewicz, 2012).

Moreover, students report that medical school is fraught with academic pressures and increasing responsibilities. First-hand accounts from medical students point to the intense competitiveness, high stakes nature of licensing exams and the stresses associated with working

in a clinical setting as trainees, where they are exposed to dying patients, trauma, and may be subjected to workplace related discrimination, mistreatment, or even violence (Brazeau et al., 2014; Hill et al., 2018; Templeton et al., 2022; Veal, 2021).

As a result, a significant number of medical students experience challenges to their mental health and well-being. Indeed, data from the past several decades indicate higher rates of burnout, depression, anxiety, and mental health issues among medical students relative to their counterparts who have graduated from college, despite efforts on the part of institutions to increase psychological support services and well-being programming and resources (Drybye et al., 2006; Dyrbye et al., 2014; Quek et al., 2020). Medical students and physicians in the United States and many other countries are reported to suffer from higher rates of burnout due to the myriad stressors they experience during their training (Brazeau et al., 2014; Dyrbye et al., 2014).

One study indicates that as many as 58% of medical students in the United States have experienced depression (Dyrbye et al., 2014). Another systematic review of the existing data on medical trainees across 43 countries found that an estimated 27.2% of medical trainees were depressed or experienced depressive symptoms, and 11.1% of medical students experienced suicidal ideation (Rotenstein et al., 2016). These challenges were exacerbated during the COVID-19 pandemic as schools curtailed students' clinical training and resorted to remote and virtual learning activities to supplement or in some instances, replace classroom and clinical experiences (Rose, 2020). According to a 2021 study of medical students at six medical schools, 60% of US medical students screened positive for anxiety related to the COVID-19 pandemic and 25% were found to be at risk for post-traumatic stress disorder (PTSD) (Lee et al., 2021). Evidence suggests that the emergence of psychological disabilities has become increasingly common among medical trainees in the United States (Brazeau et al., 2014), and a cross-

sectional survey of American workers reports that doctors reported higher levels of loneliness and social isolation than individuals in other professions (Vogel, 2018)

# Challenges for Medical Students With Disabilities

For medical students with disabilities, the challenges are even more acute as they attempt to adjust to the demands of medical school. Ironically, while medical trainees are taught to prioritize the needs of patients and their well-being, medical students with disabilities encounter a culture where disability is seen as weakness, rendering them less capable than their non-disabled counterparts (Jain, 2020; Marzolf et al., 2022). Numerous studies have highlighted a bias towards 'ableism,' in the practice of medicine and medical education; patients with disabilities have been found to experience discrimination and lower quality of care than their non-disabled counterparts (de Vries McClintock et al., 2016; Jain, 2020, Jha et al., 2002).

In a survey conducted of over 700 board-certified physicians in the United States in 2019, fewer than half, or 40.7% were confident in their ability to provide the same quality of care they would to nondisabled patients; a majority, 82.4%, indicated they believed people with significant disabilities experienced a worse quality of life than nondisabled people (Iezzoni et al., 2021). Scholars and practitioners have cited the lack of appropriate education as one of many factors impacting the disparity in treatment of individuals with disabilities (Iezzoni et al., 2021; Kirschner & Curry, 2009) and research suggests that students experience conflicting priorities in navigating what it means to be a "good student," vs. a "good patient," as medical trainees (Stergiopoulos et al., 2018).

A recent study of allopathic medical students in the United States suggested that students with disabilities face barriers to disclosure when their institutions fail to provide an informed system for disclosure and provision of accommodations (Meeks et al., 2021). The same study

cites the discrepancy between the 7.6% of graduating medical students who anonymously identified as having a disability in 2020 on the AAMC GQ, and 4.6% of students were reported to have formally registered with their institution as having a disability and requested accommodations. A follow-up study based on a survey of disability resource professionals at 154 allopathic medical schools cites a prevalence of 5.9% of medical students with disabilities (Pereira-Lima et al., 2023) while the AAMC GQ reported 10.9% of fourth-year medical students reporting a disability in 2023. <sup>12</sup>

Moreover, medical students may be disinclined to disclose they have a disability and seek accommodations due to the stigma associated with having a disability and fears of discrimination, real or perceived, by faculty and administrators. A complex array of both institutional and personal factors can impact students' willingness to disclose and seek accommodations, but studies suggest that the nature of the barriers and the difficulties students encounter are heightened in medical education (Jain, 2020, 2022; Meeks & Jain, 2018). Indeed, these studies suggest that medical students face similar challenges they may have encountered as undergraduates, but with even greater disincentives and challenges to seeking support for their disability given the culture of medicine and medical education (Jain, 2022).

# A Framework for Understanding Medical Education and the Lack of Disability Inclusion

A recently published dissertation (2020) and follow-up publication by Neera Jain described the unique challenges students with disabilities face in medical education, as one which operates on "the capability imperative," where "malleable students" expected to act as "selfless superhuman physicians," within an ableist hegemony (Jain, 2022, p. 4). Inclusion of students with disabilities is framed in terms of an individual's access to accommodations which

 $<sup>^{12}</sup> See: \underline{https://www.aamc.org/data-reports/students-residents/report/graduation-questionnaire-gq} \\$ 

only serves to reinforce this hegemony. As a qualitative study, Jain conducted semi-structured interviews with 19 disabled students and 27 school officials from four U.S. medical schools to describe the unique cultural logic of medical education and to examine how inclusion is framed for students with disabilities. Jain highlighted the limitations embedded in medical institutions' approach to inclusion for students with disabilities, describing the ableist hegemony that permeates the practices and norms of the sites of medical trainees. Calling for a fundamental reimagination of educational structures, Jain advocates for the application of universal design principles, which emphasizes practical ways educators and institutions can design learning to support diverse learners through a variety of modalities and pedagogical practices<sup>13</sup>, reconceived and transformed notions of capability, and ideas of professional identity formation rooted in a disability epistemology (Jain 2020, 2022)<sup>14</sup>.

Jain (2020) aspired to provide an in-depth analysis and understanding of the experiences of students with disabilities as the basis for a call to action. However, the study falls short of exploring how students respond to their challenges. Instead, her focus on the idea of an "ableist hegemony," overshadows the dynamic and situational nature of students' relationships with their environments and the ways that students have negotiated, navigated, and at times, resisted norms and expectations placed on them.

Moreover, this current study sought to center the voices of medical students as they described the challenges they experienced during their medical training, challenges which are distinct from their undergraduate experience. In this way, the study builds on and expands on the efforts of students and educators to address the phenomena that Jain aptly described as "the

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<sup>&</sup>lt;sup>13</sup> Interestingly, universal design principles are not elaborated on in Jain's study in depth, but information about universal design principles may be found through a variety of sources. See: <a href="https://udlguidelines.cast.org/">https://udlguidelines.cast.org/</a>

capability imperative," but highlights the ways students have interacted with their environment and the ableist culture that permeates the field of medicine. It also explores both how students perceive the challenges related to their disability, including the perceived stigma, and how they address them in different contexts during their training.

As elaborated previously, many of the students registered for disability accommodations in medical school self-report elevated levels of anxiety, depression, and ADHD, and are newly diagnosed in medical school. As such, disability is not a fixed state or identity, but one that gets created and recreated in the unique context of medicine and medical education. A subset of the disabilities that students develop and experience over time may be attributed to the ways in which medical institutions treat their own trainees; but many studies on medical students with disabilities overlook how the institution of medicine itself impacts students' disability.

Jain's (2020) study illuminates and helps to identify key components of medical education that pose as hegemonic barriers to inclusion of those with disabilities. Jain also alluded to forms of resistance but did not elaborate on what these consist of. As such, this current study identifies specific ways in which students with disabilities navigated challenges they experienced during their training. Moreover, in arguing for a fundamental redesign of medical education through, for example, universal design, Jain outlined solutions that serve to depict disabilities and individuals with disabilities as passive recipients and subject to the larger forces of a hegemonic system; one that ultimately and inadvertently serves to diminish their agency. In centering the first-hand narratives of students, this current study explored the various ways students navigated and addressed challenges, utilizing both formal and informal resources and support.

## **Efforts to Diversify the Medical Student Population**

Beyond the specific studies noted, the challenges facing students with disabilities in medical and graduate professional programs is the subject of a small, but growing number of studies, particularly as increasing numbers of students have gained entry to these programs. While admissions into allopathic medical schools is known to be highly selective and competitive, U.S. medical school enrollment has increased significantly over the past several decades, due to concerns about future physician shortages (Coleman et al., 2014). Compared to 16,488 matriculating first-year students in 2002, there were 22,239 as of 2020 (AAMC, 2021), and a total of 96,520 students were enrolled in MD-granting institutions in the United States in 2022 (AAMC, "2022 FACTS"). Similarly, the number of MD-granting medical schools accredited by the Liaison Committee on Medical Education (LCME) increased from 125 to 155 between 2002-2020 (AAMC, 2021)<sup>15</sup>. Overall, the number of students matriculating into medical school in the United States has increased by 37.5% since 2002 (Boyle, 2021).

Increases in medical school enrollment are not only a result of initiatives to address physician shortages, but also largely driven by efforts to increase the diversity of the physician workforce (Coleman et al., 2014). The LCME, which serves as the accrediting body for allopathic medical schools in the United States and judges "the compliance of medical education programs with nationally accepted standards of educational quality," lays out 12 accreditation standards. Standard 3.3 calls for "ongoing, systematic, and focused recruitment and retention activities, to achieve mission-appropriate diversity outcomes among students, faculty, senior

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<sup>&</sup>lt;sup>15</sup> For the purposes of this study, I will be limiting my analysis to medical students enrolled in allopathic (MD) medical institutions, as distinct from osteopathic (DO) schools. For more information on the distinction see: <a href="https://www.usnews.com/education/best-graduate-schools/top-medical-schools/articles/2019-11-07/the-difference-between-do-and-md-">https://www.usnews.com/education/best-graduate-schools/top-medical-schools/articles/2019-11-07/the-difference-between-do-and-md-</a>

 $<sup>\</sup>frac{degrees\#:\sim:text=While\%20allopathic\%20schools\%20offer\%20a,circulatory\%20issues\%20and\%20musculoskeletal\%20conditions.$ 

administrative staff and other relevant members of its academic community" (LCME, 2020, p. 4). Likewise, standard 3.4 calls for medical schools to have a policy in place to "ensure that it does not discriminate on the basis of age, disability, gender identity, national origin, race, religion, sex, sexual orientation or any basis protected by federal law" (p. 4).

In accordance with LCME standards, medical schools across the United States have undertaken efforts to diversify their student body, particularly as increasing numbers of studies indicate that diversifying the health care workforce improves patient outcomes (Cohen et al. 2002; Williams et al., 2014), and a growing number of advocates have called for medical schools to "recognize and eliminate barriers" faced by medical students with disabilities and increase representation of individuals with disabilities among medical trainees (Marzolf et al., 2022, p. 378). A report by the AAMC states that the first-year class that enrolled in 2021 was "larger and more diverse than any before it," and the trends reflect increases in the diversity of the applicant pool as well (Boyle, 2021).

Between 2020-2021, the number of matriculating students from underrepresented backgrounds increased by 21% for Black or African American students, 8.3% among Asian students, 7.1% among those of Hispanic, Latino, or Spanish descent, and 6.3% among Native Hawaiian and Pacific Islanders, while the number of students who identified as White decreased by 1.6% ("2021 Fall Applicant, Matriculant, and Enrollment Data Tables", 2021). Similarly, a 2020 AAMC survey of deans and administrators at allopathic medical schools indicates that 99% had undertaken specific initiatives to diversify their student population by recruiting students from under-represented backgrounds, <sup>16</sup> through specific measures such as revising their admissions criteria, engaging in high school and college recruitment and outreach, and through

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<sup>&</sup>lt;sup>16</sup> Referring to rural and urban underserved communities, racial and ethnic minorities, economically disadvantaged backgrounds, among other categories that respondents could indicate through write-in responses.

the provision of earmarked scholarships for historically under-represented students (AAMC, 2020).

# AAMC Reports and Policy Frameworks to Promote Disability as Diversity

A reflection of a larger movement to increase the diversity of the physician-trainee workforce, the American Association of Medical Colleges (AAMC) has called upon medical schools to increase institutional support to students with disabilities and promote greater inclusivity. In a 2018 report entitled, "Accessibility, Inclusion, and Action in Medical Education: Lived Experiences of Learners and Physicians with Disabilities," the AAMC reaffirmed its commitment to increasing diversity and inclusion in medical education. It also acknowledged key institutional barriers facing medical students with disabilities: the lack of consistent policies and procedures for medical students to disclose their disability and request accommodations, inconsistent and highly variable support to medical students across institutions, and a lack of understanding of the American with Disabilities Act (ADA) among administrators. In providing a rationale for increasing diversity and inclusion, the report stated:

Diversity and inclusion in the medical student body are associated with greater self-rated preparedness to care for minority patients and a stronger commitment to equitable access to care. Additionally, increased physician diversity has resulted in positive effects on patient care and access for marginalized groups, such as low-income people, racial and ethnic minorities, and nonnative English speakers. Our belief is that similar benefits can result from educating and employing physicians with disabilities. (Meeks & Jain, 2018, p. 3)

Recognizing that students with disabilities are also under-represented in medicine, some medical programs have adopted and/or updated their technical standards and policies to promote increased access and support for students with disabilities (Stauffer et al., 2022). A number of institutions have also acquired designated disability resource professionals (DRPs) to support students with disabilities (Meeks et al., 2021).

## Variation in Institutional Supports for Students With Disabilities

With the rapid movement to diversify the medical profession and promote increased access to students with disabilities, scholars have criticized the extent to which medical institutions have provided reasonable accommodations and resources to support students with disabilities. Despite increasing calls to diversify medical schools and promote increasing inclusivity and accessibility for students with disabilities, a number of medical schools still have not adjusted their technical standards to mitigate the barriers to access and inclusion (Marzolf et al., 2022; Meeks et al., 2022; Zazove, 2016). Moreover, as one scholar has pointed out, the main avenue for supporting students with disabilities in medical programs has been framed as primarily one of updating technical standards and policies as well as examining the process for handling student accommodations. Jain (2020) argued that schools should examine more broadly how they might reconfigure their curricula, pedagogy, and institutional practices to better support students with disabilities, through for example, the application of universal design principles.

Research to support evidence-based best practices to meet the needs of this increasingly diverse student body and that of students with disabilities, in particular, has been limited (Zazove, 2019). While several dissertation studies have been conducted regarding medical students with disabilities to better understand their experiences and challenges (Donlon, 2016; Jain, 2020), little by way of fundamental policy changes or solutions have been implemented to address the needs of this growing population of students. Jain's (2020) study helps to broaden the paradigm of understanding the challenges of students with disabilities in medicine as fundamentally a reflection of the medical culture and norms within which individuals are situated. However, Jain's recommendations fall short of incorporating the voices and perspectives of medical students themselves when formulating how best to address the needs of

students with disabilities based on the wealth of knowledge, experience, and know-how they possess, a perspective this study aspired to do.

## **Conceptual Framework**

This current study drew on a conceptual framework relevant to the study of disability as a social phenomenon and as a social justice issue. The social model of disability frames disability "not as a disease or as a personal deficit, [sic] [but as a] social and political condition" (Rioux, 1997, p. 103). Such a framework stands in direct contrast to concepts of disability that focus on disability as medical problems that are to be remedied and addressed at the individual level (Berghs et al., 2019; Patton et al., 2010). Instead, the social model of disability posits that disability is fundamentally a social concept that must be understood in relation to the specific norms and boundaries of society. Social practices define what is "normal" and how limitations to participation by its members are bound and constrained (Oliver, 2004; 2013). Such a framework of disability has evolved over time, as scholars and advocates have critically examined the implications of one's understanding of disability vis-à-vis societal norms and particular political contexts (Jain, 2020; Shakespeare, 2013).

## Social Model of Disability

Disability studies have undergone significant changes over the past several decades as the concept of disability has evolved. According to one scholar, concepts of disability may be grouped in two broad categories as reflecting 1) individual pathology, or 2) social pathology (Rioux, 1997). As a reflection of individual pathology, disability is framed as having a biomedical origin with prevention through biological and/or genetic screening, and treatment through medical/technological means. Concordantly, disability has also been framed in terms of functional limitations of an individual which can be diagnosed and treated through rehabilitation.

The consequences of framing disability as individual pathology are eloquently and pointedly described by Rioux, who, in writing in particular about individuals with intellectual disabilities, stated: "...research on policy, programmes and services that have an impact on individuals with intellectual disabilities have overly emphasized this perspective (of disability as primarily an individual pathology) to the detriment of the broader systemic conditions that disable people" (Rioux, 1997, p. 107).

Disability has also been framed in terms of social pathology, or as a structural issue which reflects the norms and structure of organizations, institutions, and the societies in which individuals defined as having disabilities are embedded. As such, advocates have emphasized the role of environmental factors, or social organizations and relationships as determinative of how well individuals with disabilities are able to function and thrive in society. In this framework, disability is, among other things: 1) "not assumed to be inherent to the individual independent of the social structure," 2) is "recognized as difference rather than anomaly," 3) "is viewed as the interaction of individual with society," 4) "inclusion of people with disabilities is seen as a public responsibility," and 5) "the points of intervention are the social, environmental and economic systems," as outlined by Rioux in the seminal 1997 article, *Disability: the place of judgment in a world of fact* (p. 105). When examining disability from the lens of social and environmental responsibility, the focus is on the larger structures, systems, norms, and practices that create and sustain barriers and opportunities for those with disabilities. Disability may also be viewed as a consequence of these larger systemic dynamics and conditions.

While not denying the biological and physical impairments that individuals with disabilities experience, the social model of disability emphasizes the way disability can and often is produced and reproduced through limitations placed on individuals who possess specific

impairments in different times and circumstances. By casting the lens on these societal and institutional norms and practices, theorists see disability inclusion as a social justice issue, and the burden of inclusion falls on those who uphold and create the environment and social practices, rather than defining the challenge as one which is to be addressed primarily through medical interventions or rehabilitation (Goering, 2015; Oliver 2004; 2013).

The theoretical approach afforded by the social model of disability allows for a reframing of the view of students with disabilities in medical education, not as one that inheres in the individuals, but rather as a phenomenon that is a product of the norms, structure, and practice of medicine, institutions, and society writ-large – one that creates the very conditions it purports to address and heal. Consistent with Jain's (2020) findings, disability inclusion in medical education is often addressed in a way that reflects the patient/doctor relationship: a model premised on sickness and rehabilitation, identifying sickness in the patient rather than examining the conditions which exacerbate, and even at times, create illness and disability. As a result, emphasis is placed on technical "solutions" to address students' needs. These solutions are also often premised on a "neo-liberal model" that somehow policy changes and institutional approaches will fix the problem of inclusion and provide an adequate basis for addressing what is a systemic problem, i.e., through updated technical standards, hiring a disability support specialist, earmarking resources. As Jain argued, these solutions may be simply enabling the system that serves to pathologize, dehumanize, and "other" individuals with disabilities. In centering the voices of students in their understanding and framing of disability and their experiences with disclosure and seeking accommodations, I sought to highlight the varied ways students have adapted to, navigated, and at times resisted constraints and barriers encountered in medical school.

### Conclusion

The literature on the barriers and challenges students face in higher education forms the backdrop of many of the assumptions made about students with disabilities in graduate programs. However, the particular challenges students encounter in medical school are unlike those that students experience in college or other post-secondary programs. With the increased prevalence of students with disabilities in medical education, and the call to promote greater inclusion and equity in medicine, growing research calls for additional supports and resources for students with disabilities in medicine (Meeks et al., 2020; Pereira-Lima et al., 2023), as well as a "reimagining" of how that support is configured (Jain, 2020, 2022). By centering the voices of students, I sought to highlight the ways in which students with disabilities creatively navigate, adapt to, and resist barriers and challenges through various strategies. Rather than being the passive recipients of support, students are found to dynamically co-create the educational spaces they are a part of. Moreover, this study serves to contribute to the existing literature on students with disabilities, where what it means to be disabled and how students navigate challenges related to disability, continues to evolve vis-à-vis societal and institutional norms, practices and policies.

#### **CHAPTER THREE**

#### **METHODOLOGY**

This study explored the perceived challenges students with disabilities say they face during medical school. It also provides insights into the ways they navigate these challenges through an anonymized survey of medical students and first-hand accounts of medical students with disabilities. This study builds on existing studies of students with disabilities by examining the prevalence and types of disabilities students report as well as the types of challenges they experience during their training. To interpret the findings, I draw from the insights of the social model of disability which depicts perceptions and barriers of disability as constructed in relation to society and institutions, their norms, practices, and policies. As such, challenges individuals with disabilities face must be addressed by examining how institutions, society, and legal practices serve to exclude and marginalize individuals on the basis of these perceptions (Berghs et al., 2019; Donlon, 2016; Oliver, 2004; Oliver 2014).

Three primary research questions and numerous secondary questions formed the foundation of the research study.

- 1. What are the types of disabilities medical students report?
- 2. What perceived challenges, if any, do students with disabilities say they face in medical school?
  - a. What academic challenges do they say they faced, if any?
  - b. What institutional challenges do they say they faced, if any?
  - c. What personal, social challenges do they say they faced, if any?

- d. How, if at all, are the types of challenges reported by medical students with disabilities different, if at all, from those reported by medical students without disabilities?
- 3. How do medical students with disabilities describe their experience navigating, addressing or overcoming these challenges?
  - a. To what do students attribute their ability to navigate, address, or overcome these challenges?
  - b. What resources, if any, have they used? And how have they used them?
  - c. What strategies, if any, have they implemented?
  - d. What actions, if any, have they taken to adjust and adapt to medical school?

## **Research Design and Rationale**

To explore these research questions, I undertook a mixed methods study of students with disabilities, and conducted my study in two steps: first, I employed an anonymized survey of medical students at one allopathic medical school, then I sampled a subset of students who identified as having a disability and responded to the survey to participate in semi-structured individual interviews.

This study was conducted as a mixed methods study to build on previous studies of medical students with disabilities by exploring the types of disabilities reported at one institution, and to better understand the experiences of students with several types of disabilities. I used a mixed methods approach for this study to provide a comprehensive account of medical students and their lived experiences and the challenges they experience. This study builds on previous studies by comparing the responses among students who do not report having a disability with those who do. Survey data were collected to identify prevalence and type of disability at the

study site and also ways in which various types of challenges (academic, institutional, and personal/interpersonal) were associated with disability through the use of crosstabs and Chisquared analysis. A mixed methods approach was used not only to provide a "description of trends, attitudes and opinions of a population," and analyze "associations among variables of a population." (Creswell & Creswell, 2018, p. 147) It was also designed to provide a deeper understanding of the experiences of students with disabilities as they understand and tell it (Schram, 2003, p. 71, as quoted in Merriam & Tisdell, 2016), while examining participants' perceptions and understanding of their experiences. (Merriam & Tisdell, 2016).

## **Research Design Methods**

### Site Selection, Access, and Recruitment

#### Site Selection Criteria and Rationale

Current research estimates that 5.9% of enrolled medical students have a documented disability (Pereira-Lima et al., 2023) and the results of the most recent Graduate Questionnaire (2023), indicates 10.9% medical students reporting having a disability. <sup>17</sup> To conduct the study, the site selected needed to be large enough to allow for sufficient numbers of potential participants as well as representative of other highly selective medical institutions. For this purpose, I conducted my study at an allopathic, MD-granting medical school accredited by the Liaison Committee on Medical Education (LCME) with an enrollment of at least 800 students, representing a diverse student body, and one that is representative of large, MD degree-granting institutions in the United States. In addition to selecting a site that was comparable in size and student demographics to medium sized medical schools, I sought to identify an institution where students have a designated disability resource provider, and a recognized student advocacy group

<sup>&</sup>lt;sup>17</sup>See: <a href="https://www.aamc.org/data-reports/students-residents/report/graduation-questionnaire-gq">https://www.aamc.org/data-reports/students-residents/report/graduation-questionnaire-gq</a>

for students with disabilities to better ensure that there was a participant population adequate in size and willing to participate in the study.

The site selected for this study is an allopathic medical school in the western United States that fits the criteria for selection. This institution enrolls on average two hundred new students each year. Over the past 10 years, there has been an influx of applicants to the school just as admissions has become increasingly competitive. In 2020, fewer than 2% of applicants to this institution were accepted and matriculated. In the *U.S. News and World Report* 2023 report, this institution was ranked among the top 20 in the United States as being among the most diverse medical schools; it has consistently been ranked among the best medical schools in the nation. This backdrop provides a basis for understanding the competitive barriers students face when applying to medical school; it also reflects the caliber of students who are accepted. Many students at this institution have a strong background in activism, social justice, academics, and/or research.

As with many other medical schools across the United States, this medical school formed a local chapter of the student-led Medical Students with Disability and Chronic Illness group (MSDCI). As a student-founded organization, MSDCI is focused on the primary goals of fostering community, advocating for the rights of individuals with disabilities, improving accessibility for individuals with disabilities, and promoting disability education and awareness. <sup>18</sup> In recent years, this institution also hired a Disability Services Provider (DRP) as a direct result of advocacy efforts of members of MSDCI. This institution provides an ideal site for the study given its size, demographic make-up, and existence of an active disability student

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<sup>&</sup>lt;sup>18</sup> For more information, see: <a href="https://msdci.org/">https://msdci.org/</a> According to its website, the mission of MSDCI is "to support and serve medical students with disability and/or chronic illness...increasing accessibility of medical education for trainees of all abilities as well as advocating for and improving health equity for patients with disabilities."

community, as a highly competitive public, research-based institution, committed to diversity, inclusion, and equity. In addition, there are a number of students with disabilities engaged in MSDCI's efforts to strengthen accessibility and inclusion which makes it an ideal site for potential participants.

## Access to Site and Participants

As a Director of Academic Support at a medical school, I have developed collaborative relationships with colleagues at various other medical schools in the western region through the Association of American Medical Colleges Western Group on Student Affairs (AAMC WGSA), and the Medical Education Learning Specialist (MELS) network. I was able to draw on my contacts with medical school administrators at the institution where the study took place to request access to study participants. I took steps separately to secure approval from the site's administrative leadership, including a chief of staff and a director of their evaluation and assessment department to conduct the study and disseminate my survey to the school body. After receiving IRB approval, I began recruiting participants for the study.

# Recruitment of Survey Participants

To recruit participants, I disseminated a survey to all current medical students at the medical institution, including students on a leave of absence. An email was sent to each cohort of students at the study site on October 25, 2023. The email listservs were organized by class/year and status: one email was sent to listservs for each class, as well as to students on a leave of absence. A reminder email was sent on November 11, 2023. The email included information about the purpose of the study and criteria for inclusion. The sample description is provided in Chapter 4.

Table 3.1 summarizes the participation rate for the survey in relation to the entire population at this study site. 23.3% of the student body participated in the survey. The survey was completed by those who reported a disability and those who did not. First-year students (27.0%) comprised the highest proportion of the survey sample, while second-year students comprised the lowest (14.7%).

**Table 3.1**Survey Participation Rate, By Program Year and Status

Program Year/Status	Survey Participants		Student Body		Participation Rate (%)
	n	%	n	%	
1st Year	55	27.0	176	20.1	31.2%
2nd Year	30	14.7	173	19.7	17.3%
3rd Year	45	22.1	169	19.2	26.6%
4th Year	41	20.1	198	22.6	20.7%
Leave of Absence (LOA)	33	16.2	160	18.3	20.6%
Total	204		876		23.3.%

Notes: Information about study participants based on responses to questionnaire.

Aggregate information about all students provided by the school registrar.

The survey included questions asking participants for their basic demographic information, including their gender, race/ethnicity, and type of disability (Appendix A).

### Interview Sample Selection

Purposive, criterion-based sampling was used to select interview participants from among survey respondents who represented a broad cross-section of medical students who identified as having a disability based on type of disability, year in school, gender identity, and race/ethnicity (Creswell & Creswell, 2018; Maxwell, 2013). Students at various stages of their medical training (year one through year four students) were interviewed to capture perspectives of students in their pre-clinical and clinical training. To be eligible to participate in the interview, students had to be current medical students, at least 18 years old, and identify as having a disability, and/or

formally diagnosed with a disability (self-reported). <sup>19</sup> I identified a subset of 18 participants to interview for the study and invited them to participate in a 45-minute Zoom interview. The invitation included an introduction to the study and the rationale for my study. I also communicated how I hoped the research would benefit students with disabilities, and I obtained their informed consent for the study. I proceeded to contact via email additional individuals from among those who indicated an interest in participating in the study based on the criteria noted. I provided a 1-week deadline to respond to my invitation and sign up for an interview via Sign-up Genius, anticipating that not all individuals who were invited to participate in an interview would respond to the invitation.

#### **Data Collection Methods**

## **Survey**

In the first stage of my data collection, I prepared a draft survey via Qualtrics and piloted it with eight students with disabilities at other institutions outside the study population between October 10-24, 2023. I also obtained feedback from one disability resource provider and two colleagues working in student services for medical students at separate institutions during this time period. I provided \$10 gift cards to student participants who provided their feedback on the survey and gifted staff members with a \$25 gift card for their feedback.

Once piloted and revised, the official version of the survey was launched on October 25, 2023, and responses were collected until November 24, 2023. The first 50 respondents to the survey were given a \$10 gift card for their participation. Of note, 80% of responses to the survey

<sup>&</sup>lt;sup>19</sup> According to the UCLA Center for Accessible Education, such students include those with "physical, psychological, or perceptual impairment which limits one or more major life activity, have a history of impairment, or who are regarded as having an impairment based on regulations for Section 504 of the Rehabilitation Act of 1973 and the American with Disabilities Act of 1990, the ADA Amendments Act of 2008 (ADAAA)." <a href="https://cae.ucla.edu/students/new-prospective-cae-students">https://cae.ucla.edu/students/new-prospective-cae-students</a>

were received within the first 72 hours of its launch. While respondents could complete the survey anonymously, at the conclusion of the survey, participants were given the opportunity to indicate their willingness to participate in a 45-minute interview, by providing their contact information. A separate link was provided at the conclusion of the survey with a password to complete a separate questionnaire to include their name for receipt of the gift card. A copy of the survey may be found in Appendix A.

All questions were denoted optional to allow respondents to skip questions they did not feel comfortable responding to given the sensitive nature of the questions. There were 20 potential questions participants may have been prompted to answer, depending on their responses to the survey. For example, participants who responded they identified as having a disability were asked whether they were formally diagnosed with a disability or disabilities. They were also prompted to answer questions about the type of disability they possessed as well as whether and when they began receiving accommodations for their disability. All students were prompted to indicate through a matrix grid what resources they had used to-date at their medical school.

Another question elicited whether they had experienced academic challenges related to study skills, time management, or test taking. Yet another matrix question asked participants to indicate whether they had experienced any personal or interpersonal challenges, such as finding community, dealing with the stigma of having a disability, questioning whether they belong in the program, challenges related to physical and mental health/well-being, financial hardship and/or discrimination, prejudicial or insensitive treatment by faculty, staff, or classmates, with "Yes," "No" "Not applicable" response options. Students who indicated they identified as having a disability were also asked about any institutional challenges they experienced, such as

accessing appropriate resources related to their disability, disclosing their disability or disabilities in order to seek support, as well as applying for in-house and USMLE accommodations. At the end of the survey, students were asked to indicate their gender identity and race/ethnicity.

#### **Interviews**

Ninety-one respondents to the survey volunteered to be interviewed, and forty of those who volunteered fit the interview criteria of identifying as having a disability, answering "yes," to the question, "Do you identify as having a disability?" Individuals who indicated "no," or "uncertain," were excluded from eligibility for an interview since the focus of this study is on understanding the experiences of students who identify as having a disability. Twenty-eight respondents were invited for an interview, but only 18 responded to schedule an interview after being contacted individually via email.

Between November 3, 2023, and December 20, 2023, I conducted 18 semi-structured interviews ranging from approximately thirty minutes to one hour and thirty minutes in duration. I recorded each interview by downloading a recording of the interview onto my laptop via Zoom. I also used an iPhone audio recorder to capture an audio recording of the interview as a back-up. Individual interviews allowed for more rich data collection through specific probes and follow-up questions. Open-ended questions allowed me to explore in greater depth how students experienced challenges and ways they addressed or navigated them in the form of narratives or specific examples to illustrate the context in which they experienced them.

Interview questions were formulated to allow participants the opportunity to provide open-ended responses to questions related to key constructs around the research questions. I included specific probes during the interview so that participants could expand on their narratives and provide rich, thick descriptions of their experiences and their perspectives during

medical school. More than superficial descriptions, the interview questions were designed to explore why participants perceived their challenges to be challenges and how students navigated and addressed them. (Appendix B).

## **Data Analysis Methods**

Once the survey period concluded, I reviewed the response results and eliminated any responses that were not recorded within the time period of the survey and those responses that did not meet the completion criteria of 100 percent progress or were not coded as "finished." Additional responses were excluded if all questions were seen but no response was recorded, since all questions were optional. After the additional responses were removed, a total of 204 responses were included in the study.

After downloading the survey data from Qualtrics into an Excel spreadsheet, I uploaded the data into SPSS to code and run analysis of my survey data. I ran descriptives of my survey and also conducted Chi-squared analyses to identify correlations with academic and personal challenges experienced by students on the basis of disability status.

In addition to recording each interview, I took notes during and after my interviews. I then transcribed my interviews using the Zoom transcription platform and Rev.com. I listened to each interview several times to ensure accuracy of the written transcripts. I used MAX QDA, a qualitative data analysis software, to organize and manage and code my interview data. I inductively and deductively coded the data transcripts using the research questions as the basis for creating my initial structural codes (e.g., types of challenges: academic, institutional, personal, navigating challenges) but allowed for new codes to emerge within each structural code (Saldaña, 2021). I engaged in several cycles of coding and used In Vivo Coding to "prioritize and honor the participant's voice" (p. 138). From these codes, themes were categorized and

organized based on commonalities and differences and were also grouped together around broader categories around similar topics. I also wrote a variety of memos, including reflection memos, quotation memos, and comparison memos to assist in identifying possible themes (p. 70). Coding issues or challenges were discussed with my committee members who are well versed in qualitative data analysis.

# **Credibility and Validity**

One of the main threats to the credibility and validity of my study was the potential for self-selection or sampling bias among the participants for my study as well as reactivity during the interview process. Because I am interested in learning about the experiences of students with disabilities and exploring their experiences navigating challenges and addressing them, my study might have been biased towards participants who are more inclined to have strong opinions, or very positive or negative experiences, particularly when using available resources and seeking and receiving support. To address the potential for such bias, I distributed my survey via email to elicit participation from the student body at large.

In addition, I worked to provide rich, thick descriptions from participants about their experiences and looked for ways to triangulate data sources by comparing my findings with related empirical research that depicts challenges students with disabilities face in medicine.

Because I had direct access to the Disability Resource Provider and MSDCI group at the institution where the study took place, I worked closely with these individuals during the design and implementation of my study by asking for feedback on my questions and study design. To enrich my findings, I also supplemented my observations with direct communication with members of the MSDCI group and the DRP for insight into some of the challenges they have

observed based on their work with students. Doing so helped me refine my survey and interview questions and also assisted in contextualizing students' stories and experiences.

#### **Ethical Considerations**

As suggested previously, this study had the potential to pose several ethical issues that I needed to address in the design and implementation of my study. In particular, I had to address the potential for risk to participants and confidentiality. I was mindful of protecting the identities of participants and ensuring the confidentiality of their responses. I mitigated the risk of harm to participants by reminding participants that their participation was voluntary, and by having them read an informed consent form which clearly communicated the purpose of the study as well as the steps taken to ensure that their identity and responses to interview questions would be kept confidential. I worked to ensure that participants understood that the purpose of the study is to center students' voices and perspectives in identifying best practices and developing recommendations to better support medical students with disabilities. I provided links to resources and information to respondents at the conclusion of the questionnaire to ensure that students are made aware of available resources for medical students with disabilities. I included a \$10 gift card to the first 50 participants of the survey and provided a \$25 gift card to those who participated in interviews. I also sent a thank you note to each interview participant. In addition, I made sure to use pseudonyms instead of real names when citing interview participants, so as to protect their identity. As it relates to protection of data, I stored all my data on password protected devices and will delete all records of transcripts 5 years after completing my dissertation.

#### Conclusion

This mixed methods study sought to elevate the voices and perspectives of medical students with disabilities by sharing their stories and experiences navigating, adapting to, and addressing challenges they encountered on their medical school journeys. In addition to a survey, in-depth semi-structured interviews were conducted with students at various stages of their medical training to shed light on the various challenges they have encountered as individuals with disabilities. A focus on how students with disabilities perceive their challenges and navigate them in medicine is lacking in the current literature. Thus, the findings from this study can provide insight into ways to better support students with disabilities in medicine by centering the student perspective. It also illuminates how students are already enacting change through creative forms of resistance, adaptation, and activism. More than passive recipients of the policies and resources at their disposal, students have been active in co-creating more inclusive and equitable spaces for students at the margins.

#### CHAPTER FOUR

#### **FINDINGS**

This study is a mixed methods study that explored the perceived challenges medical students experience and ways they navigate these challenges. As such, this study was conducted to answer the following research questions:

- 1. What are the types of disabilities medical students report?
- 2. What perceived challenges, if any, do students with disabilities say they face in medical school?
  - a. What academic challenges do they say they faced, if any?
  - b. What institutional challenges do they say they faced, if any?
  - c. What personal, social challenges do they say they faced, if any?
  - d. How, if at all, are the types of challenges reported by medical students with disabilities different, if at all, from those reported by medical students without disabilities?
- 3. How do medical students with disabilities describe their experience navigating, addressing or overcoming these challenges?
  - a. To what do students attribute their ability to navigate, address, or overcome these challenges?
  - b. What resources, if any, have they used? And how have they used them?
  - c. What strategies, if any, have they implemented?
  - d. What actions, if any, have they taken to adjust and adapt to medical school?

In addition to illuminating the types of disabilities reported among current medical students at one institution, this study identifies various ways in which students described their

challenges in the unique context of their medical education. It also reviews the ways in which they navigated these challenges, drawing on the social model of disability which highlights the contextual nature of disability as a social justice issue. The survey data reveals the relative prevalence of these challenges among students with and without disabilities and identifies specific academic and personal challenges that are associated with disability status. Findings from interviews are interwoven with the survey data to explore how a subset of these students made sense of these challenges and navigated them during their medical training.

## **Sample Description**

The survey was emailed to the entire student body at one institution, and a total of 204 medical students, or approximately 23% of the overall student population completed the survey. The survey was completed by both those who reported having a disability and those who did not. Respondents represented a cross section of students at various stages in their training, including students on a temporary leave of absence. Table 4.1 indicates the demographics of the student population as well as the survey and interview samples.

 Table 4.1

 Demographic Characteristics of Study Participants

Demographics	Student population (N=876)		Survey (n=204)		Interview (n=18)	
	n	%	n	%	n	%
Current Status/Year in Medical School						
1 <sup>st</sup> Year	176	20.1	55	27.0	6	33.3
2 <sup>nd</sup> Year	173	19.7	30	14.7	3	16.7
3 <sup>rd</sup> Year	169	19.2	45	22.1	5	27.8
4 <sup>th</sup> Year	198	22.6	41	20.1	2	11.1
On Leave of Absence (LOA)	160	18.3	33	16.2	2	11.1
Declined to Respond/Missing	0	0	0	0	0	0.0
Gender Identity						
Female	505	57.6	146	71.6	15	83.3
Male	368	42.0	55	27.0	3	16.7
Non-binary	1	0.1	4	2.0	1	5.5
Declined to Respond/Missing	2	0.2	1	0.5	0	0.0
Race/Ethnicity						
African American/Black	117	13.4	16	7.8	3	16.7
Asian or Pacific Islander	280	32.0	71	34.8	5	27.8
Caucasian/White	202	23.1	55	27.0	4	22.2
Hispanic or LatinX	179	20.4	54	26.5	6	33.3
Middle Eastern or North African	n/a		12	5.9	1	5.6
Multi-racial	52	5.9	13	6.2	1	5.6
Native American/Alaskan Native	n/a		1	0.5	0	0.0
Other	54	6.2	2	1.0	0	0.0
Declined to Respond/Missing	0	0	8	3.9	0	0.0

*Notes:* For gender identity and race/ethnicity, respondents could select multiple categories. As a result, the sums of the percentages are greater than 100. Aggregate information about all students provided by the school registrar. Certain categories for race/ethnicity differed between the school and the survey: e.g., Native American/Alaskan Native and Middle Eastern/North African categories were not reported by the school but were included as categories in the study survey.

First-year students (27.0%) comprised the highest proportion of the survey sample, while second-year students comprised the lowest (14.7%). According to records obtained from the

school registrar, 70.8% of the student body were students of color, 23.1% of the student body were White/Caucasian, and 6.1% either did not indicate their ethnicity or racial identity or indicated "Other." Among survey respondents, 69.1% were students of color, and 27% were Caucasian/White, reflecting the demographic characteristics of the student body as a whole. A majority of survey respondents (71.6%) were female. Likewise, 32 out of 40 (80%) of the individuals who identified as having a disability and volunteered to be interviewed identified as female. While a higher percentage of the survey respondents were female, there were also a higher number of female students relative to other male students (and other genders) at this institution: the registrar reported a higher percentage of female students (58.2%) versus male students (42.4%), while 0.3% constituted all other gender categories, among those who selfreported their gender identity in the Fall of 2023. The differences in participation rates, particularly between first- and second-year students may be due to their relative availability: in the first year of the curriculum, students' training consists of on-site lectures and labs in traditional classroom settings, while in the second year, students engage in clinical training at various hospital sites.

Of the 204 survey respondents, 71, or 34.8% identified as having a disability, 116, or 56.9% did not identify as having a disability, and 15, or 7.4% indicated they were uncertain based on the definition of disability provided on the survey (see Table 4.2). When asked to indicate whether they identified as having a disability, respondents were provided with a link to the definition provided by the institution's accommodation office, consistent with the American with Disabilities Act (1990) and the ADA Amendments Act of 2008 (ADAA): "An individual with a disability is a person who has 1) a physical or mental impairment that substantially limits one or more major life activities, 2) has a record of such impairment, or 3) is regarded as having

such an impairment" (42 U.S. Code § 12102). The survey question included the note: "you do not need to have registered with the [accommodations office] or be receiving accommodations in order to identify as having a disability."

Reasons given among those who were uncertain about whether they identified as having a disability included: uncertainty as to whether their condition constituted a disability (n=6); belief they have a disability or disabilities, but with no formal diagnosis (n=3); a previous diagnosis of a disability, but uncertainty about whether they currently have a disability due to lack of a current diagnosis, and/or because the condition was well-managed (n=3).

**Table 4.2** *Identify as Having a Disability (n=204)* 

Responses	N	%
Yes	71	34.8
No	116	56.9
Uncertain	15	7.4
Declined to Respond/Missing	2	1.0

Among participants who identified as having a disability, 67 out of 71, or 94.4% indicated they had been formally diagnosed with a disability (see Table 4.3).

**Table 4.3**Report of Formal Diagnosis of Disability (n=71)

Responses	N	%
Formally diagnosed	67	94.4
Not formally diagnosed	4	5.6

While 56.3% of those reporting a disability indicated they identified as having one disability, 43.6% reported two or more disabilities. The highest number of reported disabilities by one individual among study participants was four. The average number of disabilities reported among survey respondents identifying as having a disability was 1.54 (See Table 4.4).

**Table 4.4**Number of Disability Categories Reported (n=71)

Categories of Disability	N	%
One	40	56.3
Two	24	33.8
Three	6	8.4
Four	1	1.4

## **Interview Participants**

Among the 18 individuals who were selected to be interviewed, 12 out of 18 individuals (66.7%) reported a psychological disability, 10 individuals or 55.6% of those selected to be interviewed reported a chronic health condition, six or 33.3% reported a learning disability, three (16.7%) individuals reported a neurological disability, and two individuals reported a sensory disability (11.1%). In addition, two interview participants (11.1%) reported a mobility-based disability. Moreover, six out of the 18 interview participants (33.3%) reported one disability, eight reported two disabilities (44.4%), and three individuals or 16.7% reported three disabilities, while one individual reported having four disabilities (See Table 4.5).

**Table 4.5**Description of Interview Participants (n=18)

Pseudonym	Year/Status	Race/Ethnicity	Types of Disabilities Reported
Bethany	LOA	African American	Chronic health, Psychological
Crystal	$2^{nd}$	African American	Psychological
Emily	$3^{\rm rd}$	Hispanic/LatinX	Psychological
Evelyn	$3^{\rm rd}$	Hispanic/LatinX	Psychological
Erica	LOA	African American	Learning disability, Psychological
Hannah	$2^{nd}$	Asian/Pacific Islander	Mobility based, Neurological
Jack	1 <sup>st</sup>	Caucasian/White	Learning disability
Jocelyn	1 <sup>st</sup>	Hispanic/LatinX	Chronic health
Kimberly	$3^{\rm rd}$	Caucasian/White	Sensory disability
Lily	$3^{\rm rd}$	Hispanic/LatinX	Chronic health, Learning disability, Psychological
Liz	$3^{\rm rd}$	Hispanic/LatinX	Chronic health, Psychological
Mark	$4^{th}$	Caucasian/White	Chronic health, Psychological
Nora	$4^{ ext{th}}$	Middle Eastern/North African	Learning Disability, Psychological, Sensory disability
Paula	1 <sup>st</sup>	Hispanic/LatinX and Caucasian/White	Chronic health, Neurological
Priya	1 <sup>st</sup>	Asian/Pacific Islander	Learning disability, Psychological
Roberto	1 <sup>st</sup>	Hispanic/LatinX	Chronic health, Learning disability, Neurological, Psychological
Tina	$2^{\text{nd}}$	Asian/Pacific Islander	Chronic health, Psychological
Veda	1 <sup>st</sup>	Asian/Pacific Islander	Chronic health, Mobility based

*Notes:* Types of disabilities based on participants' responses to the survey and interviews. During their interviews, some students indicated they had additional types of disabilities or conditions within one category (i.e., psychological, chronic health, etc.). Respondents could select multiple categories; as a result, the sum of the percentages is greater than 100.

Interview participants also generally reflected the student population demographically: 77.8% were students of color, while 22.2% were White/Caucasian. 15 of the 18 participants or 83.3% identified as female, while three, or 16.7% identified as male and one of the 15 female participants also identified as non-binary. While survey participants were not asked to indicate on the survey or interview whether they were first to go to college, in the course of being

interviewed, six of the 18 interview participants indicated they were first-generation college students, and eight interview participants indicated their parents had immigrated to the United States in search of better work and/or education opportunities. When asked about their reasons for attending medical school, numerous participants shared experiences of significant adversity they and/or their families had experienced as a key motivation for attending medical school. Half of those interviewed indicated they had witnessed and/or personally experienced health care inequities and disparities as children. More than half (n=10) also shared that having a disability and/or a family member with disabilities was one of their primary motivations for pursuing a medical degree. These contextual factors form an important back-drop to this study as students at times indicated that their background and experience with adversity impacted how they perceived and responded to challenges related to their disability.

# **Types of Disabilities Reported**

When surveyed, students who identified as having a disability reported a range of several types of disabilities: the most common type of disability reported was psychological disabilities (69.4% of respondents), followed by chronic health conditions (38.9%). The least common were sensory and dexterity-based disabilities, both at 2.8%, respectively. (See Table 4.6). Examples of psychological disabilities, which were also listed on the survey, included: depression, anxiety, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, post-traumatic stress disorder (PTSD), bipolar disorder, mood disorders, and personality disorders. Sensory disabilities were defined as deaf/hard of hearing and blindness/low vision. Chronic health

conditions examples included Crohn's disease, ulcerative colitis, irritable bowel syndrome, chronic migraines, and Postural Orthostatic Tachycardia Syndrome, etc.<sup>20</sup>

**Table 4.6**Disability Categories Reported Among Survey Respondents (n=71)

Categories	n	%
Categories	n	/0
Sensory Disability	2	2.8
Learning Disability	13	18.3
Psychological Disability	49	69.0
Mobility based Disability	8	11.3
Dexterity based Disability	2	2.8
Chronic Health Condition	28	39.4
Neurological Disability	6	8.5
Other	2	2.8

*Notes:* Categories provided by campus accessibility office. Respondents could select multiple categories; as a result, the sum of

the percentages is greater than 100.

Among all survey respondents, 65 or 31.9% indicated they were currently receiving accommodations, which represents a subset of the 82 students, or 40.2% of all respondents who indicated they were either currently receiving, in the process of receiving, or had previously received accommodations (See Table 4.7). It should be noted that not all students receiving accommodations believed they had a disability as defined by the ADA. Other individuals reported previously receiving accommodations either in medical school (n=11) or prior to medical school (n=6) but were no longer receiving them currently.

<sup>&</sup>lt;sup>20</sup> These categories of disabilities were provided by the disability resource provider/accommodations office at this institution and were written out as examples on the survey.

**Table 4.7**Reported Receipt of Educational Accommodations (n=204)

Received Accommodations	N	%
Yes	65	31.9
Not currently, but prior to medical school	6	2.9
Not currently, but during medical school	11	5.4
No, neither currently nor previously	121	59.3
Other	1	0.5

Notes: "Other" indicated "currently in the process of receiving accommodations."

Among the 82 individuals who reported they had ever received academic or educational accommodations, 57.3% began receiving accommodations during medical school, while only 14.6% began receiving accommodations during kindergarten through 12<sup>th</sup> grade, as indicated in Table 4.8. Another 18.3% indicated they began receiving accommodations during their undergraduate education, while 4.9% percent began receiving accommodations during a graduate or post-baccalaureate program.

**Table 4.8**When Students First Began Receiving Accommodations (n=82)

When Received Accommodations	n	%
K-12	12	14.6
Undergrad/College	15	18.3
Graduate program/Post bac program	4	4.9
During medical school	47	57.3
Other	4	4.9

Notes: Others indicated accommodations started in pre-school or multiple start times for different disabilities.

# **Challenges Students With Disabilities Experience**

Results of the survey among students with and without disabilities highlighted ways in which disability status correlated with specific academic and personal or interpersonal

challenges. Students with disabilities were surveyed about their experience with institutional challenges. Data collected from semi-structured interviews among students who reported having a disability provided a basis for further contextualizing and better understanding the nature of these challenges and potential relationships between them. These are discussed in greater detail next.

## **Academic Challenges**

The acute challenges medical students experience as a result of the intense academic rigor of medical training are well documented in the literature as indicated in Chapter 2 (Dyrbye et al., 2014; Hill et al., 2018). Not surprisingly, most survey respondents, regardless of whether they identified as having a disability, indicated they had experienced academic challenges during their training in the areas of study skills, time management, and test taking. While academic challenges were prevalent among students with and without disabilities, analysis of the responses using a Chi-square test for association indicates that challenges with study skills ( $\chi^2 = .677$ , p > .05) were not statistically significantly associated with disability status, while challenges with time management ( $\chi^2 = 4.785$ , p <.05) and test taking ( $\chi^2 = 9.571$ , p <.05) were statistically significantly associated with disability status (Table 4.9). Students with disabilities experienced challenges related to time management and test taking at a disproportionately higher percentage than students without disabilities at this institution. Even though there was not a statistically significant association between disability status and study skills, among students with disabilities, 81.4% reported challenges related to study skills, compared to 76.9% of students without disabilities. Academic challenges as a whole were prevalent among those who identified as having a disability and those who did not as indicated in Table 4.9.

**Table 4.9**Academic Challenges Experienced During Medical School, by Disability Status (n=204)

Academic Challenges	Identify (n=71)		Not Identify (n=133)		$\chi_1^2$	р
	n	%	n	%		
Study Skills (e.g., study strategies, adjusting to volume/pace of material, selecting study resources, etc.)	57	81.4	100	76.9	.677	.411
Time Management (e.g., task initiation, prioritization, study scheduling, organization, etc.)	60	84.5	94	72.3	4.785	.029
Test Taking (e.g., test taking anxiety, pacing, performance, etc.)	56	78.9	76	58.9	9.571	.002

# **Challenges With the Volume and Pace of Information**

Among interviewees, three-fourths of students (13 out of the 18) reported experiencing challenges related to study skills. A number of these students described the academic difficulties they encountered in terms of the volume of information presented and the pace of the curriculum. Students felt pressured to learn a vast amount of information within a short time period. For example, Priya, a student with both a learning and psychological disability, reported having difficulty focusing on her studies due to feeling overwhelmed about the amount of information she was expected to cover as a first-year student:

...challenges-wise in medical school, I mean, it's a lot of information, so it's definitely been rough...being able to just, I don't know, sit down and focus sometimes because there's so much information. I also feel like medical school in general is not designed for people who are neurodivergent or whose brains work differently from a neurotypical person.

Similarly, several interviewed students cited the pace of the curriculum as a common challenge. Mark, a fourth-year student with a physical and psychological disability reflected on the challenges he experienced adjusting to the medical school curriculum:

Yeah, the biggest adjustment was just probably the quantity of information and the pace at which the information was presented and that you were expected to retain. I think it was something where I could be a bit more slow and methodical in college with coursework, and I knew there were things that I could put off and it'd be fine, but in med school, there wasn't really space to have that kind of flexibility, and there was always the fear of getting left behind.

Another first-year student, Roberto, who was diagnosed with a neurological and psychological disability as well as a learning disability, when asked about the nature of his academic challenges, shared his frustration about the pace of the curriculum and the challenge of learning a vast amount of information in such a limited amount of time:

I honestly think it's just the sheer amount of material, the sheer amount of material that we're...being taught...it's like we're being taught medicine by physicians who have been teaching or have been in medicine for 20 years, and they're expecting us to become experts in their field in a week.

#### Roberto also noted:

Everything's like, go, go, go. They're like, "Okay, you have six weeks to master this material." And I'm like, "Well, what if I need ten?" And it's like, well, that accommodation doesn't exist.

Relatedly, eight of the interviewed students shared they had experienced challenges with time management (e.g., task initiation, prioritization, study scheduling, organization, etc.), which was directly linked to challenges they encountered with the pace of the curriculum, and the volume of information they were expected to learn. Liz, a third-year medical student, when asked if she had been able to find supportive resources to address her challenges, indicated she had limited time to do so:

I barely have time to sleep and eat, and I'm eating and studying at the same time...I think that it's this pressure of having so much to do every day, and it's like I sometimes don't even have time to think about my emotions or finding a resource...I'm so focused on trying to get through everything that I have to get through in the day.

### Frustration With the Design of the Curriculum

Interestingly, students depicted these challenges as unique to their medical training, rather than reflecting their own inadequacies. Both Priya and Roberto, for example, pointed out that the design of the medical school curriculum and the lack of available accommodations for addressing these challenges contributed to the acuity of their academic challenges. However, these observations were not limited to Priya and Roberto: Eleven out of the 18 interviewees expressed frustration with the curriculum and pointed to various ways in which the design of the curriculum negatively impacted their learning. As Roberto indicated, some students pointed to what felt like unrealistic expectations on the part of faculty, and their understanding of the amount of material students could be expected to learn over a short period of time. In addition, several students like Jocelyn, a first-year student, indicated that it was often not clear what she was expected to learn amidst the vast amount of information presented:

I just wish there was more transparency and more clear guidelines on what I'm expected to know, what I'm not expected to know, because I think that in itself adds stress. I think especially our first [course] was really, really hard on figuring out what I needed to do, what I didn't need to do, what I actually needed to focus on and stuff. [There were] so many different opinions and many different talking points that I wasn't sure [what to focus on], and I think all of that exacerbated my stress.

Other students commented on the constant changes in expectations due to different instructors for different courses. Kimberly described this phenomenon pointedly during her interview: "It's difficult in medical school because you have so many different people teaching you, and they're so busy clinically...and I would say it would be great if we had one teacher the whole year."

Crystal, a second-year student, stated: "We don't have clarity of expectations. We also don't have consistency in education."

Several students expressed they often found navigating expectations during their clerkships particularly challenging given the myriad different individuals, including attendings, residents, and faculty they were expected to report to at different times. As a result, expectations seemed arbitrary or inconsistent. Erica described an experience with a senior resident she worked with for a short time. The senior resident criticized her work, which surprised her: "I was like, this is my last clerkship. I know what I'm doing." She shared that the next day a different new attending told her to "do it however you want. And I did it. And the senior resident was like, oh, I'm sorry, my bad...the same one that essentially told me that I don't know what I'm doing." She concludes, "Yeah [it was] arbitrary...standards are not clear."

As a student with a learning disability, diagnosed anxiety and OCD (obsessive compulsive disorder), Erica shared earlier in the interview that she relied on specific strategies to help her stay organized and manage her studying effectively prior to medical school; she would print the lectures ahead of time for all her courses and take detailed notes, previewing the material in advance of each class. Yet these strategies were not as effective for her during medical school, according to Erica, because often lecture slides may not be consistently uploaded or available. Academic challenges were heightened during clerkships for Erica when she encountered different standards and expectations among residents and attendings. Being able to prepare in advance and anticipate expectations for various assignments and presentations posed a unique challenge during Erica's clinical training. At the same time, because expectations seemed inconsistent and arbitrary, it was difficult for her to feel prepared or confident about her abilities. In Erica's words, when describing her experience during her clerkship: "...it was just this feeling of like, I'm not wanted, and the way I do things is wrong, across the board." In this sense, Erica's

challenges navigating the dynamics of her clerkship impacted her confidence in her academic ability as well as her sense of belonging.

#### **Challenges With High Stakes Testing**

In addition to challenges related to the volume and pace of the curriculum and time management, five students who were interviewed described experiencing challenges related to test taking, and specifically, the challenge of dealing with acute feelings of anxiety leading up to and during their medical school examinations. For these students, the experience of taking exams during medical school was fraught with anxiety and feelings of inadequacy, as well as concerns about how their performance might reflect on their ability to practice medicine. Roberto described the unexpected feelings of anxiety he experienced when taking his first exam in medical school:

It's been rough...I was in for a rude awakening...I've never really experienced anxiety or testing anxiety, but when I was in my first exam...I got the full physiologic response. My heart was beating fast, and then I was getting sweaty, and then I would get the chills, and then I would get sweaty and then get the chills, and it was through the entire exam.

Like Roberto, several other interviewed students reported high levels of anxiety when taking medical school exams, and they did not anticipate the acute feelings of anxiety when they occurred. When asked to elaborate why they experienced test taking anxiety, students pointed to the high stakes nature of these exams relative to exams they took in college or in previous educational settings.

Medical students are required to take and pass a series of standardized exams, such as those administered by the National Board of Medical Examiners (NBME) during students' clinical training, as well the United States Medical Licensing Examination (USMLE) Step 1 and the Step 2 Clinical Knowledge (CK) exams which are required of all students for medical

licensure in the United States.<sup>21</sup> The USMLE exam results are often determinative of students' residency placements and career prospects (Ozair et al., 2023). As such, students attributed a heightened level of meaning and significance to these exams, as reflected in Liz's description of the difference between the exams she took in college and the exams she took during medical school. Liz shared that she felt anxiety when taking exams in college, but that level of anxiety she experienced once she began taking exams in medical school became much more pronounced:

I think in college it was just a very different environment where I didn't feel like my performance on those exams immediately was going to have a direct impact on whatever I was doing at the moment. I thought at the very best, it's like, oh, it's between an A or B, versus for me, these exams, they mean a lot to me....to me personally, they also mean a lot because it tells me how much I've learned or how ready I am to be, I guess, seeing patients. And so when I don't perform well, to me, it makes me feel like I'm a safety hazard...To me, I think about it, like how prepared am I to be helping patients? And so I think that creates a level of pressure and then performance anxiety.

For Liz, medical school exams signified more than just her academic abilities or performance, they indicated whether she was ready to see patients. If she did not pass, it indicated she was a safety hazard. According to her, the stakes of these exams were higher than those in college, for this reason.

In short, when interviewed, most students experienced academic challenges related to study skills, but a number of these students attributed these challenges to faculty expectations, as well as the design and structure of the curriculum. When asked about the nature of the challenges they experienced with regard to test taking, several interviewed students explained that it was due to the high stakes' nature of these exams.

 $information\ about\ the\ USMLE\ licensing\ exams\ see:\ https://www.usmle.org/step-exam.$ 

<sup>&</sup>lt;sup>21</sup> The USMLE program is responsible for the administration of the medical licensing exams which are required for licensure in the United States. Currently, trainees must sit for and pass the Step 1, Step 2 CK and Step 3 examinations to be medically licensed in the United States. Typically, medical students take the Step 1 and Step 2 CK exams during medical school and must pass these exams in order to graduate. The Step 3 examination is usually a requirement after graduation from medical school and is taken during the first year of residency. For more

## **Institutional Challenges**

## Accessing Appropriate Resources Related to Disability

Among students who identified as having a disability on the survey, a slight majority of students (54%) cited challenges accessing appropriate resources related to their disability as well as disclosing their disability in order to seek support (53.5%). Less cited were challenges related to applying for and receiving in-house academic accommodations (33.8%) and USMLE accommodations (38.0%) (See Table 4.10). The challenges of disclosure and accessing appropriate resources are interrelated since students must first disclose their disability in order to access appropriate resources, including accommodations.

**Table 4.10** *Institutional Challenges Experienced During Medical School (n=71)* 

	Yes		No		NA/Missing	
	n	%	n	%	n	%
Accessing appropriate resources related to disability	38	53.5	29	40.8	4	5.6
Disclosing disability in order to seek support	38	53.5	32	45.1	1	1.4
Applying for/receiving school accommodations	24	33.8	37	52.1	10	14.1
Applying for/receiving USMLE accommodations	27	38.0	20	28.2	24	33.8

*Notes:* Other challenges included: "coordinating time off to attend doctor's appointments," "having accommodations honored after they are obtained," "identifying what accommodations will be most helpful for me," "housing accommodation denials," and "(clinical) rotation accommodations (difficulty disclosing to team)."

When interviewed, eight of the interviewed participants cited specific experiences or situations where despite receiving accommodations, they did not feel they were being appropriately accommodated. For example, a first-year student, Paula, described being in classrooms that were not equipped with the accommodations she had been approved to receive:

One of my things [accommodations] is that every time I walk into a room, I'm supposed to have a [instrument] available, and it's supposed to be a certain type of [equipment] to prevent [exacerbation of condition], and I never found those [types of equipment] available. I always have to go out of my way to find the type [sic] that works for me. And

I'm not necessarily wanting in all of those spaces to reach out to the faculty because I know that they're not the ones that are in charge of that. At times I have, but at other times I've just settled for standing.

Half of the interviewed students indicated that the burden often fell on them to access available and appropriate accommodations, even if they had been approved for accommodations. Paula shared the confusion she experienced regarding the logistics of who to contact and how to address her need for accommodations when she missed class and needed to make up course work:

And then I guess just with attendance accommodations, the process has been a little bit confusing at times. We're changing who we are reaching out to and when we had to reach out to them. So I was just a little bit confused about that. And then also the fact that if I do use my accommodations, I still have to make up a lot of the work, and then that can become a little bit overwhelming as well when it's something like a [course name] session...I don't necessarily find that useful and very accommodating when I'm still having to do everything that I missed.

Paula indicated that in the day-to-day aspects of navigating the curriculum, she was unsure who to contact and how to ensure her accommodations were to be implemented. Half of the students interviewed also shared that the nature of their accommodations seemed undermined or compromised because they were burdened with extra work to request or implement appropriate accommodations. As a result, accommodations did not feel "very accommodating," as Paula put it.

While fewer students cite challenges applying for and/or receiving accommodations for school or the USMLE, it should be noted that a third of students either indicated "not applicable" or did not respond to the question since students typically do not apply for USMLE accommodations until after their second year of training at this institution.

# Disclosing Disability to Seek Support

When interviewed, six participants cited specific instances when they did not feel comfortable disclosing their disability due to concerns about confidentiality and privacy. Liz indicated she did not initially seek support for her disability for this reason:

I started seeing a psychiatrist...and it took me so long to do that because I was worried that other residents could see my electronic health record or faculty could see it, and then they would know that I had anxiety and I was kind of scared of having [sic] faculty [see it]...and being on record...

Similarly, Mark, a fourth-year student with a physical and psychological disability, expressed concern about disclosing his disabilities due to privacy concerns which was heightened by an incident in which a document containing the identity of students receiving accommodations had been accidentally circulated to the student body:

Yeah, I think there was definitely concern and kind of worries about ways that it [my disability] would be viewed by faculty or things like that, and just as well concerns if things would be kept anonymous or not. And yeah, I think I remember one episode, I forget what year of med school this was, but an episode where there was a document that was somehow shared to the whole class, who had the names, names and everything of folks who were getting accommodations.

Others cited discomfort disclosing their disability, particularly in classroom or clinical settings, even when they were receiving accommodations. Several shared that this hesitancy to disclose was related to the limited interaction the student had with the faculty member or other individuals. They were concerned about how their disclosure might impact their relationship with the individual given the uncertainty around attitudes about disability among faculty. A second-year student, Tina, described in detail concerns about disclosing her disability to an attending during her clinical training:

I've also experienced, especially (sic) during my [clinical training], just always being faced with the decision, do I disclose or not? And I think that's a really exhausting burden to always just kind of have in the back of my mind. If I disclose, sometimes it explains a lot of my behaviors, and that way they don't get the wrong idea. It could also go in the opposite direction where if I disclose it kind of gets worse.

Tina shared a specific incident where she did not feel comfortable disclosing she had a disability. She was at a clinical site when her knee started to shake, and she felt the need to sit down. Her attending did not know about her condition or her need for accommodations and Tina experienced a similar internal struggle regarding whether to disclose her disability:

So we were seeing a patient, there was no chair around, and my knee suddenly just started just shaking a little bit, so I had to come out and [the attending] made a comment about how I was really impatient to leave that room, and I tried to say, "oh, sorry, I just really need to sit." Not to disclose, but it was in front of everyone. But he was like, well, if you can't stand that long, I don't know how you're going to be a doctor. Right? And now I know just from further conversations with them that he didn't really mean it in a malicious way, especially not knowing that I had a disability, but there, I was faced with that conflict. It's in front of everyone. I don't really want to say, well, I have an accommodation and I can't necessarily pull him aside and say that because that would just create a scene. So it's those kind of little microaggressions I have to kind of balance out.

When asked how the situation got resolved, Tina said:

At least for that, I wasn't going to see the attending again, I did talk to [the Disability Resource Provider] to see if there was any way I could have handled that better. What other ways could I have navigated it? But the reality of it is that's just how things are going to go. I am going to have these uncomfortable situations as a disabled student, and there's not really a way to prevent a hundred percent of that.

On the one hand, Tina felt uncomfortable disclosing her disability in front of the entire team, but by not disclosing her disability and asking to be excused, she faced the potential negative consequences of being perceived as less capable or, in the case of Tina, "impatient" to leave the room. There were no clear guidelines regarding how to handle this and other day-to-day interactions; as such, Tina tellingly recounts the incident as one of several "microaggressions" she has experienced during her medical training to-date. As a student with multiple disabilities, including a psychiatric condition, chronic illness, and autoimmune disorder, Tina's experience was similar to those recounted by several other students who described challenges associated with having hidden or invisible disabilities.

Despite receiving accommodations, six out of the 18 students interviewed emphasized that the burden fell on them to decide whether and when to disclose their disability at various stages of their medical training. A third-year student, Kimberly, shared she had to navigate when to alert her professors to her need for accommodations, and the embarrassment she felt having to talk to professors in class to ensure that the appropriate accommodations were in place:

So I would have to get up and then walk over to the lecture and ask them to [put accommodation in place]. And that was just kind of embarrassing, having to repeat it. And obviously...I never spoke to my class about my disability. As I said, I try to keep it as quiet as possible, so I was always worried, like I wonder if people think why is she always going up to the professors? Is she a kiss-up?...[and it would happen again] And so that was actually even more embarrassing because I would have to interrupt the lecturer to tell them to [put the accommodations in place]. So that was something that happened weekly, and that was really frustrating.

In each of these cases, concerns about disclosure were not related to disclosure of their disability in order to receive educational accommodations, which virtually all who identified as having a disability had already done. Rather, despite already receiving accommodations, they also experienced the burden of deciding when it was appropriate to disclose their disability, as well as who to disclose to, in order to seek support for their disability in various situations and contexts. As third-year student, Lily, noted:

It's like a double-edged sword, 'cause if you have a disability, on one hand, you need to advocate for yourself to get whatever accommodations or resources you have so you can succeed just as well as someone who doesn't have disabilities. But on the other side, you have to be careful about how you advocate for it because what if they flip the script on you and say, "Oh, well, if you can't perform these tasks, then can you even really be a good clinician?" So it's a very thin line you need to walk on where a lot of times a lot of students will advocate for our peers or advocate for patients with disabilities. But then when it comes to speaking up about individually what you might need, that's always a scary thing because I mean, they also tell us in your residency applications, you may not want to discuss your disability because it's so controversial and someone could use that against you. So I think there is still that..is a big part of it.

Students interviewed shared experiences facing myriad institutional challenges related to disclosing their disability to seek accommodations and support, even when they had been

approved for accommodations. Students also had concerns about privacy and confidentiality related to their disability; several students recounted the challenges of navigating when and who to disclose to, particularly when faced with individuals with whom they might have a limited interaction during their clerkships. Some of these students commented on the difficulty of navigating disclosure when they had an invisible disability, versus a physical disability. Several students with less visible disabilities, like Tina, shared they struggled with the burden of knowing when it was appropriate to disclose, given the uncertain ramifications of disclosure in different settings despite already being approved to receive accommodations. In other instances, they, like Kimberly, experienced frustration and even embarrassment when having to disclose their disability to ensure that their accommodations were implemented.

### **Personal Challenges**

When surveyed about the personal challenges students experienced during medical school, there were a specific subset of personal or interpersonal challenges associated with students who identified as having a disability based on a Chi-square association: 1) dealing with the stigma of having a disability ( $\chi^2 = 57.144$ , p <.001), 2) questioning whether they belong in the program ( $\chi^2 = 10.293$ , p <.05), 3) challenges related to physical well-being ( $\chi^2 = 11.937$ , p <.001), 4) discrimination, prejudicial, or insensitive treatment by faculty or staff ( $\chi^2 = 9.920$ , p <.05), and 5) discrimination, prejudicial or insensitive treatment by classmates ( $\chi^2 = 12.415$ , p <.001) (see Table 4.12). Most respondents, however, regardless of disability status, also reported challenges related to 1) questioning whether they belong, 2) physical well-being and mental well-being, as well as 3) financial hardship. (See Table 4.11).

**Table 4.11**Personal Challenges Experienced During Medical School, by Disability Status (n=204)

Personal Challenges		Identify (n=71)		Not Identify (n=133)		P
	n	%	n	%		
Finding community	44	62.0	64	48.1	3.565	.059
Dealing with the stigma of having a disability	41	57.7	12	9.0	57.144	<.001
Questioning whether I belong in this program	57	80.3	77	57.9	10.293	.001
Questioning career direction	56	78.9	89	66.7	3.219	.073
Physical health/well-being	62	87.3	86	64.7	11.937	<.001
Mental health/well-being	63	88.7	105	78.9	3.050	.081
Financial hardship	41	57.7	72	54.1	.244	.621
Discrimination, prejudicial, or insensitive treatment by faculty or staff	22	31.0	17	12.8	9.920	.002
Discrimination, prejudicial, or insensitive treatment by classmates	23	32.4	16	12.0	12.415	<.001

Notes: Other challenges included "family challenges, loss of a loved one," and "having an invisible disability."

The foregoing analysis focuses on those factors that were not only statistically significant but were also common among students interviewed: dealing with the stigma of having a disability, and challenges related to physical well-being. Interviewees shared incidents of discrimination, prejudicial, or insensitive treatment by faculty, staff, and classmates, but they were often framed as systemic and pervasive in nature, rather than direct or personal.

## Dealing With the Stigma of Having a Disability

A little over half of survey respondents, 57.7%, indicated they experienced dealing with the stigma of having a disability. Among those interviewed, 13 out of 18 students indicated they experienced stigma related to their disability. For some, dealing with the stigma of disability was closely tied to the challenges of disclosure as elaborated above, i.e., knowing when and who to disclose to, even if they had already disclosed their disability to receive formal accommodations

through their campus accommodations office as elaborated previously. However, while they were not necessarily hesitant to disclose their disability to receive accommodations or through formal institutional channels, several students talked about the nature of the stigma as reflective of a general stigma about individuals with disabilities in the medical professions that might hinder their future professional prospects. In this sense, there was a difference in attribution between what might be characterized as structural stigma, external/public stigma, and internalized stigma, or feelings of shame associated with one's disability due to cultural or personal experiences related to one's disability. Such findings are consistent with the literature on stigma which differentiates between structural and internalized stigma among the students who were interviewed (see Bos et al., 2013, Corrigan & Watson, 2002, Watson & Larson, 2006).

This distinction between external and internalized stigma is noted in the reflections of a third-year medical student with a sensory disability, Kimberly. Kimberly described feeling conflicted about her desire to advocate for medical trainees with disabilities to be more visible and better represented in the medical professions, while acknowledging that there is still a stigma related to disability that could impact her prospects for residency:

I have some degree of guilt in my position as a future provider that I'm not more public about it...and I think that was actually something I wrote about in my medical school essays that...in terms of this theme of wanting medicine to look more like the population, you don't see a lot of disabled doctors. I've never seen a doctor with [my disability]. And so I would in a theoretical world, like to be more open about it because I think it needs to be more visible, but I also think I still have this part of me that worries that it makes you less of a good candidate like even in residency, I don't know that I would emphasize it that much, because I don't want people to think, "Oh, if there's two equivalent applicants, I'd rather have one that I don't have to worry about not being able to [sic]."

Kimberly was comfortable disclosing her disability to receive accommodations (and even when applying to medical schools), but she recognized that there was a general stigma about disability that might influence people's perceptions about her qualifications as a medical professional. Her willingness to disclose was thus situational and not necessarily reflective of

internalized feelings of stigma. Rather, it reflected her beliefs and perceptions about medical school administrators and those who might be in a position to evaluate her qualifications as a potential physician.

Others described the stigma associated with having an invisible disability or being questioned about the legitimacy of their disability. For example, several students with ADHD described instances in which their diagnosis was questioned, or they felt misunderstood. They were therefore reluctant to disclose their diagnosis of ADHD with others. Emily, a third-year student shared, "I don't know anybody that has ADHD that is open about it...everybody's like, that's not a real diagnosis, everybody has that." Jack, a first-year student with a learning disability, acknowledged the stigma associated with his specific disability and was hesitant to disclose due to concerns about the impression that might be formulated about him:

It's always something that I think about, and it's something that I have a lot of difficulty with, disclosing before I know that people know how I work, what I do...it's sometimes hard for me when that's their first impression because I know how capable I am, and so I dislike when they have that preconceived bias before I get to prove who I am.

Another second-year student, Crystal, diagnosed with a psychological disability, shared: "I think there is still very much a stigma in medicine against really anything that's not a clear cut physical condition." These students acknowledged a stigma associated with their disability as external to their own sense of self-worth and abilities. They also defined stigma in terms of how their disabilities are perceived, rather than expressing internal stigma or shame about their disability.

In contrast, some students described internalized stigma and feelings of shame related to their disability or needing help from others. Evelyn, a third-year student, attributed the stigma she experienced to her upbringing, which resulted in her feeling reluctant to seek support or accept accommodations:

I think that for a while I was very hesitant to accept any type of help or accommodations, just because coming from a family that's not very educated, especially on these psychosocial issues, there was a stigma with accepting help, accepting accommodations, and that's something that I never had in undergrad. So there were challenges even accepting that I needed help.

Similarly, Lily, a third-year student who was not diagnosed with a psychological disability until medical school, described experiencing the stigma of having disabilities due to her family's background and culture: "I think a lot of it was because I grew up in an Asian family, and in Asian culture there's not a lot of awareness...there's like, a stigma against mental health challenges."

A fourth-year student, Mark, who was diagnosed with a physical and psychological disability, described feeling "bad" about needing accommodations for a condition that was not constant and varied over time –yet he described coming to terms with his need for accommodations with the help of his therapist:

So I know my therapist encouraged me to get support from the [disability office] and supported me with the documentation process and all of that. And I think that that encouragement definitely helped because I think there was just a fair bit of stigma, I think that I felt about seeking out services and (I was) wanting to do things on my own and feeling bad in some way about needing extra accommodations. I think especially for a disability that's not constant, but can wax and wane, it can be particularly challenging to come to terms with that might even at the moment, if I'm doing very well, it doesn't mean it's going to stay that way. And I have the life experience in the past of the ups and downs and things, and I think that was something as well, I think was helpful to come to terms with.

Some students, like Evelyn and Lily, framed the stigma related to their disability in terms of their culture and upbringing, while others acknowledged a general stigma towards people with disabilities which made them hesitant to seek support or disclose their disability.

### Imposter Syndrome

A closely related and common theme among interview participants who shared they struggled with the stigma of having a disability, was the challenge associated with imposter

syndrome. Students shared that at times, they did not feel like they belonged due to feelings of inadequacy. This type of challenge tended to occur among students who experienced academic difficulties. Notably, seven of the 18 interviewed students shared they had experienced, or were currently experiencing, imposter syndrome during their medical training. Erica described feeling imposter syndrome when she began struggling academically:

I felt imposter syndrome, and I feel like that...I had that a lot, especially those first years, because I wasn't doing well in my shelf exams or even my regular [first year] exams. Additionally, I was...it's the feeling of, I was not accepted to the program immediately; I was picked off the waitlist. So already having that, I wasn't a top choice, but I still got in and feeling like I barely got in. And then going through exams and not doing well on exams, it really felt like, am I supposed to be here?

Similarly, Emily shared that imposter syndrome resurfaced during her second year when she began failing her NBME shelf exams:

Maybe the biggest thing I've grappled with has been, I worked really hard to deal with things like imposter syndrome...and the feeling of...that I'm a failure. In my first year, I didn't feel that; I felt like I'm exactly where I'm supposed to be, and I still feel like I'm exactly where I'm supposed to be. But that failure piece, that resurfaced, and I think that's been very challenging to try to combat the pieces of confidence that have been stripped from me over and over, and it's just having to get back up.

Imposter syndrome, which was defined by students as not feeling a sense of belonging, and linked to feelings of inadequacy, often emerged or resurfaced as students encountered academic challenges.

### Challenges Associated with Physical Well-Being

While a number of students with disabilities indicated they experienced psychological and emotional challenges associated with stigma and imposter syndrome during their training, still other students with disabilities who were interviewed (n=6), elaborated challenges related to the physical demands of the curriculum. For example, Jocelyn, a first-year student, stated that the

demands of the curriculum in the form of numerous, mandatory in person activities resulted in her feeling constant stress and exhibiting "flare ups" of her condition:

It's...just been hard to be as present in things that are mandatory attendance, mandatory being here for long stretches of time, our labs, anatomy, [course name], sometimes those get a little hard to be in. Sometimes we have early mandatory workshops and stuff like that, and sometimes it's (I'm) just not fully present. That's just not how my body works. And I think especially...being under constant stress and having constant anxiety, I've just had a flareup of, I usually wouldn't have as many symptoms. I know in undergrad or my gap year, I didn't really have this many flare ups and feeling like every day I have a headache every day I have this and that. And I know it's really stressed my body because all my labs are good, like checking with my doctor, but it really is just the stress manifesting itself. And I think because of my disability, I'm just more vulnerable to the effects of that.

Similarly, Paula shared the difficulties she encountered adjusting to the physical demands of the curriculum as a first-year student:

I think definitely it's having to balance in a little bit more specific ways my health demands with the school demands, especially with, I guess the increased in-person learning. It wasn't exactly what I was anticipating. I was anticipating being able to stay home on the days or my energy's a little bit lower and I'm struggling; and so I guess I've had a tough time adjusting to so much in-person work where before I was working from home a lot. So that's been a kind of tough adjustment.

As such, several interviewed students described concerns about maintaining their physical well-being due to the rigor and stressors associated with their training which required being present and standing for long periods of time. In some cases, students indicated that physical symptoms related to their disability may have been exacerbated as a result. While physical and mental well-being challenges were listed as separate challenges on the survey, as was evident when interviewing students, physical and mental well-being challenges were intrinsically related to one another according to participants. Students described the physical demands in terms of the stress and anxiety they experienced as well as the physical manifestation of symptoms which seemed to exacerbate their underlying conditions. They compared their physical well-being before and after medical school and suggested that there was more flexibility

for them to manage their physical needs prior to medical school, while their medical training demanded much more of them physically, as well as psychologically.

#### Dealing with Discrimination, Prejudicial, or Insensitive Treatment

Among students with disabilities, dealing with discrimination, prejudicial, or insensitive treatment by faculty and staff as well as students was reported at more than double the rate of students without disabilities: 31.0% (mistreatment by faculty and staff) and 32.4% (by students), compared to 12.0% and 12.8%, respectively. When interviewed, students with disabilities often described such incidents in terms of general, but constant features of the environment, almost a by-product of the "culture" of the institution and medical education, rather than to specific individuals. Tina described dealing with insensitive comments in day-to-day interactions with faculty:

I think the most, I felt a little bit frustrated with the comments from faculty is when they make comments in the classroom where they'll be talking about an illness or a disability that someone has, and a patient, they'll make comments, "we are so lucky to be also healthy," or "you guys are all young, healthy individuals," and it just really discounts there are disabled students in the room and you're making it as if disability is the worst thing that can happen to you. And so those were always kind of frustrating, kind of alienating in that I'm not a healthy 20-something year old. I'm actually one of your patients who has that disorder, who has similar experiences (as your patients).

While such incidents were not necessarily intentional or overt or directed at specific students with disabilities who were interviewed, the subtle and systemic nature of these seemingly innocuous incidents were described as alienating and distressing. The very nature of these comments and incidents also made it difficult for them to address. Indeed, when students shared instances of discrimination, prejudicial or insensitive treatment, they attributed these incidents to larger, systemic issues, a byproduct of systemic challenges unique to the culture of medicine.

According to Lily, a third-year student who reported a learning disability, chronic illness, and psychological disability, discrimination, and prejudicial treatment to her reflected a general disregard for individuals' lived experiences. In explaining why this is the case, she described the field of medicine and medical education as having a "more conservative bent than what's out there in the real world." When asked to elaborate, Lily shared she felt the need to "police" her language and back up one's views using the "constructs of western science."

In the real world, outside of medicine and outside of academia, if you look at movements for disability justice or really any kind of movement, it really does treat people's experiences as valid sources of information. And so I think in medicine, you have to jump through all these unnecessary hoops of proving that your experience is different or how it's more difficult...just sharing your experience and your lived experience is not enough...I think there's just a layer of objectivity in medicine where it's like people don't really talk about themselves and their subjective experience...but they're more happy to talk about, oh, well, this is what's affecting patients or things that are external to the self. Whereas, yeah, like I was saying, outside of medicine, people are very happy to candidly speak from their lived experience and...be listened to.

Lily described a disconnect between her values and that of academia and medicine as a person of color with a disability from a marginalized community. She does not believe her own and others' lived experiences are viewed as valid unless packaged within the "constructs" of western science.

Crystal also commented on the phenomenon of the seeming minimization of the lived experiences of students struggling with trauma. She shared that she and her classmates struggled with seeing patients die while on clerkships which resulted in a disconnect between what was taught to prepare students and what she felt was significant for her to learn and be prepared for:

We don't get any training on managing the more traumatic aspects of clerkships...And I don't really know why it's not in [our clerkship preparation course]. I don't know why they were teaching me about fluids because I have not been asked, not once...But we did have multiple people die...but I think that's not something that is addressed...and I feel like it kind of falls into the stigma bucket a little bit where we can't talk about any form of emotional weakness, so we're not going to talk about that, but I don't think that's helping anyone.

The insights provided by students interviewed suggests that educators did not acknowledge the existence of their own disability and illness. Instead, medical providers and by extension, trainees, were positioned as "healthy" and almost immune from the same challenges patients face, whether it was illness or trauma or the effects of these phenomena. As such, there was a seeming disconnect not only between the lived experiences of these students and what they experienced as medical trainees, but also what they experienced as relevant and important for their own training. As a result, discrimination, prejudice, and insensitive treatment were experienced as a byproduct of these larger, systemic issues, consistent with Jain research on medical trainees with disabilities where physicians are trained to overlook their own needs in service to that of their patients and demonstrate "superhuman" qualities (Jain, 2020, 2022).

### **Navigating Challenges**

Jain (2020, 2022) focused on the deleterious effects of the "capability imperative" in medicine and the ways it further marginalizes students through the enactment of hegemonic normative standards and practices that force "malleable students" to conform to hyper-ableist standards. Many of the observations made by interviewed students are consistent with the findings from Jain's study, particularly as it relates to feelings of inadequacy they experienced when confronted with the intense rigor and demands of the curriculum. However, focusing solely on the challenges students with disabilities experience provides an incomplete picture of students' lived experiences. Despite the numerous challenges students with disabilities say they faced during their training, they also shared ways they navigated these challenges, demonstrating ways in which they carefully considered the context before responding. In many instances, students demonstrated hope, resilience, and even resistance in the face of these challenges.

Interviews with a subset of the students who were surveyed suggest they navigated their unique challenges in several ways, depending on the perceived scope and nature of the challenges. As indicated earlier, students often commented on the pervasive nature of the challenges when they discussed how and when they confronted these challenges. They took stock of the nature of the challenge and the context before deciding whether and when to act or confront specific challenges.

While experiences varied when they described addressing or navigating their challenges, some clear patterns emerged.

- First, it was clear that students worked out in real time how to respond to specific challenges based on the type of challenge and the context and perceived effectiveness of speaking up or acting in the moment. Notably, when students described the challenges as systemic, they often chose not to speak up. For challenges more limited in scope and related to day-to-day activities or their learning, students described engaging in a process of trial and error to help them identify more optimal ways to study or manage their responsibilities.
- Second, for several students, challenges during medical school spurred them to seek help, and many attributed their willingness to do so to prior experiences dealing with similar challenges related to their disability.
- Third, several students indicated they responded to challenges by setting boundaries to prioritize their well-being.
- Finally, students shared how they often relied on friends, family members, or trusted mentors for support.

### **Navigating Responses to Systemic Challenges**

Students described navigating challenges as a process of ongoing internal negotiation that entailed consideration of their specific circumstances. As such, there was no "one-size-fits-all" approach. For example, many students described having to make decisions about whether and when to speak up or confront a challenge related to their disability; at times, students did not feel it would be effective to address the challenge, particularly if it was perceived as systemic or pervasive. Paula highlighted this dynamic after sharing a specific incident in which she shared with fellow students in her small group that she was immunocompromised. She let her classmates know that she would be wearing a mask the entire year and indicated that she would appreciate it if everyone in the group did, too. According to Paula, only one other student in her group wore a mask. In her words, "It's difficult when you share something like that and then you don't really feel like people care about it. You know what I mean?" When asked how she confronts these and related challenges, Paula stated:

I'm going to be honest, the vast majority of the time it looks like me sucking it up and dealing with the consequences because especially in clinical spaces, if I'm at my [clinical] site and they don't have a [physical implement], I'm going to [get by, physically] because I don't want to be perceived a certain way in that space. Even when I was ... in my previous job that was in person... if I felt a certain way and if I didn't have my accommodations, I just wouldn't say anything about it; so I guess I'm still trying to figure that out. I asked in [specific class] for accommodations, so I was really proud of myself for doing that.

Despite perceiving the challenges of not being accommodated as a reflection of a lack of care on the part of individuals around her, Paula made the choice in many instances to "suck it up and deal with the consequences," because she did not want to be perceived a certain way. Yet she also described being proud of herself for speaking up to address her need for accommodations in a smaller class where she had more direct interactions with the faculty

member. Paula was comfortable speaking up in some circumstances, but she took the time to consider when it would be appropriate. She also described the pervasive nature of the challenges:

I think that people, especially in medical school, just sometimes are really wrapped up in their own lives, their own tasks for the day. And it can be hard to be aware of what other people might be needing at any given time. And it's not necessarily one of our priorities most of the time anyways, we have so much to deal with.

Like Paula, several interviewees commented on the systemic nature of the challenges they encountered which could not be attributable to a single individual, or even a set of individuals. As such, they recognized that some of these challenges would not be addressed through their own actions, and in fact, might be counterproductive, or result in a negative perception of their abilities. In such cases, they opted not to engage or address them. For Paula, mentioning that she was immunocompromised to her small group was her way of advocating for herself, but when she noticed that most students did not adhere to her request, she opted not to insist or bring it up again, but instead attributed the lack of adherence to the larger culture of medical school, where people are "really wrapped up in their own lives, their own tasks for the day...we have so much to deal with." As such, students like Paula recognized that their challenges may be linked to larger, systemic issues that go beyond any one individual or set of individuals to address; interestingly, she even implicates herself when saying, "we have so much to deal with" (emphasis mine).

Half of the 12 interviewed students who had already started or completed their secondyear clerkships expressed challenges dealing with relational dynamics during their clinical training that impacted their learning. In addition to the constantly changing dynamics of the teams they worked with on the different clerkships, several students cited larger, systemic issues at play, especially in the clinical settings – they described a type of "hierarchy" that made it difficult for students to speak up or voice concerns when they encountered challenges related to their disability. Hannah, a second-year student, stated:

I think the bigger issue, and this is more like a systems issue, is I think I'm noticing is during clerkships, because this is longstanding, hierarchical, systemic, structural...a system dynamic of being the med student at the bottom and having your attending at the top.

Yet when discussing other incidents within what Hannah perceives to be within her locus of control, Hannah acknowledged that she became aware of her need to ask those immediately around her, i.e., faculty and friends for help; "that was mostly my pride I had to let go of," when seeking help to get around on campus due a mobility challenge.

It should be noted that students described their challenges in the immediate aftermath of a significant redesign of the curriculum. The two-year pre-clinical coursework and two-year clinical experience was replaced with a four-year curriculum designed to better integrate clinical experiences early in students' education. As such, students begin their clerkships in their second year to allow for additional time for career exploration, research, and additional clinical training in their third and fourth years. Students' experiences at this institution were also significantly impacted by the COVID-19 pandemic; many lecture-based courses were offered virtually at the height of the pandemic and during the lockdowns which began in March 2020 and continued through 2022.

While most students who were interviewed did not refer directly to the COVID-19 pandemic and its impact on their learning, more than half expressed frustration with the curriculum. This backdrop helps to contextualize some of their attitudes and experiences. Several students felt there was a lack of intentional planning and organization on the part of the administration which negatively impacted their learning. Moreover, they felt their concerns were not being adequately addressed. As Lily, a third-year student, put it:

I think first, there's the challenge of our class...was sort of the guinea pig class...and so the administration didn't have much of a sense of what our schedule would look like...and if they did, it kept switching around and we would get new information every couple months...it feels like they're making up new requirements for us every couple of weeks and then just sending it to us now. And so I just feel like that, I mean, that does a disservice to everyone, but I think especially for students with disabilities, and speaking to my anxiety specifically, I need to have time to plan for things...and so there's just a lot of factors that I feel like the way they're going about things is very disrespectful to students with disabilities because they're not thinking about how their actions might add more stress to our plates and make it harder for us to accomplish our educational goals....

Shortly after sharing her frustrations with the curriculum, Lily was asked, "in response to these challenges, what do you attribute your ability to navigate these challenges? Are there things that you felt like you drew upon to help you that you haven't mentioned so far?" Lily responded by giving an example of a specific instance when she and her classmates decided not to comply with a deadline that was perceived as unfair and arbitrary:

I think the most important thing that was helpful to me was just accepting and realizing that the administration doesn't really care for us in that way and not expecting it. And also just knowing how to create my own boundaries between what they expect of us versus what I'm willing to do. And I've seen a lot of my classmates do this as well. For just as an example, last week or maybe two weeks ago, all of us got an email saying we had some detailed proposal for our [course] due, which we had never heard about before. And they said it was due in a week and a half, and our advisor was supposed to sign it, but my advisor is traveling right now, and I'm sure several...there was no heads up about it. And it was just like, you need to submit this as a requirement by this Friday. And in our classmate group chat, everyone was just like, yeah, I'm not going to whatever.... That's their fault. They can't force us to do this with this little heads up. So I think for a lot of our class, it's about building these boundaries of when we can say no and just not kind of overexert ourselves to meet deadlines that come out of nowhere.

Lily engaged in boundary setting and refused to comply with a deadline for an assignment that seemed unfair or disrespectful to her and her classmates, especially those with disabilities. She justified her response based on her perception they are being treated as "guinea pigs," and that the administration "doesn't really care for us." She shares that there was also a unified response among her classmates which may have helped validate her observation and response. Far from being the "malleable student," forced to comply with the demands of

administration (Jain, 2022), Lily and her classmates resisted the expectations placed on them in this instance: there is a sense in which Lily and her classmates recognized they had the agency to "say no" and not "overextend" themselves to meet what seemed like an arbitrary deadline.

Even when students did not speak up or act on their concerns in the moment, several indicated they felt comfortable voicing their concerns to faculty and/or administration based on their unique role or previous experience as an advocate for people with disabilities. For example, Crystal, a second-year student who indicated that she lives with severe depression, shared her frustration with the perceived disorganization and last-minute changes to the curriculum that occurred in the wake of the transition to the new curriculum:

I would say that I feel like I have less bandwidth for the structural chaos, like there's just less...if they make drastic changes, I don't have a lot of bandwidth to deal with that...and I like to plan stuff out in advance. And if I have things like significant scheduling disruptions, then that is, I think more impactful for me than maybe it would be for someone who's a little bit more cognitively flexible, who has a little bit more cognitive energy. I have to study in a very particular way in order to get through the material that I need to get through. And I think I have to be very intentional about how I engage in the group setting. And...so when there are changes or when we come in and they're like, okay, you all have to participate for the benefit of everyone in the group...you know, I'm kind of wanting to push back on that and saying, how do you know that benefits everyone in the group? I told you that everyone's not going to benefit from this because I personally am not benefiting from this. And I know other students for a range of other reasons who don't necessarily benefit from that setup. But I feel like sometimes...because again, a lot of students, I think we come as an afterthought to the institution...

Earlier in the interview Crystal shared her challenges working in pre-assigned groups for specific classes. As an outspoken medical student leader at her institution, Crystal shared that she regularly raised her concerns with the school leadership and in meetings with faculty. She expressed her desire to "push back" on requirements that she deemed unnecessarily stressful and unhelpful for her learning. Crystal indicated that she did not hesitate to articulate her concerns to leadership and address what she perceived to be challenges at the curricular level. Similarly, Nora, a longtime advocate for individuals with disabilities even prior to medical school,

described how she was able to address the challenges she experienced due to her disabilities as a medical trainee, while acknowledging the systemic nature of the challenges:

Well, for starters, I know what to do. I've been doing this [advocacy] my whole life. I know where to start. I know what level I need to get to get things done because I have a lot of experience doing it.

Nora commented on the systemic nature of the challenges as unique from college: "I think the difference is in medical school, everything adds up on top of each other...it's a higher level, deep, systemic barriers...[in] which there is a difference between a class and entire school." Several other students, like Tina and Veda, indicated that their prior experience advocating for students with disabilities also made them comfortable taking an active role in advocating for students with disabilities during medical school, despite the systemic nature of the challenges.

When describing their frustration with the curriculum, several students commented on the systemic nature of the challenges they encountered. Several, like Nora, commented on the differences between their college and medical school experiences. Students like Lily and Crystal also expressed having limited autonomy in relation to the medical school curriculum. Drawing on their experiences from college and other formative experiences often propelled students to reflect on the need for more systemic changes. It also informed how they responded to these challenges.

### **Stressors Spur Students to Seek Help**

For several students, the need for accommodations did not arise until medical school because they were able to self-accommodate or "get by" without accommodations. As a fourth-year medical student, Mark, diagnosed with major depressive disorder in elementary school, stated, "Yeah, I think I was able to get by without the extra support [in college], but I think in med school, it's a different level. I'm glad I did take it out [accommodations]." Similarly, Lily, a

third-year student with ADHD, depression, anxiety, and a learning disability who was diagnosed during medical school shared:

I was relatively high functioning for most of my life. But then I feel like, those circumstances plus the really constrictive environment of medical school and schedule my first year brought it to a point where I had to seek support and then get diagnoses...and that was my first time getting accommodations and even just getting an understanding of disability and how it related to me...

Several students interviewed described experiencing a major crisis or stressor during their medical training that was unique from that of their experience prior to medical school.

Undergoing these major challenges forced them to re-evaluate their perspective and the way they approached their unique challenges. Erica, a student on a leave of absence, indicated she began to fail her shelf exams and began questioning her approach: "I remember freaking out during the first surgery exam...so that was the real turning point that was like, I don't think I can compensate anymore. It's getting to the point where whatever I'm doing is not sufficient."

Similarly, Evelyn, a third-year student shared: "I had a full-on panic attack because I was like, why isn't this working? I'm supposed to have learned from undergrad. I was supposed to be better, because now I'm in grad school." Evelyn described receiving informal accommodations during high school and then seeking support for her psychological disabilities after college through therapy. However, relying on therapeutic support and her ability to "self-accommodate" had reached its limits when she began taking her NBME exams during medical school. While reluctant to reach out for help initially, both Erica and Evelyn eventually reached out for support and received accommodations after struggling academically.

### **Strategies for Coping with Challenges**

#### Trial and Error

Several students described specific strategies they implemented to address their challenges related to their disability or disabilities, often describing a process of "trial and error" and drawing on previous experiences navigating similar challenges in college or in their work.

Emily, a self-described, "non-traditional" student because she took time off after college and worked numerous jobs before attending medical school, shared how she navigated and identified optimal strategies for learning after being diagnosed with ADHD during college. She was intentional about keeping a checklist and writing everything down; strategies she learned after multiple iterations of learning what helps her stay organized from previous jobs and a book on ADHD:

...All of it has been trial and error because I learned that, wow, something that took me three hours, took somebody an hour. Like, why is that? I read a couple of books that one of my mentors gave me. It's like 'ADHD in Adulthood.'

Emily detailed a list of strategies she developed to help her manage her ADHD while on clerkships – a system and set of practical steps she put in place daily to help her stay organized and remember the tasks she had been assigned to complete. In addition to keeping a checklist, Emily set multiple reminders on various devices: "I realized that one place to have it isn't enough, and I need multiple checkpoints that are going to keep me on track, that are going to be like, okay, [Emily], let's focus back, let's focus back." She also wrote everything down and then set up an accountability system to help her stay on task:

People are like, oh, you write everything down because I have to. It's essential. Until it becomes second nature to me...and when it does, then I'm fine...So I practice over and over. It's like any skill set that you want to acquire and being disciplined in that way, I think...And then setting deadlines to have somebody else in a subtle way keep me accountable. So say to the resident, I'll say... I'll assign my task. And then I'll say, okay, is it okay if we check back in 10 minutes? So now I know I have 10 minutes to get this task done. And so I stay even more focused and vigilant about the time because now

someone else is depending on me. So that added pressure for me is a drive, and it makes it more interesting and engaging and fun.

Emily shared that she "figured out a system," based on trial and error and doing so enabled her to thrive on her clerkships, particularly her emergency and surgery rotations, since they are fast-paced and required her to use checklists to complete her tasks.

It's go, pick things up, do this, do this. And I'm like, all right, boom, boom, boom. This is check, check, check, check, check. And then once you figure out that system, it's just the same thing over and over and over.

Jack, a first-year student diagnosed with dyslexia as a young child, described engaging in a similar process in medical school: "a lot of times I think it's just trial and error, and especially with new tech tools, like I am always just kind of hopping on different things and they've been just helpful for me and my learning." Similar to Emily, Bethany who also was diagnosed with ADHD as a child, described having to write checklists and create templates to keep track of her patients when on her clerkships, a system she learned through experience, over time: "I have to write every little detail down, even if it's down to a small little thing that they tell me."

### Formative Influences from Parents and Past Experiences

Students often drew on their experiences and lessons from their past to help them cope with their challenges. Several students who were interviewed shared that these experiences were related to the formative influence of a parent or a role model who helped them navigate their disability at an early age. Jack shared that his mother, who was a schoolteacher, played a pivotal role in his ability to navigate his challenges with dyslexia at a young age. Jack shared the positive outlook he has regarding his learning disability, one which was instilled in him in part by his mother who encouraged him to explore various tools and try different approaches to support his learning:

So, I think in my positive way, it [dyslexia] always makes me look at things slightly differently...look, and I'm very curious for new things, new approaches, different ways of

doing things... I feel like I don't let that sit and be just challenging. I'll look for different ways of like, oh, this isn't making sense. Maybe there's some different way that I can look at this, or there's some different tool that I can bring in that can help me think through it.

Tina described the pivotal of influence of her mother in helping her develop the confidence to advocate for herself when she was not properly accommodated during high school:

I learned a lot of fighting back with my mom. I mean, my mom, I would tell her what happened, and she would be like, that's absolutely not okay. She would email the superintendent, would email the principal if they didn't email, actually would go into the office and just demand a meeting. And it was just something that I realized my mom would always have my back. And so she told me, do whatever it takes to defend yourself, and I'll deal with the consequences later. And I think that really just gave me the confidence to, as a child, I have so much leeway to do what I need to do as a kid, which is why I was like, children really should be protected because they have that leeway. And so my mom gave me that freedom to do that.

Tina also shared that she learned from her past experiences to use informal channels when advocating for herself and other students with disabilities:

Starting in high school, I started getting accommodations, but I was still very passive in getting accommodations because this was new to me. I was still in shock over my diagnoses, and I realized a lot of that passiveness was to my own (sic) detriment. I had a lot of white teachers who were abusive and did not follow my 504 Plan...I kept quiet about it, which was really detrimental to my education...so I learned that I probably shouldn't be so quiet in college. I kind of took my importance of community that I learned as a childhood and applied it and started learning the channels. There are always informal channels in university...existing, as a person of color, as a marginalized person in a violent institution, there's always going to be then the strands of resistance that you just got to find. So I think that's why going to medical school, I was very proactive, because I already had that kind of pathway in college.

Tina drew on her experiences as a disabled student who had experienced marginalization and discrimination as a child, due not only to her disability, but also her race-ethnicity, to engage in advocacy during high school and college. Heavily involved in disability advocacy at her own institution, Tina learned the importance of being vocal about the need for greater equity and support for students with disabilities because of her upbringing and through the influence of her mother who was outspoken in advocating for Tina when she was a child. For Tina, her experiences informed her strategy of developing "informal channels" to help her navigate

challenges with disabilities during medical school. Tina talked about strategies she has developed to navigate challenges as a student with disabilities:

I don't know about strategies. I mean, I do have plans in that I really want to strengthen those informal connections that we've started with the formation of DCI...I really want to be able to strengthen that (informal channels) in different ways, making a private group chat that we have, or finding different forums that we can anonymously put our thoughts in. But it's a complicated process...but I don't want to institutionalize a lot of, some support because part of the power of these informal channels is that [the school] doesn't know about them or can't pinpoint them.

For Tina, her formative childhood experiences led her to believe in the power of informal channels, ones which fall outside formal, institutionalized practices as a key means of navigating challenges related to her disabilities. As a result, she has taken the initiative to get involved in advocacy efforts for medical students with disabilities.

### **Setting Boundaries to Prioritize Well-Being**

In many instances students described re-evaluating their prior ways of coping with challenges by, for example, setting boundaries, prioritizing their well-being, and/or seeking help. Often, the demands of medical school spurred them to reflect on their own limitations and the need to prioritize their well-being despite the demands and expectations placed on them as medical trainees. Evelyn stated:

I...think [it's important] just knowing and respecting your limitations and also not seeing them as limitations. Like, I can't do 5,000 things at the same time, I can't do all that. I personally can't handle it, because I'll value my mental health and I know that I need more time to dedicate towards my mental health, so I make time to go to the gym. I make time to take care of my dog. I make time to do all these things that are not school related, that I feel like makes me a better student in the long run. And if that means not doing an extra research project like everyone else, if it means not studying for (USMLE) Step and instead going on a vacation because you need it, then that's something that I'm going to have to do. And it's hard to really accept that because everyone is so ambitious here and everyone wants to do the utmost that they can do, but sometimes you just can't.

Erica shared a common sentiment when she stated the need for drawing boundaries with her time and energy and needing to prioritize her well-being after experiencing a series of stressors that resulted in her re-evaluating her priorities:

...it got to a point where I was like, I'm spinning all these plates and I'm trying to take care of everyone else. It's like, when do I take care of myself? And realized that I had to drop those plates and didn't want the things to break, but also realizing that I had to do so in order to better my overall life.

Erica opted to take time off from the curriculum to focus on her well-being and afford more time to make-up exams she had failed during her clerkships. She also used that time to prepare for her USMLE Step 1 and Step 2 CK exams.

Similarly, Mark, a fourth-year student, reflected on his previous experience with imposter syndrome related to his disabilities and status as a first-generation student which resulted in him sacrificing his other interests and passions outside of medical school during his first year:

I've realized as I've gone into med school, is there's always going to be more studying that I could do or more work I can do...and to really better set boundaries between work time and personal time to explore stuff that's outside of medicine.

Other students, like first-year student Roberto, described realizing the importance of setting aside "me-time" in the form of his artistic hobby and exercising daily. Evelyn shared how she got an emotional support animal after recognizing her need for better balance during medical school. Despite the extra time she knew it would take to care for a dog, Evelyn stated:

I've always grown up with animals, and that's just something that makes me really, really happy. And for me, I felt like the burden of taking care of an animal was less than the benefits that I would gain from it.

More importantly, students described adjusting their perspective about what it means to seek help and receive support as a key difference between their experiences prior to medical school and their medical training:

In college, I think I was more persistent in terms of doing things on my own and less open to seeking out support...And (in) med school, I really began to see seeking out support as a strength instead of a weakness and [accepting] that it was okay to get support. (Mark)

In addition to prioritizing well-being and self-care, students also described ways in which they drew on their own experiences with adversity to help them navigate challenges from a broader, systemic lens. Lily shared how her experiences as the daughter of immigrant parents from Bangladesh, struggles with adversity prior to medical school, and background and previous work in anthropology have informed her views and her approach to medical education:

I think another big source of strength for me is my Indigenous heritage and just learning a lot about decolonial...ways of existing and resisting. And so I think at the end of the day... like with any institution, especially in America, in a capitalist society, and we're in this, even though it's like a [type of school] which is state-funded or whatever, it's still an institution at the end of the day. And it being a [type of school], their job is to put out the workers of tomorrow's doctors and stuff. So I think from the Indigenous wisdom side, remembering that work and labor is just one aspect of life. And also knowing to not let that get to me or just not let...if I don't like the way that other paradigms are set up, I don't have to abide by them...

Lily took the concept of self-care even further by elaborating on the structural and systemic demands of the medical system. Lily asserted her personal need for setting boundaries around what is asked of her, and how that is tied to self-worth:

So obviously the concept of self-care, but deeper than [that] .... not just spa nights and whatever. I think what would be very, very helpful for people to learn coming into med school ... is that the asks from administration or the asks from the hospital or ask from the US medical system, they're only going to increase. And at the end of the day, you're a worker to them. And I think having that realization so that you can make your own boundaries of where your self-worth lies and how much you say yes to, and just making your own path of making your career and labor valuable for you and meaningful for you, aside from these delineated things like, oh, how many papers have you published? How many fellowships have you done? Blah, blah, blah. How high have you ascended into the academic hierarchy? I think it's really important for people to make other kinds of value and meaning from their career besides that, because a lot of people, I think, get stuck into, they just buy into that, but then by the time they're middle-aged or just they realize that it never ends and they're not necessarily fulfilled. So, I think [it's important] for people to just think about that more deeply before they enter this hamster wheel.

Lily's statement represents a powerful reflection of the resilience, hope, and resistance that students demonstrated when discussing their experience with adversity both prior to and during their medical training. Far from depicting herself as a victim or passive recipient of these larger inequities and injustices she observed in the context of her medical education, students, like Lily, made a point to share how their previous know-how, background, and experiences informed their response to systemic and day-to-day challenges and how they engaged with these challenges by choosing to set boundaries and prioritize their well-being.

#### **Relational and Informal Support**

In interviews, students with disabilities cited the importance of personal relationships and informal networks when seeking support. For example, they mentioned peers, family members, as well as staff/faculty with whom they shared a cultural affinity as helpful with their diagnosis and with coping with the challenges of medical school and their disability.

Priya, a first-year student with an ADHD diagnosis, described first being introduced to the idea of a possible ADHD diagnosis by a close friend:

...one of my best friends was like, "Hey," because we hang out 24/7 - he had been diagnosed with ADHD from a pretty early age, middle school, I think, and he was just like, "Hey, I really think you have ADHD." He just gave me everything that I did that matched with the symptoms of ADHD. And I was like, oh, you know what, maybe. But for a very long time, I think almost a year, I kind of gaslit myself into being like, no, I don't. But then I brought it up in therapy once, and then my therapist was like, "Oh, I actually think you might be right." So we ended up doing some testing and yeah, she ended up diagnosing me with it.

Despite being in therapy for her psychological disabilities, Priya did not recognize she might have ADHD until a close friend mentioned it to her. This informal interaction resulted in her seeking a formal diagnosis.

Other students with psychological and learning disabilities similarly described having informal conversations with a loved one, family member, or friend who were pivotal in helping

them seek or connect with resources related to their disability. Even for students with an existing diagnosis of disability, friends served as an important source of support when seeking and receiving more formal support. Erica described how a close friend from college who was also a medical student at the same institution, provided her with encouragement to seek out formal accommodations:

I feel like everyone should have a (classmate name) ...she has been so encouraging to me, and I think especially going through all this, I knew that I could talk to her without any judgment. And when I was like, "Hey, I think I'm applying for accommodation," she was like, "All right, that sounds good. Make sure you do X, Y, and Z." She was always able to connect me with people that I could ask questions to other students that might be going through the same thing as me.

When asked to share advice for students going through similar challenges related to their disability, Emily emphasized the importance of finding close friends:

I have no embarrassment with her because she's actually been one of the few friends that I was able to talk to about this (her disability), because I was having a really hard time and I was like...I think identifying at least one person in med school that is a friend that will, for lack of better terms, keep it real with you, have grace with you, and be...how do I explain it? That you can find support in, and I know I mentioned, oh, there was no one because there was no one at the beginning. And then once I was like, I feel like [she is] someone that I can trust, she has been one of the only people that I feel like I can mutually confide in. And I think if you have one person that you don't feel like you're being a burden to, but that you can have this mutual exchange, I think try to find that person.

In addition to close friends, a number of students interviewed shared that their mothers served as important sources of support, particularly during their childhood, as Jack shared when he described the influence his mother had in encouraging him to seek out different tools to help him with his learning disability at a young age.

For a subset of interviewed students, these same individuals sometimes acted as a "bridge" connecting students to more formal sources of support; several students who had not previously received accommodations before medical school described how a trusted friend or mentor connected them to the disability resource professional or other institutional support

resources to get a formal diagnosis or seek support. Students indicated that these trusted confidentes were pivotal sources of emotional support and encouragement as individuals underwent challenging circumstances or confronted their need for help related to their disability as indicated by Priya, Erica, and Emily.

Trusted friends, family members, and colleagues were key to students feeling comfortable discussing and entertaining the idea of seeking support. Being able to open up to friends about their struggles often became the means through which students recognized their need for more formal support or even a diagnosis.

#### **Resources Utilized**

When surveyed about their use of various campus resources, the highest rates of utilization among students with disabilities were for the campus accommodations office (88.7%), counseling and psychological services (78.9%), in-house tutoring services (77.4%), student health and wellness center (71.8%), and the academic support office (69%). However, only use of the campus accommodations office was found to have a statistically significant association based on a Chi-squared analysis ( $\chi^2 = 120.483$ , p <.001).

In contrast, students who did not report a disability reported higher rates of participation in a student organization (82.7%), and use of a faculty mentor (67.7%) and peer mentor (66.1%) than students without disabilities. 64.8% of students with disabilities indicated involvement in a student organization, 43.7% reported having a faculty mentor, and 45.1% indicated use of a peer mentor. A Chi-squared analysis indicates that there was a statistically significant relationship for use of a faculty mentor ( $\chi^2 = 11.005$ , p <.001), peer mentor ( $\chi^2 = 8.504$ , p <.004), and involvement in a student organization ( $\chi^2 = 8.260$ , p <.004), but these were negatively associated with disability status. That is, students without disabilities were more likely to use these services

than those who reported a disability. The lowest rates of utilization among students reporting disabilities and those who did not were for the career development office and well-being office resources (See Table 4.12).

**Table 4.12**Use of Medical School Services, by Disability Status (n=204)

Use of Services by Disability Status		tified =71)	Iden	ot tified 133)	$\chi_1^2$	p	
	n	%	n	%			
Academic Support or Learning Specialist	49	69.0	96	72.1	.226	.635	
Student Health and Wellness Center	51	71.8	91	68.4	.161	.688	
Counseling & Psychological Services	56	78.9	93	69.9	1.882	.170	
Career Development Office	15	21.1	32	24.1	.225	.636	
Campus Accommodations Office	63	88.7	14	10.5	120.483	<.001	
In-house Tutoring Services	55	77.4	90	67.7	2.161	.142	
Faculty Mentor	31	43.7	90	67.7	11.055	<.001	
Peer Mentor	32	45.1	88	66.1	8.504	.004	
Student Organization(s)	46	64.8	110	82.7	8.260	.004	
Well-Being Office Resources	17	23.9	40	30.1	.864	.353	

The use of these resources is consistent with the prevalence of the types of challenges students with disabilities indicated they encountered during their medical training. All of the students who were interviewed indicated they had connected with the campus accommodations office and were receiving or were in the process of receiving accommodations. More than half (n=10) shared the importance of connecting with their designated disability resource provider (DRP) to receive accommodations. Several students who had experience working with the campus accommodations office prior to the establishment of a designated disability resource provider for medical students commented on the importance of having a DRP who was familiar

with the medical school curriculum and their unique needs. According to Mark, who compared his experience prior to having a designated DRP for the medical school and after:

My experience was that the [campus accommodations office] was just so overloaded that it was sometimes really hard to get a response back from my disability counselor there. And things like appointments and things like that were sometimes hard to set up. I think as well, my disability counselor at the campus accommodations office before [the Disability Resource Provider] came on board was unfamiliar with how the med school curriculum worked and what additional supports might be helpful, and what the potential options were, so I think having someone in-house who specialized in that was really helpful, and I didn't feel those same challenges afterwards.

The fact that fewer students with disabilities used a faculty or peer mentor or engaged with student organizations, relative to students who did not report a disability, and the presence of a statistically relationship with these resources, may reflect the common sentiment expressed among interviewees about the limited time they felt they could devote to extracurricular activities and engagement with formal resources on campus. As students like Liz indicated when reflecting on the use of campus resources:

I barely have time to sleep and eat, and I'm eating and studying at the same time...it's like I sometimes don't even have time to think about my emotions or finding a resource...I'm so focused on trying to get through everything that I have to get through in the day.

In addition, Paula, commented on her frustration about the lack of a supportive environment and the inactivity of the disability and chronic illness group:

I know we have a chronic illness and disability group, but we don't really...I'm in their group chats and nobody ever says anything. Nobody supports each other. I wanted to discuss a certain issue that I was seeing on campus in solidarity with the undergraduates' disability student union, and I got silence in return and nobody's talking. And so it really feels like there isn't a space for us at all, honestly...

While Paula's views may not reflect that of other students with disabilities, interviewees emphasized the importance of personal relationships rather than student organizations or faculty or peer mentors as key sources of support. Paula illustrated this contrast during her interview when asked about the factors that helped her to cope with challenges related to her disability:

I think that I've built a certain support system in my personal life and also my medical team that I feel completely safe in, and I feel very accommodated in. And leaning into those support systems allows me to vent when I need to and just talk things out when I need to. And also when it comes to my support system as it pertains to my family, I think reconnecting with them almost always gives me another reason to continue on this pathway...it's not just for me, it's for a lot of people that can be impacted by the things that I do in my life.

Paula was the first to go to college in her family and was one of many students interviewed who shared that she had witnessed healthcare disparities as a child. Like other students, Paula shared that she found comfort in safe spaces and supportive communities that consisted of close family members, friends, and her medical team.

#### Conclusion

When interviewed, students at this institution described a range of challenges they experienced in relation to study skills, navigating disclosure, seeking support related to their disability and dealing with the stigma of having a disability, as well as systemic challenges that often resulted in them feeling they were treated unfairly, disrespected, or provided with inadequate support related to their disability. While survey results indicated the prevalence of the challenges students experienced in different domains of academic, institutional, and personal challenges, only a subset of these challenges were found to be statistically significant in relation to disability status: in particular, time management, test taking, dealing with the stigma of having a disability, challenges related to a sense of belonging, and maintaining one's physical well-being were found to be associated with disability status.

Interviews with a subset of the students surveyed yielded rich insight into the lived experiences of students as they described their challenges and shared how they confronted and navigated challenges during their medical training. Of note, interviewed students, when describing challenges as systemic in nature, often did not speak up or advocate for themselves in

these instances, unless they felt comfortable doing so, often because they had prior experience advocating for students with disabilities.

In day-to-day interactions or when describing specific strategies for dealing with challenges related to their diagnoses, some interviewed students described engaging in a process of trial and error or exploration with various tools and approaches to help them adapt to the demands of medical school. A number of students described the importance of setting boundaries to prioritize and protect their well-being when navigating challenges during their medical training. Finally, many students indicated they relied on trusted friends and/or family for support when dealing with challenges related to their disability. The findings from this study aimed to build on previous studies by systematically exploring the prevalence of challenges in the domains of academic, institutional, and personal challenges. It also illuminated how students described navigating these challenges.

As a descriptive study, I found that the frameworks of the social model of disability helps to contextualize the ways in which students experienced their challenges in relation to the environment of medical school; and the sociological literature on stigma provides key insights into the different ways in which students experienced stigma in relation to their disability. The application of these conceptual frameworks to my findings are elaborated in Chapter 5, along with additional avenues for research and implications for practice.

#### CHAPTER FIVE

#### DISCUSSION

This final chapter begins with a summary and interpretation of my findings in relation to the existing literature on medical students with disabilities. I then share some of the implications of my research before discussing some limitations of this study. I conclude with my personal reflections. Though limited to one allopathic medical school, the findings from this study build on and shed light on potential limitations of other studies. It also contributes to future lines of inquiry for this understudied population.

#### **Study Overview**

Recent studies on medical students with disabilities have focused on the prevalence of disability (Meeks at al., 2020, Meeks et al., 2022; Pereira-Lima et al., 2023), challenges associated with disclosure of disability and help seeking, as well as a culture of hyper-ableism students with disabilities encounter during their medical training (Jain 2020, 2022). Yet, there has been limited research from the point of view of students themselves regarding how they respond to and navigate these challenges. I aimed to contribute to existing literature by exploring the experiences of students with disabilities at one allopathic medical school, highlighting through an anonymized survey, the type of disabilities reported as well as the challenges students say they faced. I compared their responses with students not reporting a disability to identify associations of specific challenges with disability status using a Chi-squared analysis in the domains of academic, institutional, and personal challenges. Semi-structured interviews with 18 students who identified as having a disability provided deeper insight into the perceived challenges they experienced and the ways they navigated these challenges.

### **Summary and Interpretation of Findings**

The findings from this study are consistent with the existing literature on students with disabilities and the challenges medical students experience in general. The most common types of disabilities reported were psychological and cognitive disabilities. Most students, regardless of disability status, reported experiencing academic and personal challenges. However, a number of these challenges were found to disproportionately impact students with disabilities. There were also some unexpected findings that pointed to the dynamic nature of disability, with some students being newly diagnosed during medical school or receiving accommodations for the first time. When interviewed, students pointed to the systemic nature of their challenges which made it difficult to disclose and speak up to address challenges. For some, the challenges with disclosure had more to do with appropriate implementation of accommodations rather than disclosing a disability to receive accommodations. When describing how they addressed challenges related to their disability, several students said they engaged in trial and error. They also discussed the importance of setting boundaries to promote self-care. Finally, several students shared they relied on close friends, family members, and trusted mentors for support.

## **Types of Disability Reported**

While the types of disability reported at this institution may not be representative of the population at large given the limited scope of the study, among those who reported a disability in this study, the most common types of disability included psychological and chronic health related disabilities. The least common types of disabilities were sensory and dexterity-based disabilities. Similarly, the American Association of Medical Colleges annual Graduate Questionnaire (GQ) (2023) which surveys graduating medical students in the United States each year, reported psychological disabilities, ADHD, and chronic health related disabilities at higher

rates than any other category of disability. Moreover, a recent survey conducted of disability resource providers in 2021 similarly found that students receiving accommodations and reporting a disability had doubled between 2015 to 2021 with "significant increases in ADHD, chronic health disabilities, and psychological disabilities" (Pereira-Lima et al., 2023, p. 3). These findings are consistent with that of other studies that have highlighted the high rates of psychological and mental health challenges as well as chronic stress medical students experience relative to their same-aged counterparts. (Drybye et al., 2006, 2014; Lane et al., 2020; Langness et al., 2022; Rotenstein et al., 2016; Veal, 2021). Among students surveyed in this study, most of those reporting a disability and in receipt of accommodations, reported they began receiving accommodations during medical school.

### Social Model of Disability

Far from being a static characteristic or one that pre-exists students' entry into the medical profession, the findings from this study suggest that both disability status and the need for accommodations may be reflective of the social context and environment. The social model of disability sheds light on this important aspect of disability in relation to existing studies by highlighting the fact that context and environment matters and can be determinative of the prevalence and presence of disability among types of populations. Moreover, this study points to the importance of examining the context in which disability occurs and emerges, consistent with the social model of disability framework.

These findings are consistent with existing research on medical student mental health and well-being, which revealed that medical students start out with better mental health measures, in terms of rates of burnout, depression, and quality of life measures when compared to their sameaged counterparts at the start of matriculation to medical school, but that the inverse holds true

over time (Brazeau et al., 2014, Dyrbye et al., 2014). This has led researchers to conclude "that the training process may contribute to the deterioration of mental health in developing physicians" (Brazaeu et al., 2014, p. 1522). The findings from this current study support this framework: Most students who were surveyed, regardless of disability status, reported academic and personal challenges, and virtually all students who were interviewed experienced stressors which impacted their well-being.

Among students with a disability who were interviewed, several, like Jocelyn and Nora, reported they experienced acute stressors which resulted in an exacerbation of symptoms. There were other students, like Erica, Evelyn, Lily, and Mark, who indicated they were able to "get by" or "self-accommodate" until they got to medical school. Something about the environment of medical school and the unique stressors they experienced seemed to instigate the need for accommodations. Even among students who had accommodations in place at the start of their medical training, there was a common acknowledgement of longstanding structural and systemic challenges, such as challenges with the structure of the curriculum and the hierarchical nature of medicine, as elaborated by a number of students interviewed (many of whom were students of color from marginalized communities), which often made it difficult to address the challenges they experienced.

## Disability Status is not Static

The findings from this study suggest that disability status is not static. There were students who had been diagnosed with a disability during childhood and were able to go through schooling in K-12 and even college without accommodations, but had a condition re-emerge or experienced a new set of diagnoses in medical school. Several students described how the physical symptoms of their condition varied at different times prior to and during their training.

While perhaps a unique characteristic of this study population, an interesting finding from this current study was the prevalence of students who reported multiple types of disabilities: 43.6% of students with a disability reported more than one disability. Among interviewees, most possessed both a psychological and physical disability.

Recent studies of medical students with disabilities tend to depict disability as a static concept rather than as one that can and often does "wax and wane," as one student put it, over time. For example, research conducted by Meeks et al. (2019, 2020, 2021) focused on the prevalence of disability and types of disability among medical students and does not discuss the dynamic nature of students' disability status, such as when they were diagnosed, or when they began receiving accommodations. In addition, these studies do not discuss the extent to which students report multiple disabilities with distinct sets of challenges and outcomes. For example, a seminal and oft-cited publication by Meeks (2020) distinguished between students with cognitive/psychological and learning disabilities from those with physical and sensory disabilities and identified differences in educational outcomes between the two groups, when in fact a number of students may possess both types of disabilities and experience newly emergent disabilities during medical school, as described by numerous interview participants.

## Some Challenges Disproportionately Impact Students With Disabilities

Students with and without disabilities experienced similar challenges, but the findings from this study indicate that some of these challenges disproportionately impacted students with disabilities. Most of the students surveyed, regardless of disability status, indicated they experienced academic and personal challenges. A subset of these challenges was found to be statistically significant and positively associated with disability status, such as challenges with time management and test taking, dealing with the stigma of having a disability, sense of

belonging, physical well-being, and discrimination, prejudicial, or insensitive treatment by faculty and administrators as well as students.

Academically, most students, regardless of disability status, emphasized difficulty coping with the volume and pace of the curriculum as well as challenges with test taking. The findings from this study were consistent with the existing literature about the academic stressors medical students experience, as elaborated in Chapter 2 (Dyrbye et al., 2005; Dyrbye et al., 2006; Dyrbye et al., 2014; Hill et al., 2018). In comparing the prevalence of students experiencing academic challenges among students with and those without disabilities, only two of the three types of academic challenges, time management and test taking, were positively associated with disability status, while challenges associated with study skills were not. Thus, academic challenges were not unique to students with disabilities, but specific types of challenges were found to disproportionately impact students with disabilities. When interviewed, students indicated that the sheer volume of information they were expected to learn as well as the rapid pace of the curriculum was such that even with accommodations, students had difficulty managing their time effectively. In addition, the high stakes nature of the exams resulted in some students experiencing anxiety they had not experienced prior to medical school. More importantly, rather than discussing their academic challenges in terms of their own inadequacies, students pointed out their frustration with the curriculum, both in classroom and clinical settings.

## External vs. Internalized Stigma

When it came to dealing with stigma, findings from this study suggest that there were differences in the way students experienced stigma related to their disability. For some students, stigma as they described it was structural and institutional; they recognized that there was a general stigma about people with disabilities that might impact how they are perceived and how

others might view their capabilities as medical students (Bos et al., 2013; Corrigan & Watson, 2002). However, they did not view their own disability as reflecting anything negative about their own self-image. Other interviewed students described internalized feelings of stigma associated with their condition, but often attributed such feelings to cultural influences and/or their upbringing. Interestingly, while much of the literature on students with disabilities assumes that students experience self- or internalized stigma (Bos et al., 2013; Corrigan & Watson, 2002), several students in this study did not describe their challenges with stigma in this way. According to them, feelings of stigma were linked directly to the structure and culture of medicine which made it difficult for some students to navigate disclosure in specific settings and day-to-day interactions, even though most had already disclosed their disability to receive accommodations.

## Barriers Students With Disabilities Face are Systemic (not Just Personal or Institutional)

What is striking about the findings from interviews was how often students attributed challenges to the curriculum, their learning environment, or the culture of medicine (e.g., characterized as "conservative," "hierarchical," based on western science, minimizing the lived experiences of individuals, etc.). Several students attributed the challenges they experienced to systemic factors rather than indicating they were reflective of personal- or individual-level factors. Indeed, a recent study found that medical students' perceptions of the learning environment tend to become more negative over time, particularly as students transition from their preclinical to clinical training (Dunham et al., 2017). The finding from Dunham's study explains some of the experiences shared by medical students with disabilities in this study. Among those interviewed, a number expressed frustration about the lack of clear expectations and consistency during their medical training, particularly once they entered clinical settings. Several also shared incidents of discrimination, prejudice, or insensitive treatment they

experienced with faculty and fellow classmates, which they attributed to larger systemic issues, such as the "hierarchy of medicine." The findings from this study are also consistent with others that point to a number of common, widespread, acute stressors facing medical trainees in the United States and across the globe (Quek et al., 2019; Rotenstein et al., 2016). In particular, Hill et al. (2018) highlighted similar academic and personal challenges among medical trainees and concluded that "students self-report stressors that may be better addressed through system-level changes" (p. 1087). Moreover, many of the shared perceptions of students with disabilities are consistent with Jain's (2022) depiction of medical education as premised on a "capability imperative," in which "malleable" students are expected to conform to ableist standards to demonstrate competence as a "selfless superhuman" in the "real world" of medicine (p. 6).

## Barriers to Disclosure: More Than Meets the Eye

When asked about institutional challenges students with disabilities encountered, only a slight majority of respondents indicated they experienced challenges accessing appropriate resources or disclosing their disability in order to seek support (each was reported by 53.5%), and less than half of respondents reported challenges associated with applying for and/or receiving either school accommodations or accommodations for the United States Medical Licensing Exam (33.8% and 38%, respectively). Several scholars have consistently cited the barriers to disclosure as a key challenge among medical students with disabilities (Meeks et al., 2019, Meeks et al., 2020, Meeks et al., 2021; Pereira-Lima et al., 2023). These studies suggest that these barriers explain why students who might otherwise be eligible to apply for and receive accommodations refrain from doing so. However, the findings from this study suggest a more nuanced understanding. Among study participants, the challenge with disclosure had less to do with disclosing to seek formal accommodations and more to do with the implementation of these

accommodations. Students also shared experiences navigating challenges with disclosure in day-to-day interactions with faculty and staff. They pointed to specific ways navigating the implementation of their accommodations could be fraught with confusion or ambiguity when appropriate accommodations were not in place. There were also instances when students experienced uncertainty about whether to disclose their disability when they had limited interactions with faculty, particularly during their clinical training.

Recent studies focus on the importance of an institutional infrastructure to support students with disabilities through, for example, strong technical standards and disabilityresources professionals to mitigate the barriers to disclosure (Meeks et al., 2021). However, the current study, though limited in scope to one institution, suggests that the structural barriers go much further than the mere absence or presence of these resources or disclosure in order to seek accommodations. All students who were interviewed indicated they were receiving accommodations and/or were in the process of receiving accommodations. Nevertheless, there were deep systemic issues that made it difficult for them to see their accommodations actualized in classroom and clinical settings. As described above, students still experienced the burden of needing to disclose to be properly accommodated. They shared that the nature of these challenges was tied to general issues with the curriculum, the lack of attention and care to those with disabilities when designing and implementing the curriculum, and a general lack of understanding of their lived experiences. Throughout this study, students indicated that the challenges were reflective of a culture of medicine, a system that often has resulted in students experiencing a variety of academic and mental health stressors that are now well documented in the literature on medical students and medical trainees (Dyrbye et al., 2005, 2006, 2014).

### Navigating Challenges

On the one hand, Jain's (2022) observations of medical education as perpetuating and reinforcing hegemonic hyper-ableist norms serves as an accurate and pointed description of what students in this study experienced. However, one key area missing from Jain's account is how students respond to these systemic challenges. While students' approaches to navigating their challenges varied, often medical students with disabilities were reluctant to confront others or speak up to advocate for themselves to receive appropriate accommodations, particularly when the challenges were perceived as pervasive and systemic in nature. Some described the systemic nature of the challenges and attributed them to the limited time and bandwidth of people in medicine (both students and faculty) and indicated they would opt to "suck it up" and "deal with the consequences." Several other students who had experience advocating for themselves and others with disabilities, however, described how they felt comfortable speaking up or resisting demands of others when perceived as unfair or disrespectful.

When the challenges were limited in scope and within what students perceived to be their locus of control, they engaged in "trial and error" or drew on previous experiences to help them devise practical ways to help them navigate their challenges. Some examples elaborated in Chapter 4 included students with ADHD who applied various checklists and reminders, and a student with dyslexia, Jack, who was encouraged by his mother at an early age to embrace a "growth mindset," explore different approaches, as well as apply assistive technology to facilitate his studying.

#### Relying on Family, Friends, and Trusted Colleagues

When it came to navigating challenges, at times, an acute crisis or stressor provided the impetus for students to seek help and re-evaluate their approach to dealing with challenges.

Often students described relying on family members, friends, or trusted colleagues for support. As elaborated in Chapter 2, there is a wealth of literature about the high level of burnout and stress medical professionals face in the course of their training and during their practice (Dyrbye et al., 2005, 2006, 2014; Quek, 2019). In a recent memoir entitled, *We Are All Perfectly Fine: A Memoir of Love, Medicine and Healing*, Dr. Jillian Horton (2021) recounts her experience with burnout and depression as a medical professional, and comments on the "unrelenting nature of the work" (p. 21). Horton drew parallels between her life as a medical trainee and that of an incarcerated prisoner who has limited contact with the outside world: "Medical students, residents and prisoners wear uniforms, eat bland food, have limited contact with the outside world, and inhabit a hierarchical culture" (p. 33). Horton's is a searing commentary of the medical profession and the degree to which physicians are expected to sacrifice their own well-being at the expense of caring for their patients. As Horton noted:

We split from our bodies so we can learn to be doctors. Isn't that ironic? We deal with corporeal failures, but we think we can program bodies, *our* bodies, to run without sleep, or food, or hydration. We learn to work through utter exhaustion. (pp. 77-78)

Horton's (2021) account mirrors the stories students shared with me about their experiences navigating challenges as trainees with disabilities. Several students commented on the need to draw boundaries in order to prioritize their health and well-being in response to the enormous demands placed on them as trainees. In doing so, several acknowledged a level of dysfunction they believed characterized the medical profession. Some were outspoken about the need to shed light on and resist these demands. In some cases, students felt the need to "suck it up and deal with the consequences," as Paula recounts, but many recognized the need to prioritize their health and well-being, even if it meant sacrificing their long-term career goals.

### Sources of Support

As evidenced by the experiences students shared about confronting and navigating their challenges, many were intentional about building on previous experiences and leaning on support systems, even if informal, to help them navigate challenges. Other students described leveraging their previous experiences with adversity to help them navigate current challenges. Several students highlighted the importance of friends, family members, and trusted mentors as sources for ongoing support. In some cases, these same individuals also served as a bridge for students getting connected to more formal avenues of support for their disability. Parents, especially mothers, were mentioned by several students as role models who inspired them to pursue their medical education and persist in their training. For example, Emily shared that, despite not having a formal education, her mother provided her with significant support, and the adversity her family and community experienced continued to inspire her to pursue medicine.

## **Implications for Practice**

Much of the research to-date on medical students with disabilities emphasizes the importance of putting in place appropriate technical standards and designated disability resource providers to support students with disabilities. However, as is evident from this study, not just the *what*, but the *how* and the *why* are important when attempting to understand the types of supports and resources that are effective in supporting students with disabilities. The establishment of disability-resource provider(s) and stronger technical standards is an important step schools can take to strengthen support for students with disabilities, but this study suggests that more work can be done to address the deep, systemic, and structural barriers that disproportionately impact students with disabilities, and in some cases, exacerbate the conditions

associated with students' disability, creating the conditions for students to seek accommodations in the first place.

### Incorporate the Student Perspective When Designing Support Services

This findings from this study emphasizes the key point that it is important to consider the student perspective whenever designing and implementing support services. To support an increasingly diverse student population and better support the training of a robust cadre of medical professionals, including those with disabilities, institutions should seek out student input when designing resources and programming at the outset. Several students in this study commented on the disconnect between faculty and administration expectations and students' experiences. Even when formally approved for accommodations, students encountered numerous challenges implementing their accommodations and often felt that the burden fell on them to ensure that their accommodations were appropriately put in place. Particularly in clinical settings, students encountered challenges knowing when it might be appropriate to disclose their disability. Those responsible for implementing accommodations should examine how they might create more streamlined processes to help students navigate disclosure prior to and during the process of receiving and implementing accommodations. Providing regular opportunities for students to offer feedback on quality improvements and creating a more robust system for implementing accommodations that does not rely on student initiative to follow-through on implementation would help lessen the burden students experience.

#### **Consider how to Connect Students to Resources**

Simply putting in place a disability resource provider and improving technical standards is not enough. School officials must consider how students connect with these resources. This study suggests that students often rely on trusted friends and mentors to connect them to more

formal avenues of support. In addition to strengthening formal sources of support as Meeks et al. (2021) recommended, institutions should also consider strengthening informal networks and connections, through for example, affinity groups, which may be students' preferred modality. Moreover, building awareness about available resources and strengthening informal sources of support could be effective in mitigating the impact of stigma some students experience in relation to their disability. It might also encourage students to advocate for themselves and others when it comes to implementing the appropriate accommodations and identifying opportunities for programmatic improvements.

#### **Build a Supportive Environment**

In addition, this study suggests that more can be done to build a supportive environment for students with disabilities by raising awareness among faculty and students about the prevalence of disability. To the extent that faculty at times have generalized that students are "young and healthy," doing so discounts the fact that students may be experiencing health ailments similar or even identical to the ones they are teaching about. Faculty development initiatives should be aimed at creating an environment where doctors and health professionals are not depicted as immune or separate from the very conditions they are being trained to diagnose and treat.

#### Raise Awareness About Different Aspects of Disability

Finally, and perhaps most importantly, administrators, faculty, and members of the medical community, should be aware of the dynamic and contextual nature of disability, examining and acknowledging ways in which systemic factors may be contributing to the various academic, institutional, and personal challenges students with disabilities experience.

Regular feedback sessions with students, anonymized surveys, and focus groups could help elicit

ways that students experience stressors and how administrators can think about alternate ways to address the institution level barriers that are tied to the organization and structure of the curriculum and the challenges that students face during their clinical training.

## **Study Limitations**

As a descriptive, mixed methods study conducted at one allopathic medical school, there are several limitations that are important to acknowledge here. First, the findings of the study are limited in terms of generalizability. The characteristics of the student body may not be reflective of other medical schools, as indicated previously. Most of the students at this institution were students of color and most of the survey respondents and interviewees were female. Many of those interviewed indicated they were first-generation college students and/or had experienced significant adversity during their childhood due to their family's socioeconomic status and background. In addition, the experiences students shared regarding their challenges may reflect, to some extent, the specific idiosyncrasies of the institution, since the school had recently undergone a significant redesign of their curriculum.

Other contextual factors that immediately preceded the study may have also impacted how students perceived their challenges and how they chose to navigate them. In addition to the curriculum redesign, several students indicated that the COVID-19 pandemic had exacerbated some personal and familial challenges they experienced leading up to and/or during their medical training. As such, the scope and nature of the challenges students experienced may have been impacted by these external factors.

While the study attempted to compare the differences in challenges among students with and without disabilities, the Chi-squared analysis conducted as part of this study did not control for factors such as gender, race/ethnicity, year in school or type of disability, among other

factors. In addition, I did not examine differences in challenges between students who began receiving accommodations in medical school versus those who previously had received accommodations, though most students did not begin receiving accommodations until medical school. There may have been differences in the perception of challenges based on these and other factors that were not controlled for in this study.

In general, self-selection bias may also have impacted the results of this study. While the survey was anonymous, students who volunteered to participate in the study may have been those most willing to disclose their disability and/or impacted by the stigma associated with their disability. Likewise, students who volunteered to be interviewed may have represented a particular subset of students who were more eager to share their experiences and were more comfortable disclosing their disability.

## **Suggestions for Future Research**

This study provided a number of potential lines of future inquiry. For one, future studies could focus on more than one institution to offer greater generalizability of results, particularly as it relates to types of disabilities and challenges reported. A multi-institutional study would also help to illuminate whether there are institution-level factors that impact students' perceptions of challenges. To the extent that students expressed frustration with the curriculum in the aftermath of a curriculum redesign, a comparison with a population of students at other institutions where students did not experience the same type of institution-level changes might yield interesting insights and help to identify factors which may be common across institutions.

While not the focus of this study, most study participants were female students of color, and most of the students interviewed shared significant experiences with adversity related to their families' immigrant and/or low-income background. It would have been helpful to control

for varied factors such as gender, race/ethnicity, socio-economic status: there may be unique challenges faced by students with disabilities who are also from marginalized backgrounds.

A surprising finding was the high number of students, more than one third (34.8%) of the 204 respondents, who reported a disability at this institution, particularly given estimates of 10.9% prevalence of disability by the AAMC GQ (2023) of fourth-year medical students, and a recent study which cites 5.9% of medical students with documented disabilities (Pereira-Lima et al., 2023). It was also surprising that a high proportion of students began receiving accommodations during medical school or were newly diagnosed during their medical training. Further studies could examine the prevalence of disability using alternate survey methods, for example, by conducting a comprehensive survey of students in all years, including students on a leave of absence to gain a more accurate understanding of disability prevalence. Further research could also be done to ascertain how much disability prevalence shifts over time.

More than emphasizing the challenges students face, future studies should also focus on how students respond to and navigate these challenges. To the extent that students at times navigated their challenges in unexpected ways, it would be helpful to examine and further explore how students respond in ways that resist conformity to existing norms and narratives of a "good student" or a "competent doctor" as described by several scholars (Jain 2022; Stergiopoulos et al., 2018).

There are clearly opportunities to develop a more robust theoretical and conceptual framework when examining the challenges of medical students with disabilities. In addition to widening the scope of future studies and examining disability as a dynamic concept that can emerge in the context of one's training, centering the voices of trainees can yield rich insight into

how students navigate challenges, thereby informing the resources and practices that are enacted to support this small but growing population of students.

#### **Reflections and Conclusion**

In the end, I have come to appreciate the sentiment expressed by several disability scholars and advocates, as stated by the World Health Organization that, "Disability is part of being human. Almost everyone will temporarily or permanently experience disability at some point in their life" (2024). Similarly, Mitchell (2016), a disability advocate, stated, "Most of us will have a disability in our lifetime. We think it's something that happens elsewhere and impacts others. It's not. Disability is relevant to us all." The binary distinction individuals draw between those with disabilities and the ways in which this population is treated, understood, and supported ultimately reflects values that are held about all people, but especially those perceived to be on the margins of society or those who have been "othered" in some way.

The findings of this study illuminate a variety of perspectives and the ways in which the struggles of medical students with disabilities reflect a much larger set of systemic challenges in medicine and medical education, while also showcasing the resilience, hope, and resistance of students who have been disproportionately impacted by them. The aim of this study was to shed light on this important population of students and to explore ways that medical education can be better designed to support students, regardless of disability type or status. My expectation is that individuals will be spurred to think about ways medical education can be universally designed with the needs of students at the margins in mind. Medical education is predicated on trainees adopting the Hippocratic Oath to serve others with integrity and "do no harm." The same principle should be applied in the reverse. Not only patients, but the physicians who treat them should feel cared for, thrive, and flourish. My firm belief is that this can only happen when the

voices and perspectives of individuals on the margins are brought to the forefront of this endeavor.

#### APPENDIX A

### **Survey Instrument**

### **Survey on Medical Students With Disabilities**

#### **Instructions:**

The following survey should take approximately 5-10 minutes to complete.

You have been selected to participate in this study because you are a student currently enrolled in medical school. This study is about challenges faced by medical students with disabilities and the way they navigate these challenges. A desired outcome of this study is to strengthen support services available to students in medicine, particularly those with disabilities. For more information about the study please see this Study Information Sheet.

You need not be a student with a disability to participate in this study. The main requirements are that you are currently:

- 18 years of age or older
- Full-time medical student (or on a temporary leave of absence from medical school)

Your participation in this survey is anonymous and completely voluntary; you may skip any questions or end the survey at any time and there are no consequences for declining to participate or respond to every question. Your decision whether to participate in the research will not affect your current educational or professional standing. Your data, including de-identified data may be kept for use in future research.

For any questions that you do not feel comfortable answering, please leave blank. There is no negative consequence for not answering a question or series of questions.

Upon completion of the survey, you will be asked if you are interested in participating in a follow-up interview. The first 50 respondents to the survey will receive a \$10 Amazon gift card. Those who participate in an interview will receive a \$25 Amazon gift card. At the end of the survey, you will be prompted to complete a separate form, de-identified from the survey, to receive your gift card.

If you consent to participating in the study, please click on the right arrow -> button on the bottom right corner to begin the questionnaire.

If you have any questions or would like more information regarding the study, you may contact the primary investigator, Sue Nahm at: sxxxxx@ucla.edu.

Thank you for your participation!

Sue Nahm

I an	n currently a medical student at:
•	
•	Other (please specify)

W	That is your current status/year in medical school?  1st year
•	2nd year
•	3rd year
•	4th year
•	Leave of Absence (LOA)
F N	o you identify as having a disability?  For a definition of disability, please see:  For a definition of disability please see:
•	No
•	Uncertain
•	Other/an option not included here
Di Ye	isplay This Question: If Do you identify as having a disability? For a definition of disability, please see: [sic]. = es
	ou indicated you identify as having a disability. Please indicate which of the following applies you:  I have been formally diagnosed with a disability.
•	I believe I have a disability, but I have never been formally diagnosed.
•	I was previously diagnosed with a disability, but do not believe I have a disability currently. Other
	isplay This Question: If Do you identify as having a disability? For a definition of disability, please see: [sic] = ncertain
	ou indicated that you are uncertain whether you identify as having a disability. Please use this ace below to explain your response:

Display This Question:  If Do you identify as having a disability? For a definition of disability, please see: [sic]. =  Other/an option not included here
You indicated "other/an option not included here" regarding identifying as having a disability. Please use this space below to explain your response:
Display This Question:  If Do you identify as having a disability? For a definition of disability, please see: [sic] =  Uncertain
Or Do you identify as having a disability? For a definition of disability, please see: [sic]. = Other/an option not included here
You indicated "uncertain" or "other" regarding having a disability. Please indicate which of the following applies to you:  I have been formally diagnosed with a disability.
<ul> <li>I believe I have a disability, but I have never been formally diagnosed.</li> </ul>
• I was previously diagnosed with a disability, but do not believe I have a disability currently.
• Other (please explain)
Display This Question:  If Do you identify as having a disability? For a definition of disability please see: [sic] =

You indicated you identify as having a disability. Please describe the nature of your disability or disabilities. Check all the apply:

- Deaf/Hard of hearing
- Blind/Low vision
- Learning disability

- Psychological disability (e.g., Depression, Anxiety, ADHD, Autism Spectrum, PTSD, Bipolar disorder, Mood disorders, Personality disorders, etc.)
- Mobility based disability
- Dexterity based disability
- Chronic health condition (Crohn's, Ulcerative Colitis, Irritable Bowel Syndrome, Chronic Migraines, Postural Orthostatic Tachycardia Syndrome, etc.)
- Neurological Disability (Stroke, traumatic brain injury, etc.)

•	Other						

## Display This Question:

If Do you identify as having a disability? For a definition of disability, please see: [sic] = Yes

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Incertain

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Other/an option not included here

Are you currently registered with your campus accommodations office, or the

7

- Yes
- In the process of registering
- No
- Unsure

Are you currently receiving academic or educational accommodations? (e.g., testing accommodations, adaptive technology, notetaking services, housing accommodations, transportation assistance, clinical accommodations, attendance support, etc.)

- Yes
- I am not currently receiving accommodations, but I received accommodations prior to medical school.
- I am not currently receiving accommodations, but I previously received accommodations during medical school.
- No, I'm not currently receiving, nor did I previously receive accommodations.

#### Display This Question:

If Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = Yes

Or Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = I am not currently receiving accommodations, but I received accommodations prior to medical school.

Or Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = I am not currently receiving accommodations, but I previously received accommodations during medical school.

When did you begin receiving academic and/or educational accommodations for your disability?

- Kindergarten -12th grade
- College/undergraduate education
- Graduate program (non-medical) or Post-baccalaureate program
- During medical school
- Unsure

<ul><li>Oth</li></ul>	er				
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### Display This Question:

If Do you identify as having a disability? For a definition of disability, please see:[sic].. = No

And Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = Yes

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = No

And Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = I am not currently receiving accommodations, but I received accommodations prior to medical school.

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Uncertain

And Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = I am not currently receiving accommodations, but I received accommodations prior to medical school.

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Uncertain

And Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = Yes

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Other/an option not included here

And Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = I am not currently receiving accommodations, but I received accommodations prior to medical school.

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Other/an option not included here

And Are you currently receiving academic or educational accommodations? (e.g., testing accommodations... = Yes

You indicated you are receiving, or previously received accommodations. Please describe the reason for your receiving accommodations (if applicable). Check all the apply:

- Deaf/Hard of hearing
- Blind/Low vision
- Learning disability
- Psychological disability (e.g., Depression, Anxiety, ADHD, Autism Spectrum, PTSD, Bipolar disorder, Mood disorders, Personality disorders, etc.)
- Mobility based disability
- Dexterity based disability
- Chronic health condition (Crohn's, Ulcerative Colitis, Irritable Bowel Syndrome, Chronic Migraines, Postural Orthostatic Tachycardia Syndrome, etc.)
- Neurological Disability (Stroke, traumatic brain injury, etc.)

What resources have you used to-date at your medical school, if any? (Please indicate all that apply.)

	Yes	No	Unsure	(not available at my school) Not applicable
Academic Support or Learning Specialist	•	•	•	•
Student Health and Wellness Center	•	•	•	•
health/counseling center	•	•	•	•
Career Development Office resources	•	•	•	•
Disability Services or your campus accommodations office	•	•	•	•
In-house Tutoring services	•	•	•	•
Faculty mentor	•	•	•	•
Peer Mentor	•	•	•	•
Student Organization(s)	•	•	•	•

Well-Bein	g Office	resources
W CII-DCII		1 CSO UI CCS

Please list any other campus or school resources you have used:

Have you experienced any of the following academic challenges during your time in medical school?

	Yes	No
Study Skills (e.g., study strategies, adjusting to volume/pace of material, selecting study resources, etc.)	•	•
Time Management (e.g., task initiation, prioritization, study scheduling, organization, etc.)	•	•
Test Taking (e.g., test taking anxiety, pacing, performance, etc.)	•	•
Other	•	•

Have you experienced any of the following institutional/logistical challenges during your time in medical school?

	Yes	No	Not applicable
Accessing appropriate resources related to a disability or disabilities	•	•	•
Disclosing a disability or disabilities in order to seek support (even if you have disclosed and/or are receiving support for your disability)	•	٠	•
Applying for and/or receiving accommodations for in-house courses or (non-USMLE) exams, including shelf exams (even if are receiving or previously received accommodations)	•	•	•
Applying for and/or receiving testing accommodations for Step 1 and/or Step 2 CK USMLE exams (even if you previously received and/or are currently receiving accommodations)	•	•	٠
Other	•	•	•

Have you experienced any of the following personal/social/inter-personal challenges during your time in medical school?

	Yes	No
Finding community	•	•
Dealing with stigma of having a disability	•	•
Questioning whether I belong in this program	•	•
Questioning career direction	•	•
Physical health/well-being	•	•
Mental health/well-being	•	•
Financial hardship	•	•
Discrimination, prejudicial or insensitive treatment by faculty or staff	•	•
Discrimination, prejudicial or insensitive treatment by classmates	•	•
Other	•	•

# Display This Question:

If Do you identify as having a disability? For a definition of disability, please see: [sic] = s

	se use the space below to describe any other challenges related to your disability experienced during your time in medical school:	that you
-		
_		
_		
_		

# Display This Question:

If Do you identify as having a disability? For a definition of disability, please see: [sic] = No Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Uncertain

Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Other/an option not included here

Please use the space below to describe any other challenges that you have experienced during your time in medical school:	
Display This Question: If Do you identify as having a disability? For a definition of disability, please see: [sic] = No	
Or Do you identify as having a disability? For a definition of disability, please see: [sic]. Uncertain	
Or Do you identify as having a disability? For a definition of disability, please see: [sic] = Other/an option not included here	
What recommendations, if any, do you have for strengthening support services for medical students at your institution?	
Display This Question: If Do you identify as having a disability? For a definition of disability, please see: [sic]= Y	Yes
What recommendations, if any, do you have for strengthening support services for medical students with disabilities at your institution?	

	·
Ιi	dentify as: (select all that apply)
•	Female
•	Male
•	Non-binary
•	Transgender
•	Other
•	Prefer not to answer
W	hat is your race/ethnicity? (select all that apply)
•	African-American/Black
•	American Indian or Alaskan Native
•	Asian or Pacific Islander
•	Caucasian/White
•	Hispanic or LatinX
•	Middle Eastern or North African
•	Other
•	Prefer not to answer
Eı	nd of Block: Default Question Block
St	art of Block: Conclusion - next steps
	you are willing to participate in a 45-minute interview via Zoom, please indicate your contact formation below.  Name (first, last)
•	Email address:
•	DI I

For more information about the American with Disabilities Act and national regulations pertaining to individuals disabilities in the United States, please see the <u>U.S. Department of</u>

# Labor, American Disabilities Act.

For a list of local and national resources for individuals with disabilities, please see: Disability Resources [hyperlink removed].

To submit your responses and complete the survey, please click on the right arrow -> button on the bottom right corner of the page.

**End of Block: Conclusion - next steps** 

#### APPENDIX B

### **Interview Protocol**

Interviewee Name:
Selected Pseudonym
Date:
Гime:

Hello, [participant name]. Thank you for agreeing to be interviewed! My name is Sue Nahm and I am a doctoral candidate in the Educational Leadership Program at UCLA.

As I shared previously, I am conducting this interview as part of my dissertation research and the information from this interview is meant to highlight the experiences of students with disabilities. I would like to learn more about your experiences dealing with challenges you may have encountered (or currently are encountering) in medical school, and ways you have addressed these challenges. I am hoping a key outcome of this study will be to strengthen support services available to students in medicine, particularly those with disabilities by centering the perspective of students.

## **Consent**

This interview will last approximately 45 minutes. I will be using a digital recorder on my phone, so I can accurately reference our conversation. The recording will be used by me only and not be shared with anyone else. I will use a pseudonym for you, your school as well as any individuals you name. The transcript will contain no identifying information and will not be shared with anyone else. If at any point in the interview you would like me to stop recording, please let me know.

Some questions may focus on sensitive topics related to the nature of your disability and your experiences dealing with specific challenges related to your disability. If you are uncomfortable answering any questions, please feel free to let me know and we can move on to the next question.

Do you have any questions before we begin? Great, let's begin.

### **Background:**

Just want to confirm: are you ok with having this interview recorded?

1. What inspired you to pursue a career in medicine?

Listen and ask for elaboration, particularly if it relates to disability.

- 2. How has medical school been for you so far? Is it what you expected it would be?
- 3. What would you say was the biggest adjustment to medical school from college/previous work/educational experience (if anything)?

## Disability status, experiences and challenges:

**Bridge:** As you know this study is on exploring the perspectives of students with disabilities in medicine. I want to switch gears and ask about your experiences as it relates to your disability, if that's ok.

- 4. Could you tell me more about your disability?
- 5. How would you say that your disability has impacted your experience as a medical student so far, if at all?

**Transition:** You mentioned that one of the biggest challenges has been x – that relates to the next topic I wanted to explore...

Or

**Bridge:** now I want to explore some different aspects of the challenges you indicated you experienced during medical school.

Let's start with academics (studies, testing, time management, etc.):

6. In the survey, many students say they experienced academic challenges related to their disability.

Could you tell me more about any academic challenges you experienced? How would you say your disability is related to these challenges?

Probes: When did they occur?
Why do you think they occurred?
How did you respond to these challenges?

**Bridge:** I'd like to know talk about the institutional challenges (if not discussed above) you experienced:

Institutional (applying for and receiving accommodations for in-house or USMLE exams, working with faculty or administration, accessing resources, disclosing a disability to seek support):

7. A number of students indicated they experienced specific institutional challenges. Which of these challenges, if any, did you experience?

Probes: When did they occur? Day to day Why do you think they occurred? How did you respond to these challenges?

Finally, I wanted to go over some of the personal and social challenges you experienced: belonging, social, interpersonal, familial, etc.

8. On the survey, I asked if students experienced personal institutional challenges. Some of these include: finding community, dealing with the stigma of having a disability, questioning whether I belong in this program, discrimination, prejudicial or insensitive treatment by faculty, staff or classmates, questioning career direction, physical healthwell-being, mental health and well-being, financial hardship. Could you share with me any specific personal challenges you may have experienced, if any?

Probes: When did they occur?
Why do you think they occurred?
How did you respond to these challenges?

9. How were the challenges you experienced in medical school different, if at all, from challenges you experienced in college or previous educational and work settings (i.e., college, post-bac, master's program) before medical school?

## **Ways Students Navigate and Overcome Challenges**

**Bridge:** Thanks so much for sharing about your experiences so far. We talked about the various challenges you experienced so far. It sounds like you made a number of adjustments when entering medical school (list specific and probe).

Now, I want to go over ways you have navigated these challenges, particularly the challenges that related to your disability, and how you addressed these challenges.

- 10. For example, you mentioned that in response to some of the academic, institutional or personal challenges, you (did X, action). Could you tell me more about that?
- 11. To what do you attribute your ability to navigate/address, or overcome these challenges?

Probes:

What factors, if any, encouraged you to seek support for your disability? What factors, if any, discouraged you to seek support?

If resources are not mentioned in question #11: or ask for elaboration.

12. On the questionnaire students indicated they used a number of resources or support services during medical school. Were there any particular resources you found helpful in dealing with the challenges you experienced (outlined above)?

How were they helpful?

Probe: What personal experiences prior to medical school (cultural, social, parental, etc.), if any, do you attribute to your ability to navigate challenges related to your disability during medical school?

Probe: Could you elaborate specifically on: Peer support

Family support

Faculty
Mentor(s)
The impact of role models or any other influential individuals
Other?

13. What factors that haven't already been discussed have helped you deal with these challenges? (if not already elaborated above)

If not already discussed above #6-8, summarize back and/or ask for elaboration based on what was previously shared in terms of challenges:

#### Probes:

What actions did you take to address these challenges, if any? What strategies did you take to address these challenges, if any? How did you adapt to these challenges, if at all?

**Bridge:** It's clear that you have adopted a lot of different ways of dealing with the challenges you've encountered in medical school as it relates to your disability.

14. How did your approach to navigating these challenges as it relates to your disability differ (if at all) from the approach you took in college or previous educational (or work) environments?

Probe: Why do you think that is?

15. Is there anything else related to your experience as a medical student that we haven't discussed yet that you'd like to share?

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