Disability Inclusion and Accessibility in Biomedical Research

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Abstract

Disabled people are the largest minoritized group in the United States, however, they are frequently left out of conversations surrounding diversity, equity, and inclusion. Disabled communities are significantly affected by biomedical research, yet they are severely underrepresented in the STEM workforce. This underrepresentation is also made evident by the general disconnect between the desires of disabled communities and the goals of biomedical research. This study sought to determine what factors contribute to the lack of disability representation in biomedical research and to understand the experiences of disabled biomedical researchers. Four biomedical researchers with disabilities were interviewed about their experiences in research related to accessibility and their perceptions of disability inclusion. In collecting these perspectives, I aimed to increase awareness of inaccessibility in biomedical research and make recommendations to improve accessibility and disability inclusion.

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Introduction and Background

Representing over a quarter of the US population, disabled people are the largest marginalized group in the country, yet they are constantly left out of conversations about diversity, equity, and inclusion (DEI) (Brinton & Bernard, 2022; CDC, 2024a). In 2023, the Bureau of Labor Statistics found that only 22.5% of working age people with disabilities are employed compared to 65.8% of people without disabilities (US Bureau of Labor Statistics, 2024). In the 2019-20 school year, 21% of all undergraduate students report having a disability, but only 9.1% of doctoral degree recipients reported having a disability (National Center for Education Statistics, 2020; National Science Foundation, 2019). Despite the fact that 28.7% of American adults meet the criteria for one or more disabilities, disabled people make up only 3% of the total STEM workforce (CDC, 2024a; National Science Foundation, 2023). Disabled people should be included in STEM as a whole, but it is of particular importance to increase disability representation in biomedical research.

Biomedical research refers to the body of scientific research concerned with developing an understanding of the biological systems that control human life with the goal of improving treatments and diagnostic tools (Chameettachal & Pati, 2017). While disabled people are significantly affected by biomedical research, their lived experiences are rarely incorporated into the research process. Non-disabled researchers and clinicians make assumptions about the needs of disabled individuals and populations, and these assumptions are often inaccurate at best and harmful at worst (Hammell, 2006).

As Eli Clare, a disabled, genderqueer activist, describes, medical institutions contribute to the pervasive view that disabled bodies are inherently medicalized (Clare, 2017). The medical model of disability frames disability as a problem with the individual that needs to be “fixed” rather than a natural variation of human experience. This model of disability is intrinsically tied with the definition of the normate subject (a privileged cisgender, straight, white, non-disabled man) as the gold standard of human experience against which all others are compared (Garland-Thomson, 1997). This model places no responsibility on the communities that surround disabled people, and it portrays non-disabled ways of being as superior to disabled life. The framing of able-bodied and neurotypical states as superior lays the groundwork for ableism (Jammaers et al., 2016). The medical model of disability perpetuates the perception of disability as inherently negative when it is really neutral (Silvers, 2003). The social model, on the other hand, does not view non-normative body-minds as inherently disabling; this model demonstrates that inaccessibility creates disability (Brinton & Bernard, 2022). According to the social model, it is not the responsibility of the individual to fundamentally change themselves to fit into the ableist, normative standards of existence. The social model instead places the onus for change on the communities that disabled individuals live in and calls for a dismantling of the ableist structures that are perpetuated by society at large.

A societal shift is necessary to improve accessibility and quality of life for disabled people, but the reality is that disability cannot be neatly separated from the medical. Many disabled people rely on medical institutions for healthcare, but this care often lacks a disability-informed approach (McBride-Henry et al., 2023). Despite popular misconceptions among non-disabled people, medical interventions for disability should not aim to eradicate disability through “cures” (Brinton & Bernard, 2022; Clare, 2017; McManus, 2013). The idea of “cure” relies on the concept of a restoration to a previous, non-disabled state, but for many disabled people this state simply does not exist or is no longer reflective of the person they have become through their experiences of disability (Clare, 2017). Cure has also historically served as a tool for oppression as it allows people in power to label anything that differs from the normate subject as a “sickness” (Clare, 2017). Many disabled people view their disability as part of their identity, so they do not want a cure that would allow them to fit neatly into the normate model (Clare, 2017; Dunn & Burcaw, 2013). Despite this acceptance of disabled identity, some people do desire symptom relief from pain and struggles that they experience even in accessible spaces (Burdick, 2022; Clare, 2017). It is necessary to both recognize the injustices disabled communities face and to have empathy for those that desire tools for symptom management.

Biomedical research holds the potential to create exciting adaptive technologies and treatments that help to provide the comfort that some disabled people are looking for. Despite this potential, biomedical research currently does not meet the needs of disabled communities. The medical and research realms are overwhelmingly dominated by non-disabled people, and there is often a clear disconnect between the desires of disabled communities and the innovations pushed by non-disabled researchers (Kitchin, 2000). Even research that works directly with disabled subjects rarely provides an opportunity for participants to provide feedback about the research (McDonald et al., 2013). In this thesis, I hope to address the gap that exists between biomedical research and disabled communities by sharing the experiences of people who exist at the intersection of the two worlds: disabled biomedical researchers. As expected, my interviews demonstrated that biomedical research does not currently address the true needs of disabled communities as researchers or as patients.

The disconnect between research and disabled communities presents an unwanted threat to the existence of some disabled communities and leaves others without the funding and support that they need (Brinton & Bernard, 2022; Lane, 2005). Medical institutions pathologize disabled ways of being that are best understood as natural variations in human experience (Baar, 2017).

This unwanted pathologization results in the portrayal of non-normative ways of being as inherently in need of “repair.” This narrow perception is not equipped to address the genuine struggles that disabled people face that could be improved through biomedical research (Rabiee & Glendinning, 2010). The only way to bring research into alignment with the needs of disabled communities is to involve disabled individuals and communities in research. It is not sufficient for this involvement to only take a passive role; it is essential that disabled researchers be involved in every stage of the production of new knowledge.

The National Institutes for Health (NIH) recently began to push for increased disability representation in biomedical research. This effort began with the establishment of a subgroup focused on individuals with disabilities within the diversity working group. The group quickly found that they could not truly address the underrepresentation of disabled researchers without addressing the health disparities that disabled people face (Brinton & Bernard, 2022). Biomedical institutions frame disabled people as the passive recipients of care, yet disabled people frequently do not receive the care that they need and deserve (McBride-Henry et al., 2023). In 2023 the NIH declared disabled people a population with health disparities (Calman & Barnes, 2023). This designation was given for a range of reasons, not the least of which include lack of access to care, lack of accessibility, and intersections with other social drivers of health. Disabled communities also report a lack of satisfaction with care and experiences with ableism (Calman & Barnes, 2023). In order to fill the gaps in healthcare for people with disabilities, it is essential to increase disability inclusion in research because disabled researchers are best equipped to recognize the needs of disabled communities (Brinton & Bernard, 2022).

The establishment of the NIH working group was an important place to start improving disability representation and accessibility in biomedical research, but they did not collect personal stories from disabled researchers. Interviews have been used to explore the experiences of disabled academics in the humanities and social sciences, however, to my knowledge there have not been any that have focused on the experiences of disabled biomedical researchers (Mellifont et al., 2019). A preprint was released earlier this year investigating the accessibility barriers that disabled scientists encounter in academia, however, this study did not exclusively feature biomedical researchers and did not include early career scientists in training (Castro et al., 2024). Calls for improvements in access and inclusion for disabled biomedical researchers are beginning to enter the mainstain scientific press; however, there is still a long way to go to meet the needs that have been expressed (Niedernhuber et al., 2021; B. Swenor & Meeks, 2019; Yerbury & Yerbury, 2021). My own realization that disability inclusion is essential for the improvement of biomedical research has had a significant impact on the ways in which I understand the pursuit of knowledge.

My sophomore year of college, I read excerpts from Eli Clare's *Brilliant Imperfection* for a class on critical disability theory. I had first begun my entry into the world of biomedical research the summer prior to reading this work, and I loved my experience. I worked on a project investigating the involvement of dopamine signaling in decision making, and I was exposed to a wide range of other research topics through presentations by others in my cohort. Throughout this experience, I heard time and time again about how our research had the potential to improve the lives of people living with a range of diseases and disorders, and I believed it. I still do believe that biomedical research has the potential to make a significant positive impact on people, but I realized that this potential cannot be realized without reconsidering the goals of our research.

In my experience, the underlying assumptions that drive biomedical research often go unquestioned and unchallenged. For example, the quest to identify a genetic cause for autism has been a popular research topic for years (Zafeiriou et al., 2013). While there are some potential benefits that could arise from genetic research about autism, autistic communities have raised valid concerns. Many autistic advocates worry that this research could be used for eugenics if the proper safeguards are not in place (ASAN, 2022). Despite the prevalence of genetic autism research, few non-disabled people step back and question who it would truly benefit to determine a genetic cause of autism. How would solving this "mystery" improve the lives of autistic people? What is defined as "improvement"? Is genetic research the best use of funding to support autistic individuals? Since the people who stand to gain or lose the most from biomedical research are often excluded from scientific pursuits, these questions go unanswered.

Through this thesis, I aim to identify how the field could be made more inclusive and accessible. By improving accessibility and disability inclusion, it will be possible to conduct research that is truly beneficial to disabled communities. When I began this work I sought to answer four primary questions:

1. Is inaccessibility responsible for the dearth of disabled researchers in biomedical fields? If not, what is, in the experience of the people I interview?
2. Do disabled voices guide the direction of biomedical research?
3. Does the disability someone has correlate with the amount/type of barriers they encounter when entering or staying in the field?
4. What recommendations can be made to improve accessibility in the biomedical research field?

I anticipated that the experiences of the people I interviewed would vary, but I expected to find some common themes across the interviewees' experiences.

I hypothesized that in my interviewees' experience, the lack of representation of disabled researchers is due to four main causes:

1. Prohibitive access barriers in early career training required to become a researcher.
2. The cultural normalization of inaccessible and ableist demands on energy and physical ability in biomedical research.
3. Limited availability of accessible lab spaces due to associated funding constraints.
4. Underreporting of disabilities due to a fear of prejudice.

I hypothesized that the lack of representation of disabled researchers was due to a lack of accessibility since disabled students display similar rates of interest in STEM fields as their non-disabled peers (Pfeifer et al., 2023). Since there is not a difference in early interest, then it stands to reason that the underrepresentation in biomedical research is a result of the access barriers disabled people encounter in education and training (Dutta et al., 2015; Hong, 2015). Biomedical research is notorious for its intense work culture and "publish or perish" mentality (Boitet et al., 2023; Rawat & Meena, 2014). This work environment is extremely harmful for disabled and non-disabled researchers alike, with nearly half of researchers reporting high levels of distress due to a broadscale lack of support and unmanageable workloads (Boitet et al., 2023). This lack of support for wellness is indicative of an inaccessible work environment, so these cultural norms are likely hostile to biomedical researchers with disabilities and contribute to the lack of representation.

I hypothesized that disabled biomedical researchers face additional funding barriers and struggle to find accessible lab spaces based on my own observations. If there are some tasks that a disabled researcher struggles with because of their disability, then a lab would need additional funding to hire lab assistants to complete those tasks. I have also noticed that the majority of the labs I have worked in are not physically accessible, so funding would be required to make adjustments to the physical space. I also suspected that the lack of representation of disabled researchers is in part due to an underreporting of disability. Many people choose not to disclose their disabilities in the workplace due to discrimination, and this sentiment has been echoed by researchers (Castro et al., 2024; Sherbin et al., 2017).

Based on the underrepresentation of disabled biomedical researchers in the field as a whole and the disconnect between biomedical research and disabled communities, I predicted that interviewees would report that disabled voices do not currently direct biomedical research. With respect to my third question, I anticipated that the type of disability researchers have would influence the types of access barriers that they encounter. This expectation was based on the findings of previous research that people with visible and invisible disabilities face different types of stigma (Moriña, 2024; Saal et al., 2014; Ysasi et al., 2018). Before I conducted the interviews, I anticipated to recommend that biomedical research institutions should increase consultation with disabled communities, improve the physical accessibility of lab spaces, and address ableist cultural norms.

Personal Connection

Disability has been part of my life in various forms for as long as I can remember. My twin sister is autistic and non-speaking, and growing up together I was exposed to many of the unique challenges that disabled people face. One of the most salient challenges was the difference I observed in our education. I recognize that the scientific opportunities that were presented to me in mainstream schooling were very different from those that were presented to her in special education settings. I have also observed the negative and blatantly incorrect assumptions that many non-disabled people make about disabled people. Many non-disabled people readily doubt the intelligence and capabilities of disabled people just because they interact with the world in an “atypical” manner.

During my sophomore year of college, I also began to experience my own medical challenges, and this forced me to consider my own position within the disabled community and relationship with invisible disability. I am lucky in that I have never felt entirely dissuaded from participating in research due to my medical issues. This being said, I have also found myself in positions where I felt as though I had to grit my teeth and bare it or push myself in ways that I knew would make me feel worse. I chose to attempt to “power through it” for fear of being perceived as unreliable or not caring about the project. I have also faced instances where my capabilities were called into question when I requested flexibility due to my health challenges. While I have faced barriers and struggles because of these experiences, I have also been afforded the opportunity to connect with many of the researchers that I interviewed for this project due to shared experiences. I am thankful for the awareness of disability in the world around me that I gained from my sister’s and my own experiences and for the opportunities to refine this awareness through my educational exposure to disability theory.

As I’ve become more enmeshed in the world of biomedical research, particularly preclinical work, it has become abundantly clear how separated our experiments can feel from the humans they will affect. Scientists often fall into the trap of viewing science as a purely objective venture, but I believe that it is paramount to consider the far-reaching implications of science for marginalized communities. As a Black, queer woman I am no stranger to being in the minority, yet it is my experiences with health challenges that have had the most salient impact on my feeling of acceptance in biomedical research. The positive experiences that I have had boosted my confidence and passion for my work. Experiences of inaccessibility and lack of understanding have been enough to make me consider leaving research. I do not want disabled researchers to feel alone in their struggles, and I want to help bridge the gap between research and disabled communities and individuals.

Methods

I recruited participants for this study by reaching out directly to colleagues and mentors that I have met through a range of educational and research experiences. The participants had all previously disclosed their disability to me either publicly or privately prior to their interview. Inclusion criteria were that participants are currently pursuing a career in biomedical research or they strongly considered a career in biomedical research but did not pursue it due to access barriers and/or the lack of disability inclusion. Their experiences reflect a wide range of career stages, however, there is an evident bias towards those involved in neuroscience research, as that is my area of study. Participants' preferred language for their disabilities and disabled identities varied, so terminology was adjusted accordingly during the interview and in their respective chapters. Three of the four participants have invisible disabilities, and one (HS) has a somewhat visible disability that she is often able to mask to some degree. Participants' names have been changed to reflect their current career stage and/or training.

Participants were asked a set of 13 pre-planned questions and relevant follow up questions that arose throughout their interviews (Appendix A). Participants were given time to think about their answers before moving on to the next question. When participants' answers did not directly answer the original question I posed, I let the interview follow their lead. I made this choice to allow for the opportunity to learn about thoughts and experiences that I did not anticipate when writing the interview questions. My presentation as a soft spoken and unintimidating woman and my own experiences with health challenges likely contributed to participants' comfort in opening up to share their experiences. All responses were sorted into the four categories based on the research questions described in the introduction.

Participant Demographics:

Name	Career Stage	Disability	Race	Gender
BA	Undergraduate student	Chronic illnesses	White and Asian/Pacific Islander	Nonbinary
DS	PhD student	Arthritis	Hispanic, Indigenous, and White	Woman
TF	Tenured faculty	Dyslexia, hearing loss, auditory processing issues, and chronic pain	White	Man
HS	Undergraduate student*	Post-stroke	White	Woman

* HS considered a career in biomedical lab research, but she decided not to pursue it while in high school due to access barriers.

Undergraduate Student: BA

BA (she/they) is an undergraduate student at a small liberal arts college. She has been involved in research for four years. Their research has covered a wide range of subjects including neuroendocrinology, public health, environmental studies, and psychophysiology. In the biomedical realm, they are interested in researching the maintenance and management of chronic illnesses as well as clinical work regarding stigma reduction. Their experiences reflect those of an early career scientist who has been interested in research since high school, and this interest began with a focus in medicine.

Their research interests are varied and relate to both their own experience and those of others who they are in community with. They are interested in the broader systems that impact health outside of a specific diagnosis and in addressing health concerns at their root cause. This awareness of the roots of disabilities and desire to research how to improve the management of chronic conditions speak to the valuable perspectives that disabled researchers bring to the conversation. While a large portion of research conducted by non-disabled people focuses on cure, BA focuses more on symptom relief and acknowledges that a single treatment is unlikely to “fix” someone’s disability.

They align themselves with disability communities and view those spaces as more accepting and as a refuge from ableism they face in other environments including life in higher education and research spaces. They are vocal about their desire to decrease stigma surrounding disability and mental health conditions, and they are currently involved in advocacy work to raise awareness and educate others. They self-identify as having a disability or being “differently abled,” and they prefer person-first language rather than the term disabled. Their choice in labels is a way to emphasize their abilities as a capable researcher since others perceive their disability as a reason to view them as unreliable.

Question 1: Is inaccessibility responsible for the dearth of disabled researchers in biomedical fields? If not, what is in the experience of the people I interview?
Response: BA has struggled with inaccessible expectations of work hours, progress, and deadlines. They are often pulled to work in a rigid fashion and expected to take on excessive lab responsibilities in addition to making progress on their thesis. While they are grateful for everything they've been offered, they have also had opportunities taken away from them due to misunderstandings surrounding their accessibility needs. For example, they were strongly pushed to change their senior thesis project and "lower their expectations" because their advisor did not believe that they would be able to deliver work on the level required to complete their original project. Their advisor's belief reflects a trait based stereotype that generalizes the severity of their illness to all parts of BA's identity. Their thesis advisor spoke to them in a way that insinuated that they should be grateful for even being allowed to work with her. BA's advisor also accused them of a lack of progress and communication, when in reality, these updates were sent to the advisor's inbox and ignored. BA has had to downplay the effect of their disability because people view bringing up their symptoms as an excuse. She has also found that even when professors don't have a negative reaction to her disclosing her disability, they suggest going to student disability services and tend towards more formal, solution oriented approaches. Many professors, even those with well-meaning intentions, decrease their expectations of her after she discloses her

disability. People also tell BA that they're doing too much even though they do not feel as though their responsibilities are being what they can handle. BA does not need to do less, others just need to accept that she makes progress in a different way: often in a non-linear fashion with bursts of productivity when her symptoms are lower and a need for breaks during flare-ups.

Inaccessible work hours and expectations have played a role in the barriers that BA has faced, but a lot of these issues are more directly related to others' perception and stigmatization of disability. When BA is not able to meet deadlines as expected they are interpreted as not caring or not having a strong work ethic. These interpretations are not reflective of BA's work ethic, instead non-disabled people are forcing their own assumptions about BA.

BA is often forced to disclose their disability to access accommodations or to respond to assumptions about their work ethic and investment in their projects. This disclosure places them at risk for further discrimination because people decide that they can't handle their projects even though the problem is the expected timeline of the work, miscommunication, or lack of supportive guidance. In this regard, much of the inaccessibility that BA faces stems from a lack of awareness of the normative expectations that are tied into the culture surrounding biomedical research. Within disability communities, there is a greater understanding of the fact that different people need to work differently, and this is often referred to as "crip time" (Samuels, 2017). Spaces designed for and by non-disabled people do not leave room for flexibility that both disabled and non-disabled people would benefit from. Non-disabled researchers perceive disability as a limitation of BA's capabilities to succeed/accomplish tasks but this is not the correct response.

Question 2: Do disabled voices guide the direction of biomedical research?
Response: To BA’s knowledge, disabled people are not involved in determining the directions of their current lab’s research, or even if there are, there is a lack of acceptance of disability as an identity. It should be noted that as an undergraduate, they do not have a significant say in the way that their lab’s research projects are developed (which is typical of an undergraduate institution). Looking into the future, BA wants to include other people with disabilities in their work and create a more welcoming environment. Many of the research projects that they are interested in taking on or that they are independently working on directly stem from their personal experiences of disability.

BA hopes to center disabled voices in their own future research, so there is potential that early career researchers with disabilities will be able to make a difference in disability inclusion throughout their career. However, at present, people who are early in their research careers are forced to work within the bounds of their current position, so they are not able to make a large scale change in this present moment.

Question 3: Does the disability someone has correlate with the amount/type of barriers they encounter when entering or staying in the field?
Response: BA’s disabilities are invisible chronic health conditions. They experience symptoms that affect their ability to see, impact their energy levels, influence fundamental procedural movement, and at times they struggle to remember and think clearly. Due to these

symptoms, they rely on notes. In research meetings she is often expected to respond to questions and prompts on the spot, but this approach is not the most accessible for her. They often find themselves knowing how to answer questions, but are unable to articulate it within the clarity that exists in her head. Other researchers often use the ability to respond to questions on the spot without referencing notes and convey information in a manner that reflects a “standard” linear way of thinking as a measure of intelligence. As a result of others’ assumptions, many of her requests for accommodation are interpreted as personal failures and/or a lack of commitment and work ethic.

I believe that the fact that BA’s disabilities are invisible leads non-disabled people to make character-based assumptions about BA’s symptoms. BA masks their disability often and (anecdotally) pretty convincingly, so when her symptoms flare up for an extended amount of time, supervisors assume that BA is electing not to work rather than handling symptoms of her disability that often consume the majority of her time. There is a widespread notion among non-disabled people that disability is almost always visible, but in reality many people deal with more dynamic disabilities that vary in severity over time (Benness, 2019). This lack of understanding of dynamic and invisible disability leads non-disabled people to evaluate disabled people based on their best days or worst days as opposed to accepting whatever symptoms a person is experiencing on a given day and responding accordingly.

Question 4: What recommendations can be made to improve accessibility in the biomedical research field?

1. Increase inclusion of people with disabilities in higher education, and make the overall environment more accepting and welcoming.
2. Create more and improved policies at a systemic level with equal input from disabled people. This input should include intersectional and intergenerational collaboration.
    a. Improved policies could include the incorporation of more disability awareness and accessibility training.

BA's experiences reflect the effects of inaccessible expectations, struggles with unhelpful responses to disability disclosure, and experiences with prejudice. They have been denied educational opportunities as a result of ableist perceptions of their capabilities and misunderstandings of what it means to have a disability. They also have been shamed for suggesting that ableist tendencies exist. The solutions BA proposed for improving accessibility in biomedical research boil down to increased representation and inclusion and the development of policies that reflect the genuine needs of researchers with disabilities. This work should include not only researchers at more advanced career stages, but also early career researchers. There should also be an active inclusion of researchers from a range of backgrounds. These suggestions are representative of the adage "nothing about us without us" which is the underlying message of many liberation movements. The phrase was first coined by the South African disability rights movement and it asserts that decisions about disabled people cannot be made without the proper inclusion and centering of disabled voices (Charlton, 1998). As it stands today, biomedical research institutions do not abide by this mentality, so it is imperative that the system changes to accommodate the wills of disabled people and the active participation of a large community of researchers with disabilities.

Doctoral Student: DS

DS (she/her) has been involved in biomedical research for just under four years. She is currently a PhD student at a large university, but she is seeking to transfer degree programs. Her research is centered in substance use disorders/addiction in rodent models. In the future she is interested in studying the role of neuroinflammation in addiction. Her experiences are reflective of an early career researcher who has made it through the access barriers that undergraduate education presents and who has encountered many access barriers during graduate school.

In our conversation, DS and I made some interesting observations about the ways in which addiction overlaps with disability. Addiction/substance use disorders generally are not viewed as disabilities in and of themselves even though addiction and its physical effects can be disabling. This separation of addiction from disability may be due to the fact that blame is often assigned to people experiencing addiction rather than recognizing the biopsychosocial influences on the development of addiction (Amaro et al., 2021). This difference in perception may speak to the prevalence of a purely medical model of disability in research spaces that is not well informed by social determinants of health such as race and socioeconomic status that increase the likelihood of developing a disability (CDC, 2024b; Courtney-Long et al., 2017; Dorsey Holliman et al., 2023).

Since drug addiction often arises from the effects of systemic issues, addiction may be better understood as a disabling experience through the social model of disability. People experiencing addiction are often pushed to the margins of society and do not have access to the necessary support for improved quality of life (Ingram et al., 2020). This marginalization is similar to the health disparities and isolation that disabled people face (Macdonald et al., 2018). While this discussion is outside of the scope of this thesis, I think that it is important to acknowledge the fact that disability studies-informed perspectives could reshape the way that biomedical research as a whole is conducted.

DS and I also discussed the notion of a disabled “community.” In DS’s experience, it is difficult to make connections with other disabled people in research since there are not that many people who openly disclose their disability status, and many people have invisible disabilities so she finds herself looking out for subtle cues. In the lab when someone in the lab complains about back pain she is curious “Are you like me, or are you not?”

Question 1: Is inaccessibility responsible for the dearth of disabled researchers in biomedical fields? If not, what is in the experience of the people I interview?

Response: DS experiences discomfort with disclosing her disability and tends to frame her needs to labs as having “health concerns” rather than calling it a disability. She often needs to modify her work to accommodate herself (eg: focusing on data analysis remotely rather than data collection in person), but she is uncomfortable disclosing her disability since naming it draws more attention to it. DS sometimes feels pressure to “play up” when she is feeling sick so that people see her need to stay home at times as valid and justified.

In her current lab, she has found that her research mentor (principal investigator: PI) has a very narrow idea of what a “hard working” person is, but this definition is ableist. For example, her supervisor expects that researchers maximize the amount of time they spend collecting data in person in the lab even when there are other, less physically demanding, productive tasks that need to be done. DS would benefit from more of a sliding scale of expectations.

DS's favorite part about research is the bench work (ie: carrying out experiments), and she thinks that the physical limitations of her disability will eventually limit her ability to continue working at the bench. Having a more accessible work environment may extend the amount of time that she is able to continue this work in the long run. DS hopes that despite the access barriers in training, earning a PhD will give her some flexibility in her career options. When she isn't able to do the bench work anymore, she will still be an asset in other elements of lab work such as data analysis.

The accessibility barriers that she has encountered in her journey to becoming a biomedical researcher have not been restricted to experiences in the lab. As an undergraduate she encountered several issues with housing (since the honors college was not accessible) and parking accommodations. As a graduate student she has continued to face access barriers in the physical design of lab spaces and a lack of accessible, affordable parking. She has also encountered financial challenges since graduate students are underpaid, and she has additional medical bills due to her disability.

DS has predominantly encountered physical and cultural barriers, but she has also dealt with additional disability related financial stressors. The cultural barriers are intertwined with ableist notions of productivity that are defined by consistent maximal output. This expectation of constant "peak performance" is unreasonable and largely unattainable for both disabled and non-disabled researchers. Like BA, DS finds the physical demands imposed by supervisors that subscribe to this definition of productivity to be inaccessible, and her approaches to accommodating herself are perceived as laziness. Some disabled researchers, like DS, are wary of disclosing for fear of discrimination or unwanted attention, but it is difficult to access formal accommodations without disclosure. This lack of accommodation may also shorten the careers of disabled researchers by creating unnecessary physical strain that could be prevented by creating truly accessible work environments.

Ableist standards of what it means to be a "hard worker" leads to non-disabled researchers to look down upon disabled researchers for working differently. This can only be combated by challenging the perception of what hard work and productivity look like. This focus on what researchers "should" do to contribute also limits the development of creative accessibility solutions, but, as DS pointed out, physically disabled researchers still have valuable skills to contribute in less hands-on work like data analysis.

The financial barriers that DS has encountered also represent an intersection between disability and socioeconomic status as barriers in higher education. While PhD students receive an annual stipend during their training, this income is often below the living wage and this does not account for the significant additional costs associated with living with a disability (A. Carlson, 2023; Goodman et al., 2020). In order to make graduate education truly accessible, students need to be paid a wage that is sufficient to cover their living and medical expenses.

Question 2: Do disabled voices guide the direction of biomedical research?
Response: DS believes that disabled people bring a lot of personal experience to the table that non-disabled researchers are not in touch with. As the inclusion of disabled voices relates to her own current research, while she has not personally experienced addiction, she has family members that have experienced addiction. Working with animal models can sometimes lead to a disconnect between the work and the actual patient populations that it will impact, so she

stays involved in addiction-support spaces to maintain that connection.

DS has arthritis, and she is interested in researching the link between neuroinflammation and addiction. While her arthritis was not the sole reason for her interest in neuroinflammation, research has uncovered a link between conditions that cause inflammation (like arthritis) and depression. Addiction research is also relevant to people dealing with chronic pain conditions since opioids are highly addictive, but they are effective pain relievers. The relationship between opioids and pain management did in part influence her decision to research addiction and her addiction research has influenced her choices for pain management.

There is not currently a formal avenue for people experiencing addiction to be involved in DS's lab research. As an individual, DS makes a concerted effort to maintain an awareness of and a connection with the people that her research will impact. It was particularly interesting that DS not only uses her experiences to contextualize her research but her research also influences her decisions for symptom management. This suggests that broader inclusion of disabled people in research would not only benefit specific disabled communities but also provide an opportunity for disabled communities to learn from one another. Even though DS has not experienced addiction, as a disabled researcher she is in a unique position to identify some implications and uses for research that non-disabled researchers would miss.

Question 3: Does the disability someone has correlate with the amount/type of barriers they encounter when entering or staying in the field?

Response: DS has arthritis which is invisible, but she also experiences additional judgment due to being plus size. This combination of factors leads people to assume that her access needs are laziness. Much of the pressure to downplay her disability arises from an internal pressure rather than explicit pressure from other people.

DS also noted that while graduate students are expected to work in inaccessible lab environments, faculty offices are equipped with standing desks as the standard.

Similar to BA, DS faces assumptions that her symptoms of disability and need for accommodations are due to laziness in part due to the fact that her disability is invisible. DS also faces additional discrimination and judgment as a result of the intersection between ableism and fatphobia (Binder, 2023). Both of these forms of discrimination, as well as racism, are rooted in the fact that white, skinny, non-disabled body-minds are upheld as the norm and as superior (Smith, 2016).

The lack of accessibility in lab spaces in contrast to the accessibility of professors' offices may be a result of the intersection between ableism and ageism. Labs are mainly staffed by young graduate students, and there is an assumption that all young people are physically able (Gutterman, 2023). This indicates that it is not simply the type of disability that a person has that determines the access barriers they face but also the ways in which their disability interacts with their other identities like race, gender, age, class, etc.

Question 4: What recommendations can be made to improve accessibility in the biomedical research field?
1. Have more open dialogues about disability and providing spaces for community building. 2. Create resources for PIs and grad students on how to navigate disability. 3. Make it a cultural norm to ask if people have access needs/how anything can be improved to accommodate them. a. Asking makes people feel more welcome and takes some of the pressure off of disabled people to have to initiate the whole process to get accommodations and handle it alone 4. Modify attendance policies to be more accessible.

DS's experience reflects some of the challenges that early career researchers face in finding accessible work environments, the ways in which different forms of discrimination and marginalization intersect with ableism, and some of the isolation that disabled researchers face. Fostering community between disabled researchers may make the space more accessible for current disabled researchers and make the environment more welcoming for future researchers. Increasing awareness of disability and shifting the culture towards one that preemptively considers access needs will also remove some pressure from disabled researchers to be the sole advocate for their needs.

Tenured Faculty: TF

TF (he/him) is a tenured faculty member at a large state university. He has been involved in research for 32 years. He started off in engineering research, but he transitioned to hearing research during college. He has auditory processing issues, dyslexia, and hearing loss. Throughout his career he has had to find ways to accommodate himself and advocate for access to the accommodations that he needs. As a faculty member, there are limited resources for disability accommodation even though accessible work environments are supposed to be ensured by the ADA (Americans with Disabilities Act, 1990). TF has an interesting perspective as a person with multiple disabilities. Even though his disabilities are all invisible disabilities, there are clear differences in how willing his colleagues and supervisors are to provide necessary accommodations for different access needs. His experiences also reflect the effects of the normalization of suffering that is built into biomedical research training that leads to a lack of understanding of access needs.

Outside of laboratory research, he is heavily involved in DEI efforts within his university. In his role as a DEI advocate, he has made a conscious effort to include disability as a feature of diversity and accessibility as an important consideration for inclusion. He has also served as chair of the external relations committee, and during his time in the role he led efforts to improve communication between researchers studying hearing and the Deaf community. The initiative he led while in this position may both serve as a template for future outreach efforts to disabled communities and provide an opportunity for reflection on how to improve the success of these efforts.

Question 1: Is inaccessibility responsible for the dearth of disabled researchers in biomedical fields? If not, what is in the experience of the people I interview?

Response: TF has not been explicitly told he should hide his disabilities, but his job often requires a significant amount of reading, so he feels a lot of embarrassment surrounding his dyslexia. As a faculty member and senior researcher, TF is expected to read grant proposals for study sections, but due to his dyslexia it takes him more time to read than his non-disabled colleagues. During study sections he is often assigned more grants than he can read in a reasonable amount of time. TF often uses text-to-speech software to make reading more accessible, however, he has to pay for this software himself. Early on in his career, his supervisors told him that he would need to “get over it” and find a way to read all of the grants. Now, when he is asked to serve in study sections he tells his supervisor that he will only read ⅓ of the number assigned to everyone else as an accommodation.

TF was diagnosed with dyslexia in adulthood after his son was diagnosed. Both in his own experiences with inaccessibility during his education and in advocating for his son he has become very familiar with the range of access barriers in academia. With respect to dyslexia specifically, he has found that as technology has advanced, people have been able to get further and further into their careers and education before hitting a wall. While there are more resources available for dyslexia in K-12 settings, it is more difficult to find accessible textbooks in higher education. This lack of accessible textbooks directly contributed to TF’s son’s choice not to continue studying biomedical engineering.

When TF has advocated for accommodations for his lab space and reading materials he has encountered resistance from the university. Despite their resistance to accommodate the needs of current faculty members, the university has made insincere attempts to increase accessibility without actually listening to disabled researchers. For example, the lab facilities were remodeled to incorporate wheelchair height sinks, however, these sinks are not actually deep enough to safely wash experimental materials. The remodeling also did not incorporate any accessible lab benches, so the lab would still not be accessible for a standard wheelchair.

Like DS, TF has encountered access barriers in physical lab spaces (see question 3) as well as ableist assertions that disability is something that needs to be overcome rather than accommodated. Due to his position as a tenured faculty member, TF has additional research-related responsibilities that early career researchers may not be aware of. These responsibilities, like serving on study sections, present additional access barriers and these tasks are not representative of one's capabilities as a researcher. The access barriers created by these responsibilities may limit the advancement of some disabled researchers' careers. The lack of access in undergraduate and graduate education plays a direct role in stopping some people, like TF's son, from pursuing careers in biomedical science.

TF's experiences also make it clear that the accessibility initiatives that currently exist in biomedical research are not effective. While building wheelchair accessible sinks would make the space more accessible in theory, in practice this change was not useful since the new sinks are not functional for their intended purpose. This inauthentic and unsuccessful attempt at improving accessibility is indicative of a failure to incorporate the "nothing about us without us" mentality that is essential for disability inclusion. If disabled researchers were consulted in making this design decision, then the result would have likely been genuinely useful for researchers who use wheelchairs. Despite his university's willingness to use funds for unhelpful attempts at increasing accessibility, TF has encountered barriers to accessing funding that would allow him to create a genuinely accessible research environment (see question 3).

Question 2: Do disabled voices guide the direction of biomedical research?

Response: TF's personal experiences with hearing loss and auditory processing challenges, his interest in music, and his family members' experiences with hearing loss influenced his decision to research hearing. Much of TF's research is basic science oriented, but he is also involved in some projects with clinical applications. Anecdotally, TF has found that there are a lot of researchers that study hearing that have hearing loss. Despite this demographic overlap, there is a tension and distrust between Deaf communities and biomedical researchers.

TF chaired his department's external relations committee for six years, and during that time he organized outreach events to connect with the Deaf community. These events included hosting a talk with a Deaf WNBA player and an opportunity for community members to meet researchers and learn about what they're studying. In organizing these events, he encountered suspicion from both the Deaf community and scientists who were resistant to change.

TF also used the opportunity to improve accessibility in children's sports teams by providing sign language education to coaches and teammates. TF advocated for the installation of light cues on starting blocks for swimmers so that kids do not have to rely on an auditory cue that they cannot hear. During his time on the committee, he was able to make some headway and start to build trust with the local deaf community, but he no longer has the capacity to lead the committee. Since TF left the committee, it has returned to the more isolationist, scientist-centric state it began in.

TF’s observation that there are many hearing researchers who have hearing loss indicates that there are some niches that have researchers with disabilities/lived experience with the topics they’re researching. However, even when someone has a lived experience with a disability, they are not always integrated into the community/culture that surrounds that disability. The reluctance of some researchers to interact with Deaf communities, despite the number of researchers with hearing loss, is reflective of this separation. Any person’s lived experience of their disability is valid, but it is important to remember that individuals don’t necessarily reflect the desires of the community at large. While community input is important, it is essential that a range of experiences are considered. Not all disabled individuals will have the same opinions on what research would be beneficial, and it is important to provide options that allow disabled individuals to make their own decisions.

TF’s experiences in scientific outreach also serve as an important reminder that disabled communities should be involved at all points in research. Disabled people should be involved in directing and carrying out research, and care should be taken to ensure that the results of this research are accessible to disabled communities. Effective, accessible scientific communication is an important part of research, and increased transparency about the goals and results of studies may improve trust between researchers and disabled communities at large.

Question 3: Does the disability someone has correlate with the amount/type of barriers they encounter when entering or staying in the field?
Response: There is a widespread assumption that reading ability is a marker of intelligence, so the fact that dyslexia is a reading disability has placed TF in awkward and tense scenarios in

research settings. Many researchers don't even consider the fact that reading is an access barrier or that people with reading disabilities can be researchers, so there are no efforts made to accommodate those needs.

TF has found that many people are willing to accommodate his hearing loss/auditory processing issues, however, it is harder to access accommodations that inconvenience others in some way. For example, he also deals with chronic pain so he needs equipment to be organized in a certain way to minimize pain. When the university remodeled his lab, they wanted to place the equipment in a space that was not accessible to him. TF had to relentlessly advocate that the setup be changed to accommodate his needs, and these changes cost a large amount of money. TF has attempted applying for ergonomics grants, but the university deems that those funds are for office supplies, not lab equipment.

TF also has chronic pain and other researchers often do not take his pain seriously since there is a cultural norm in his research setting that "[everyone] has back pain." Due to this normalization of suffering through pain, others overlook the fact that his pain isn't something he can just take ibuprofen for and power through it. This lack of understanding for why he needs physical accommodations contributes to the struggles he faced in accessing those accommodations.

In TF's experience, the type of disability that one is requesting accommodations for does influence the extent to which others are willing to accommodate. TF's colleagues do not even consider the fact that people with reading disabilities can be researchers, so they do not consider text-based access barriers. The normalization of suffering through pain in research that TF mentions is an indicator of how unhealthy research environments can be. Wellbeing is often neglected in academia, and in TF's experience it has contributed to a lack of understanding of his access needs (Roemer et al., 2024). Others may become desensitized to the fact that pain can be disabling because they have accepted some degree of pain as the norm. This lack of understanding is likely also a reason why the university was so unwilling to pay for a more accessible lab design that would decrease his pain.

It is also important to note the fact that disability-associated costs not only impact medical bills, like in DS's case, but they also create a need for funding to cover accessible equipment and tools like text-to-speech software. It would be beneficial to disabled researchers to create specific grants to fund the creation of truly accessible lab spaces rather than expecting disabled researchers to use their project funding on what would otherwise be basic equipment.

Question 4: What recommendations can be made to improve accessibility in the biomedical research field?
1. Improve representation of disabled people at all levels. 2. Reduce the stigma associated with disclosing disabilities.

TF's experiences demonstrate that accessibility and support for disabilities is limited not only during undergraduate and graduate training but also for biomedical researchers with well established careers. The efforts that have been made thus far to increase accessibility have largely been superficial bandaids for a more deeply rooted problem. As BA suggested, accessibility can only be systemically improved by increasing the representation of disabled researchers. This increase in representation must be accompanied by a consistent commitment to meeting the access needs of disabled students, faculty, and staff. Even though there are already disabled biomedical researchers, many people, including BA and DS, are uncomfortable with disclosing. TF has reached the realization that he will not receive the accommodations he needs without disclosure, but he is still affected by other’s assumptions about his disabilities.

Research Beyond the Bench: HS

HS (she/her) is an undergraduate student at a liberal arts college, and she predominantly studies the social sciences and humanities. Her primary interest is in the intersection between the humanities and health. Her current research explores the role of narrative in healing, and she works directly with people who have experienced disability/illness. In the future, she is interested in working with youth who have experienced medical trauma. In the more traditional biomedical realm, she co-authored a literature review on stroke recovery during high school in collaboration with one of her own doctors.

After experiencing a stroke early on in high school, HS became interested in sensation loss. Stroke recovery is largely focused on regaining function, so the effects of stroke on perception are understudied. HS has made significant progress with her functional abilities, but the way that she moves through the world was changed by her stroke. Even though she has been experiencing the effects of her stroke for years, she has only recently begun identifying as disabled. Despite her interest in biomedical research, HS was unable to pursue this career path due the access barriers present in STEM education. HS's choice to study humanities and social sciences were in part influenced by the fact that those fields have fewer physical demands than biomedical research.

As BA, DS, and TF described, biomedical researchers are expected to conform to the restrictive and ableist standards of productivity, and lab benchwork is often physically demanding. Even though researchers can make important contributions to research without physically carrying out the experiments, these roles are not offered to early career researchers. Instead, researchers are expected to work up through the ranks by doing hands-on lab work before they are given the option to contribute in a purely intellectual capacity. This expectation serves as a form of gatekeeping that makes it more difficult for researchers with physical disabilities to continue in biomedical research.

Question 1: Is inaccessibility responsible for the dearth of disabled researchers in biomedical fields? If not, what is in the experience of the people I interview?

Response: HS really enjoys the intellectual component of biomedical research, but the physical lab work is inaccessible. Her decision not to pursue biomedical research was largely due to the access barriers she faced in a college-level biology lab in high school (this course was hosted by a research university). During this lab, she was required to stand for extended periods of time and move quickly. The time-restricted nature of lab periods created time pressure beyond any inherent time sensitivity in the experiment, and she felt a need to keep up with her lab partner's pace. HS was also constantly scared that she would accidentally knock over the supplies required for the experiment. The teaching assistant in the lab offered HS assistance if needed, there was no clear structure that indicated what types of accommodations she could reasonably request. HS was able to pivot from biomedical research to other career avenues fairly easily since she ran into those access barriers early on.

HS hasn't encountered any explicit undermining of her research abilities, but she has faced implicit exclusion due to the lack of accessibility in the biomedical sphere. When she talked to doctors and researchers about their work during her recovery, she was told that she would not physically be able to do their jobs. HS doesn't feel as though those researchers were putting her down; they were really just acknowledging the reality that there are some things she is not physically able to do because of her disability. Even though there are some research tasks that she would not be able to do even with accommodations, there are other elements of research where scientists are needlessly held to ableist standards. She thinks that the unreasonable expectations placed on researchers are linked to the perception of people in biomedical jobs as caregivers that need to be "strong" all of the time and disabled people as recipients of care.

In her day to day life in academic settings, HS feels pressure to downplay her disability and consciously tries to walk in a way that looks as typical as possible. HS uses orthopedic braces, and she got a smaller, more see-through brace in addition to her standard brace so that she would be able to wear more "professional" shoes for interviews. HS also needs to sit down for presentations which is outside of the norm of what people perceive as professional behavior, but this standard of professionalism is ableist. When HS was younger, she was often met with pity because of her disability, but she doesn't want to be pitied in professional contexts.

The access barriers that HS encountered in educational lab settings and the minimal access to opportunities to participate in traditional biomedical research in a less hands-on manner led HS to pursue alternative career options.

When disabled people are able to enter STEM educational settings, they face an unfair burden to be their own advocates (Hong, 2015). TF's experiences also make it clear that this need for self-advocacy is not just limited to early biomedical career stages. Since HS was a high school student who was also relatively new to living with a disability, she did not know what accommodations were possible or what would be useful to her. In order to create genuinely accessible environments, universities and educators should work with disabled students and faculty to help them determine what accommodations can be provided to address their needs.

The lack of disability inclusion in STEM education and biomedical research indicates that non-disabled people generally don't even consider that disabled people can (and should) be involved in the production of research. The lack of disability inclusion in biomedical institutions perpetuates the perception of disabled people as the passive recipients of research and research subjects. The ableist standards of professionalism that HS described are applicable to a wide range of career fields including biomedical research.

Question 2: Do disabled voices guide the direction of biomedical research?

Response: HS's experience in biomedical research focused on stroke since that was the most relevant to her own experience. Her experience with stroke is also directly tied to her interest in working with kids who have experienced medical trauma and her interest in narrative medicine. HS has found that the lack of disability representation amongst biomedical researchers has led to significant gaps in research. For example, recovering sensation loss is not necessary for functional stroke recovery, but this perceptual change has significant impacts on quality of life from the patient perspective.

The lack of input from disabled communities is also apparent in brace manufacturing. Many of the options are bulky, difficult to conceal, and there are few neutral color choices. The pure prioritization of function over form indicates to HS that the people that design most braces do not actually use them. In fact, her smaller, see-through brace was designed by a physical therapist in response to feedback from people who use braces.

HS felt as though she didn’t have as much to share in response to many of the pre-designed interview questions in this section, but her contributions to a literature review on stroke recovery was an example of the genuine inclusion of disabled voices in research. Even if she is not involved in the behind the scenes elements of research design, she did have several insights on the negative consequences of the exclusion of disabled researchers. From the patient perspective, there are areas of research that are clearly lacking that non-disabled researchers overlook. If biomedical research effectively included disabled researchers and consulted with disabled community members, then these gaps could be filled.

Question 3: Does the disability someone has correlate with the amount/type of barriers they encounter when entering or staying in the field?
Response: The lack of accessibility in physical lab environments in STEM education directly resulted in HS’s inability to pursue a biomedical research career (see question 1 for descriptions of these experiences). At times HS chooses to make her disability more readily apparent by stopping her attempts to hide her limp or by letting her arm assume a less typical posture. She allows her disability to become more visible when she needs to ask for help from those around her. When she is masking her disability people assume that she is just clumsy or slow and become frustrated, but people are more empathetic when they realize that she is disabled.

The challenges that HS has faced in STEM education as a person with a physical disability that limits her speed and some motor functions directly led to her choice to pursue a career outside of traditional biomedical research. Some people with physical disabilities, like DS, are able to address some of their access needs in the lab through informal accommodations and choosing their work for a given day based on their symptom levels. HS was not able to accommodate her own needs informally, and she was unable to access truly useful accommodations through formal avenues. HS would have benefited from changes to the lab's physical structure, but these changes are difficult even for faculty members like TF to obtain.

HS's decision to make her disability more visible at times could be a way to side-step the issue of direct disclosure. BA, DS, and TF all expressed general discomfort with disclosing, and this sentiment is echoed by others (Yerbury & Yerbury, 2021). Making her disability more visible is a disclosure of sorts, and even though acknowledgement of a disability can lead to discrimination, disclosure is valuable for accessing accommodations (Moriña, 2024; Saal et al., 2014). However, even disclosure of her disability was not sufficient for HS to gain access to useful accommodations to continue pursuing traditional biomedical research.

Question 4: What recommendations can be made to improve accessibility in the biomedical research field?

1. Improve clarity of what accommodations can be made, and provide more support for accessing those accommodations
2. Broaden the idea of what a researcher does.
    a. Broadening the scope of researchers' jobs would allow disabled people to participate more fully in research without the need to physically conduct experiments.

HS’s experiences are reflective of the types of barriers that disabled people may encounter that preclude them from becoming biomedical researchers. Efforts must be made to improve the accessibility of STEM education at all levels, and we need to recognize the potential for disabled people to make non-standard contributions to research. The reality is that there are some tasks that are inherently inaccessible to some people even with significant accommodations. Rather than removing these individuals from research entirely, they could be involved in less physically demanding roles. Some potential roles could be as disability consultants, in experimental design, or in data analysis. If a disabled person wishes to conduct hands-on research then institutions should work with them to design accommodations that would meet their access needs.

Conclusions and Limitations

The participants interviewed in this study shared a wide range of experiences with inaccessibility and ableism in biomedical research. Their experiences provided valuable insights that I hope will contribute to a reshaping of the relationship between people with disabilities and biomedical research. It is clear that biomedical research as a field stands to gain a lot from the perspectives of disabled people, and direct involvement with biomedical research benefits disabled individuals and communities. To assess the causes of inaccessibility and the lack of representation of disabled individuals and communities in biomedical research, we return to the questions that I posed in the introduction.

1. Is inaccessibility responsible for the dearth of disabled researchers in biomedical fields?

The participants in this study encounter inaccessibility and ableism frequently in research environments. It would be accurate to conclude that inaccessibility is responsible for the lack of disabled biomedical researchers, and HS provides a clear example of how access barriers prevent disabled people from entering traditional biomedical research. As I hypothesized, participants encounter access barriers that are tied to an inaccessible and ableist work culture and a lack of physical accessibility. In addition to access barriers precluding disabled people from pursuing biomedical research careers, the perception of disability in biomedical research limits visibility of disabled researchers. My hypothesis that the limited representation of disabled researchers is in part a result of underreporting due to fear of disclosure was supported by DS and TF's experiences. As BA explained, inaccessibility also contributes to the creation of an environment that is not welcoming to disabled researchers. Unwelcoming environments make disabled researchers reluctant to label themselves, and this hinders the formation of disabled communities in research.

I also hypothesized that the lack of representation is due to struggles to fund and find accessible lab spaces. DS and TF provided evidence that disabled researchers face unique funding challenges. These funding issues serve as barriers to the creation of accessible lab environments. While funding barriers are evident there was not direct evidence that financial barriers prevent disabled researchers from entering the field. Other studies have found that disabled researchers have more difficulty in securing grant funding than their non-disabled peers, so it is likely that funds become a more significant barrier after becoming a faculty member or PI (Castro et al., 2024; B. K. Swenor et al., 2020). It is possible that HS's negative experience in the lab was in part due to a lack of accessibility-focused funding for teaching labs, so funding constraints may impact early career training as well. Future research should further investigate funding as an access barrier by including the perspectives of faculty members across a range of career stages and course lab instructors.

Across all training and career levels, participants encountered particular struggles with inaccessible standards of productivity. This unreasonable standard of productivity appears to be ingrained in biomedical research culture as evidenced by the expectation of high output, unforgiving hierarchical structure, and constant competition (Burns et al., 2023). Many disabled people experience a wide range of variation in their symptoms due to dynamic disabilities and chronic illnesses (Benness, 2019). A disabled researcher's output and access needs may vary as their symptoms fluctuate. As a result, many disabled employees struggle to maintain consistent productivity that conforms to ableist norms (Jammaers et al., 2016). Despite this reality, disabled researchers are not given the option to adjust their work flow to accommodate these fluctuations

(Castro et al., 2024). In BA and DS's experiences, variations in productivity are perceived as laziness and unreliability by non-disabled researchers, but this interpretation lacks an understanding of disability.

In addition to the normalization of ableist standards of productivity, there is also a normalization of suffering through pain and symptoms. TF's experience with other researchers not taking his chronic pain seriously because "everyone's back hurts" provides a particularly salient example of the normalization of an inaccessible work culture. This expectation to push through pain makes it difficult to effectively manage symptoms. In a study of disabled faculty members' experiences, one person reported that people who do take leaves to manage their health are met with stigma and gossip (Castro et al., 2024). TF's supervisor's assertion that he needs to "get over" his dyslexia and read more for the study section is another example of the normalization of ableism in biomedical research. In BA's experience, mentioning her symptoms is sometimes perceived as an excuse when it is intended as an explanation. DS's need to emphasize how sick she feels to feel justified in staying home when she needs to is a response to the inaccessible physical demands that are placed on biomedical researchers. These experiences illustrate the prevalence of ableist cultural norms in biomedical research.

Some prospective disabled biomedical researchers, like HS, have been precluded from pursuing this path as a direct result of access barriers in STEM education. For HS, the expectation to remain standing throughout the lab period and strict time constraints were inherently inaccessible. Even though these expectations are common in educational and training settings, they would not actually be required to complete experiments in an accessible lab environment. This lack of accessibility is prevalent across educational institutions, including those that are well funded (Campanile et al., 2022). Even though students have a right to accessible education, high school students with physical disabilities face disproportionate access barriers in STEM (Lee, 2011; Moon et al., 2012). Since these barriers are present within K-12 education, it is likely that there are many more students like HS who were not able to pursue biomedical research due to educational inaccessibility.

Access barriers early on in education limit the number of disabled students that choose to pursue biomedical research, and the barriers do not disappear at later career stages. In DS's experience, the lack of accessibility in the lab may lead to an early end for her participation in benchwork. TF was able to overcome the access barriers that he encountered early in his career, but even after 30+ years in the field he continues to encounter a lack of institutional understanding and funding resources to make the lab space genuinely accessible. TF's institution has made some efforts to create a nominally accessible environment (ie: the installation of wheelchair accessible sinks), however, these modifications are not truly useful and accessible. These unsatisfactory attempts at accessibility demonstrate that academic institutions are not in touch with the actual needs of their disabled employees. This ineffective approach to access suggests that current accessibility initiatives are likely spearheaded by non-disabled people.

In order to attain personalized accommodations that are genuinely useful, it is often necessary to disclose one's disability status. Despite this necessity, disclosure is stigmatized and places disabled researchers in a vulnerable position (Castro et al., 2024). Discomfort with disclosure was evident in BA, DS, and TF's responses, and reluctance to disclose has been previously reported by other academics with disabilities (Yerbury & Yerbury, 2021).I hypothesized that the lack of disability representation is in part a result of underreporting because of fears of prejudice, and this evidence of limited disclosure supports this hypothesis.

Even though formal accommodations are difficult to obtain without disclosure, direct acknowledgment of a disability can lead to other unwanted perceptions. Other scientists have reported that they are reluctant to disclose because they fear discrimination (Castro et al., 2024; Yerbury & Yerbury, 2021). BA has seen that many professors and mentors lower their expectations of her following a disability disclosure. This discrimination contributes to the stigmatization of disability in biomedical research and the creation of environments that do not welcome disabled researchers. As BA expressed, it is not helpful to lose faith in researchers with disabilities' abilities. Supervisors should instead work with individuals to accommodate their needs and help the individual to reach their personal goals and further the lab's research. While several interviewees are reluctant to disclose their disabilities, it is important to note that this study is limited to the perspective of researchers who do elect to disclose in some research settings. Further study would be required to understand the experiences of researchers with disabilities who categorically do not disclose their disability status.

2. Do disabled voices guide the direction of biomedical research?

As I predicted, disabled voices do not currently guide the direction of biomedical research. HS had the opportunity to contribute to a literature review on stroke recovery, but this involvement of disabled people/patients in research does not seem to be the norm. In BA and DS's lab experiences, there is very little direct formal communication between research teams and disabled communities. The lack of collaboration between disabled communities and researchers is evident in patient experiences including HS's experiences with orthopedic braces. Despite the limited opportunities for formal collaboration with disabled communities, some researchers like BA and DS make an individual effort to be involved with the communities their research affects. This attention to connecting with disabled communities may be a direct result of their personal experiences with the disconnect between researchers and disabled people.

In his position on the external relations committee, TF made concerted efforts to connect disabled communities to the research world. In this experience he became acutely aware of the amount of time and effort required to build trust with disabled communities. Meaningful collaboration with disabled communities can only be achieved through a relationship that prioritizes trust and the needs of disabled communities. The responsibility for bridging communication between researchers and disabled communities cannot be placed solely on the shoulders of individual researchers, but many non-disabled researchers are not currently invested in addressing this gap. Disabled researchers' experiences are essential for addressing the gap between biomedical research and disabled communities, but non-disabled researchers need to gain awareness of the importance of collaboration with disabled populations. While disabled researchers should take the lead on these projects, it is also important to recognize that individual disabled researchers cannot be viewed as spokespeople for entire disabled populations.

While all of the participants in this project identify as having a disability, this interview was the first time that some participants reflected upon the connection between their research and their disabled identity. The limited awareness of the role of disabled identity in research also limits opportunities for community building among disabled researchers. DS's experiences in particular shed light onto how early career researchers with disabilities would benefit from increased disability visibility. Improving accessibility and awareness of disabilities is an important first step in lessening the stigma surrounding disability inclusion and building communities of disabled researchers. Increasing awareness of the connection between disabled identity and biomedical research would benefit disabled communities, patient populations, and disabled researchers.

3. Does the disability someone has correlate with the amount/type of barriers they encounter when entering or staying in the field?

This study is limited by its small sample size and the fact that most participants have invisible disabilities. Due to these limitations, it is difficult to draw definitive conclusions about what experiences are unique to specific subpopulations. Future research should include more participants with visible disabilities and more racial and age diversity. Despite the limitations of the present study, some trends were notable and warrant further investigation.

Perceptions of laziness and a lack of work ethic were particularly evident in others' judgments of BA and DS who are both young researchers with invisible disabilities. It is possible that their invisible disabled identity makes them particularly vulnerable to character-based judgments because of the lack of visual cues of disability. As a result of the interplay of ableism and ageism, there is an assumption that early career researchers "should" be physically able because they are young. Since people assume that young researchers *can* keep up with the extreme physical and mental demands of the biomedical research culture, there is an assumption that failures to meet these standards are due to a lack of effort and commitment. Assumptions of laziness and low work ethic may also be compounded by the intersections of fatphobia and racism with ableism (Binder, 2023; Johnson, 2024; NMAAHC, n.d.). It is difficult to draw definitive conclusions about whether these struggles are unique to young people with invisible disabilities due to the small sample size and limited age range.

TF's experience with discrimination against reading disabilities was unique within this sample of disabled biomedical researchers, but his experiences likely resonate with other scientists with reading disabilities. Those with reading disabilities may face unique challenges since there is an expectation that educated people, like scientists, are able to read quickly and with ease (Collinson, 2020). This assumption translates to the ways in which science is communicated. For example, poster sessions are a very common way for scientists to share their research, and this form of communication relies heavily upon reading. Discussion about how to make poster design accessible for those with dyslexia or colorblindness is limited, but some scientists, like TF, are making an effort to change this. TF's experience is also reminiscent of BA's struggles with the expectation to respond to questions on the spot and without notes. Normative standards of what it means to be intelligent and express intelligence are inherently ableist, and this ableism leads to discrimination against disabled researchers (L. Carlson, 2017). Further research should investigate the experiences of scientists with disabilities that impact reading and communication.

4. What recommendations can be made to improve accessibility in the biomedical research field?

Conducting these interviews increased my own awareness of how deeply ableism and inaccessibility are ingrained in biomedical research. All participants in this study struggle to gain access to accommodations in research settings. In many cases, this lack of access to accommodations is due to non-disabled scientists' lack of awareness and understanding of disability. Many participants also reported that the lack of resources for disabled researchers limited their ability to advocate for themselves to receive accommodations. Broadly increasing awareness of the range of potential access needs could reduce the number of early career disabled researchers that are precluded from continuing in the field. These changes need to start in early STEM education and continue through all career stages.

Multiple interviewees reported that less hands-on tasks are more accessible to them than lab bench work, but the more hands-on parts of science are what are emphasized in early career training. HS does not think that most hands-on biomedical research can be modified to meet her access needs, however, this does not mean that disabled people should be entirely removed from the research process. Disabled people who do not find lab benchwork accessible still have incredibly important lived experience that could guide the course of research to better respond to the needs of disabled communities.

Based on the suggestions made by interviewees, my personal experiences and observations, and suggestions proposed by other researchers I make the following recommendations (Brinton & Bernard, 2022; Meeks et al., 2024):

1. Conduct reviews of current institutional policies, and adopt accessible and disability-informed practices. These reviews should be conducted by researchers of diverse ages, races, genders, socioeconomic backgrounds, and abilities.
2. Create standardized processes for accommodation requests and oversight to ensure that approved accommodations are provided. Accommodations offices should provide examples of potential accommodations, and accommodations should be tailored to individual needs.
3. Standardize accessible design in research and teaching labs, and consult with disabled communities to create these designs.
4. Increase collaboration with disability-centered community organizations. These

collaborations should be led by disabled people, and institutions should take the steps required to build and maintain genuine trust from disabled communities.

5. Create spaces for disabled researchers to build community. These spaces should also provide opportunities for early career researchers with disabilities to gain mentorship from established faculty members with disabilities.
6. Make it a cultural norm to ask if students and researchers have any access needs.
7. Incorporate disability awareness, anti-ableism, and accessibility into DEI training.
8. Give early career researchers the opportunity to participate in less physically demanding tasks like data analysis and experimental design.
9. Promote more accessible standards of productivity that are not based on ableist expectations of constant linear progress. This redefinition of productivity should also include the normalization of prioritizing putting health (however that is defined for a given individual) and symptom management.
10. Implement more interdisciplinary collaborations between disability studies and biomedical research.

My recommendations are not exhaustive, but I believe that implementing these changes would improve accessibility, disability inclusion in biomedical research.

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Appendix A: Interview Questions

1. How long have you been involved in biomedical research?
2. What specifically do you research or hope to research? If you do not know, what general area are you interested in?
3. Does this research have the potential to impact disabled communities?
   1. If so, what communities are (or could be) affected?
   2. Are you personally connected to any of these communities? If so, which one(s)?
   3. As you conduct your research, do you seek feedback from members of these communities? Which communities? At what point in the research (design, analysis, etc.)?
4. Do you identify as having a disability or as being Disabled? If so, are you comfortable with sharing some basic information about your disability? I am not seeking any particular information, just whatever you find important to tell me.
5. Have you ever felt pressured to hide or downplay the effects of your disability (or disabilities) in the workplace or classroom? Would you share with me an example or two?
6. Have you ever felt as though others have undermined your biomedical research capabilities due to your disability or disabilities? Would you share with me an example or two?
7. Have you felt as though others have seen your presence in the lab as an example of tokenism? Would you share with me an example or two?
8. Have you encountered access barriers in research environments (ie: in the workplace, during graduate or undergraduate education, etc.)?

    1. If so:
        1. Have these been physical barriers due to the physical lab space, including the furniture and instrumentation, or due to expectations of the work?
        2. Have there been any access barriers relating to the culture within biomedical research spaces?
        3. Have there been barriers relating to funding or disability-related finances?
    2. If so, are there any particular instances that stand out as examples of these barriers?
9. Did your disability/disabilities impact your decision to become a biomedical researcher and the goals you have in that capacity?
10. Did your disability/disabilities influence the field of biomedical research that you chose? If so, how? You can be as detailed or general as you wish here.
11. Do you feel as though disabled people are well represented in biomedical research spaces?
    1. If not, why do you think that is?
    2. Do you think the low representation of disabled researchers is due to inaccessibility in terms of physical barriers and/or in terms of culture and/or in terms of funding opportunities?
    3. Do you think that representation of disabled people is important in biomedical research spaces? If so, why?
12. What recommendations would you make to improve accessibility and the inclusion of disabled communities in biomedical research? You can be as specific or general as you want, but I would appreciate it if you could make at least three recommendations.

13. Would you like to elaborate further on any of your responses or is there anything else that you would like to discuss that my questions did not address?