

# The “New Normal” for Disabled Students: Access, Inclusion, and COVID-19

Paul D.C. Bones<sup>1</sup> and Vanessa Ellison<sup>2</sup>

1 Texas Woman’s University, Denton, TX, USA, [pbones@twu.edu](mailto:pbones@twu.edu)

2 Texas Woman’s University, Denton, TX, USA, [vellison@twu.edu](mailto:vellison@twu.edu)

## Abstract

During the COVID-19 pandemic, disabled students were vulnerable not just to the virus, but disruptions in education as schools shifted to remote delivery. Using Jackson and Mazzei’s thinking with theory methodology, this qualitative study centers the voices of disabled students and their lived experiences with access and inclusion in higher education, before, during, and after the COVID-19 pandemic. We identified the social model of disability as our theory to “plug” into interviews. Results indicate that disabled students turned to self-accommodations during COVID-19, creating DIY accessibility. The lack of required outside meetings allowed many disabled students to better focus on their health and education by avoiding physically taxing activities. Furthermore, interviews revealed that disabled students see disability as a commonplace event, similar to work or family commitments, and advocate for a reimagining of how we frame fairness in higher education. Although student experiences with pandemic learning and accessibility varied, nearly all participants expressed a desire to keep the flexibility and grace they experienced during the COVID-19 pandemic, and advocated for an ethic of care for all students as most schools return to full, “normal,” education. Based on the interviews, we provide suggestions for how to increase accommodations and access in the post-COVID-19 classroom.

**Keywords:** Disability, Education, COVID-19, Accessibility, Accommodation, Social model

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## Introduction

According to the U.S. Department of Education (2021), approximately 20% of college undergraduates identify as disabled<sup>1</sup>. Even in the best of times, disability impacts student success, as the traditional model of higher education assumes neurotypicality, a lack of learning or intellectual impairment, and perfectly functioning bodies. In truth, the “average” student is more of an ideal than a reality. As a result, many students rely on disability accommodations, or adjustments to the method of delivery or mode of

assessment, for course materials and assignments. The COVID-19 pandemic fundamentally disrupted education, as universities were forced to move online. This had a disproportionate impact on disabled students.

Not only were disabled persons most likely to be impacted by the COVID-19 virus (Shapiro 2020, BBC News 2021), but COVID-19 also created disability through “Long COVID” symptoms (Emanuel 2021). Additionally, attempts to minimize the effects of the virus, alongside the public discourse surrounding “acceptable loss” may have led to a break in necessary

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<sup>1</sup>In this article, we use identity-first language, as opposed to person-first language. Both researchers identify as disabled and use identity-first language for ourselves. Although person-first language is often thought to be a “kinder” way to describe disability, the disabled community continues to insist on identity-first language (Dunn and Andrews 2015, NCDJ 2018). This has led to changes in the way that organizations such as the Associated Press recommend writers label disability (<https://twitter.com/APStylebook/status/1397262123139571715?s=20>).

routines, increased isolation, and deleterious effects of eugenicist rhetoric on individuals (Lebrasseur et al. 2021). While all students had to contend with these issues, most did not have to grapple with them while dealing with potential changes in access needs and accommodations.

This qualitative study uses Jackson and Mazzei’s (2011) thinking with theory methodology to explore how disabled students dealt with the COVID-19 pandemic by comparing how well their access needs were met before the pandemic, what changed during COVID-19, and what they hope for the future of access in higher education. This research is important because too often the voices of disabled students and educators are absent from discussions of best practices, inclusion, and access. This is the norm for higher education, as disabled students are more likely to be spoken for, rather than be allowed to speak. We hope that by centering the voices of disabled students, we can help to shine new light on the barriers they face in higher education, and how they created ways to thrive during this challenging time.

We identify the social model of disability (Oliver 2004) as our guiding theory for analysis. A reaction to the medical model that defined medical impairment as the only barrier to access for disabled people, the social model separates the condition (impairment) from social ideas about disability that reinforce difference and rationalize exclusion. More of a heuristic device than a true theory, the social model allows us to examine student narratives about their disabled lives in higher education, while noting what barriers were directly related to a specific medical condition which result from ableism in the institution itself. Given that access and accommodations are more often treated as a given in college, combined with the fact that this was an unprecedented global pandemic, we started with a relatively broad research question. Specifically, this research aims to address the question of, “what does the social model look like in a digital world, under COVID-19?” However, as interviews progressed, we found our question shifted to a more phenomenological exploration of what it means to be disabled in higher education, how students utilize their own resources to succeed, and what they think about access in general.

## Theoretical and Empirical Background

### *Models of Disability*

Disability scholars typically rely on models to explain the complex nature of disability. Gabel and Peters (2004) breakdown paradigms, models, and theories in their work proposing resistance theories of disability. They state that paradigms are larger assumptions about

the nature of the world itself, while theories provide “a framework or perspective that permits an understanding of the world, proving an organization for investigation and communication” (587). Models then serve as a kind of middle ground, which “clarify and organize a set of practices and tools for testing or deconstructing theories” (588). They go on to note that models are typically derived from multiple theories, and allow the user more flexibility in their application. In relation to disability, models are seen as preferable because our understanding of the phenomenology of disability is constantly changing, and generating discourse on this topic is encouraged.

Originating in the 19th Century, during the Age of Enlightenment, the medical model of disability views disability “as a problem that exists in a person’s body. As a consequence, the individual is thought to require treatment or care to fix the disability, to approximate normal functioning, or perhaps as a last measure, to help the individual adapt and learn to function despite the disability” (Goering 2015:134). In other words, it situates disability as solely a medical condition. A medical fact, being cured from one’s disability is seen as the ultimate goal, and the only way to achieve this goal is to work towards a solution through allopathic medicine. Centered completely on ableness, the medical model has been routinely critiqued because a) some disabilities cannot be cured, b) some people do not want to be cured, and c) this is fundamentally an exclusionary model (Oliver 2004, Shakespeare 2006). The medical model still dominates much of the public discourse on disability, as well as how institutions treat disability. For example, in order to be officially considered disabled in higher education (and to be granted accommodations), students need to have medical documentation “proving” their disability status. Absent this medical credentialization, from an institutional perspective, no disability “exists.”

The medical model has never sat well with disabled people. The social model of disability was born from the 1975 disability rights organization, Union of the Physically Impaired Against Segregation (UPIAS) in the United Kingdom (Shakespeare 2006). Though the term “social model” was not coined until 1983 by Michael Oliver, its creators saw it as an alternative way to view disability (Shakespeare 2006). The UPIAS was a “small, hardcore group of disabled people, inspired by Marxism, who rejected the liberal and reformist campaigns of more mainstream disability organizations” and desired for people with disabilities to have control over their lives; to live fully in society (Shakespeare 2010: 2). Tom Shakespeare explains that “the social model is distinguished from the medical or individual model. Whereas the former defines disability as a social creation – a relationship between people with impairment and a disabling

society – the latter defines disability in terms of individual deficit” (2006: 198). At its core, the social model separates the medical side of a condition (referred to as impairment) from the social barriers and stigma that defines disability as a social problem (referred to as disability). Consequently, the social model carries with it the goal of liberation by dismantling physical barriers created by societies that privilege non-disabled bodies by preventing disabled access and inclusion (Oliver 2004, Shakespeare 2006).

The social model has, rightly, been critiqued for several reasons. First, many have treated it as a static theory on disability, as opposed to a useful tool for exploring the way that society disables people with certain kinds of bodies. This is something admitted by the model’s creator (Oliver 2004), who sees it as one of many possible tools for understanding disability. Second, it was conceived with only physical conditions in mind, something Shakespeare (2006) and others have contended was a specific goal of the model, even though this means it excludes mental, intellectual, and chronic pain/illness conditions. Third, the social model ignores the very real impact impairments have on daily living. Many conditions are limiting even when a person is fully accommodated, and disabilities are fully destigmatized. For example, pain is not something that can necessarily be controlled by eliminating physical barriers to access.

Other models have been proposed, such as social-relational theory (Thomas 2004), which combines both the medical and social models, and resistance theory, which states that models themselves are often the product of active resistance on the part of disabled people to push back against otherizing and reductive understandings of disability that center ableds (Gabel and Peters 2004). However, we still contend that the social model is best suited to examine accommodations in higher education for four reasons. First, it is a lens that allows researchers to separate impairment from disability. Though simplistic and potentially artificial, this split provides more direct action than alternative models. Second, relatedly, the social model is the most well-known, which makes framing policy recommendations easier than it is with unknown models. Third, we contend that many of the critiques of the social model can be minimized if we recognize that non-physical disabilities are often rooted in the corporeal world. For example, though anxiety disorders are mental in terms of their cause, their effects are largely physiological (Locke, Kirst, and Shultz 2015). Furthermore, anxiety triggers are physical in nature (locations, contexts, persons, etc.), as are remedies for panic attacks (finding a safe space, avoiding triggering situations, etc.). Therefore, we argue that the social model is still a useful tool for identifying barriers to access and inclusion for “non-

physical” conditions. Fourth, the very disagreement over what constitutes an impairment versus a disability can itself be illuminating. As mentioned above, the originators of the social model saw disability as what excludes disabled people from full participation in society, but where do educational accommodations fit into this narrative?

#### *Access Denied: Accommodations and Barriers*

Prior to the Rehabilitation Act of 1973, universities were under no obligation to accommodate disabled students (Ketterlin-Geller and Johnstone 2006). Based on the medical model, disability was seen as disqualifying for many academic programs. The Rehabilitation Act prevented all institutions receiving federal funding, including public universities, from discriminating against disabled people. Further strengthened by the 1990 Americans with Disabilities Act (ADA), reducing prejudice and discrimination has typically taken the form of disability accommodations (Ketterlin-Geller and Johnstone 2006). Accommodations are practices put in place to increase access to course materials. They can include a university provided or volunteer note taker, access to lecture materials, an ASL interpreter, video captioning, time and a half on timed activities, large-print textbooks, a distraction-free test environment, and other post-hoc adjustments to learning and/or assessment to help level the playing field for disabled students. From a social model standpoint, these are remedial measures to mitigate the ableism inherent in academia. This ableism is derived from the norms of higher education, which prioritize non-disabled experiences when considering the appropriate amount of time allowed on an exam, the size of text used in lecture and course materials, and overstimulating classroom assessments, to name a few.

But accommodations are not available to everyone. Most universities have a dedicated Disability Services Office (DSO), which may go by a variety of names (Disability Services Center, Disability Resource Office, etc.). Because each school has their own disability apparatus, the accommodations process can vary from institution to institution (Ketterlin-Geller and Johnstone 2006). Accommodations are generally tied to specific impairments, and once approved, students are only able to get those specific adjustments. For example, a student with ADHD would be entitled to extra time on exams because their condition can make it hard to focus, but not for an ASL interpreter or captioning on all videos. Sometimes these restrictions make sense (such as with the ASL interpreter for ADHD), but other times this narrow definition of what is and is not appropriate may exclude students from practices that

would benefit them (captions can provide a way for ADHD students to focus on the material). The medical model also plays a gatekeeping role in the accommodations process because most schools require verification from a medical professional to ensure that students are actually entitled to accommodations (Ketterlin-Geller and Johnstone 2006, Krebs 2019). While this might seem like a way to ensure fairness, it makes the accommodations process a barrier to access in-and-of itself.

There are many reasons why disabled students may not pursue accommodations. First, the reliance on medical certification can make this process prohibitive because not everyone has access to medical care. A lack of insurance, the cost of medical care, stigma related to disability and diagnosis, and/or past medical trauma and discrimination can all prevent students from acquiring necessary medical documentation, and therefore accommodations (Krebs 2019, Marshak et al. 2010, Trammell 2009, Cawthon and Cole 2009). Second, DSO staff themselves can act as gatekeepers, encouraging some students to not pursue the accommodations they are entitled to. This can take the form of outright ableism on the part of professionals entrusted to make sure disabled students are not discriminated against or benign/unintentional practices such as being difficult to find, not including required information on a website, being overly bureaucratic, or encouraging disabled students to “overcome” their impairments (Marshak et al. 2010, Cawthon and Cole 2010, Krebs 2019). Third, students may either be unaware of their impairments or may seek to “prove” themselves by not seeking accommodations (Marshak et al 2010). Or, they may feel they lack what Williams-Whitt calls “disability credibility” (2007:405), if they do not see themselves as “disabled enough” for accommodations. Fourth, just because accommodations are granted, this does not ensure that faculty comply with these legally required adjustments, as they are allowed to decide if accommodations are or are not “reasonable” (Krebs 2019). While there has been some scholarly research on why students do not pursue accommodations, many either frame these as “student behaviors,” “student success strategies,” overly focus on disclosure decisions, or are centered on DSO staff (Barnard-Brak et al 2009, Cawthon and Cole 2010, Barnard-Brak and Sulak 2010). We find this ironic because if a substantial percent of the disabled population is eschewing accommodations, we have to wonder to what extent this is “personal choice” versus viewing the accommodations process as inaccessible.

One proactive attempt to address these barriers has been the implementation of Universal Design for Learning (UDL). UDL asks instructors to ground their courses in accessibility, instead of relying on post-hoc accommodations. This pedagogical practice involves creating multimodal learning, including captions and alternative text for images, and ensuring all documents are screen reader friendly (Story 2001). More in line with a social model approach to course design, the preemptive nature of UDL makes it an improvement over the standard accommodations process, as it can sidestep many of the barriers described above. However, unlike academic accommodations, UDL is not enforced by the ADA. Additionally, it is focused primarily on sensory disabilities, and there is no way to tell how many instructors utilize it.

### *Present Study*

Prior to the pandemic, the accommodations process largely worked, but failed to address the needs of all students. By adhering to the medical model, it created as many barriers as it resolved. Although many people assume the ADA and DSOs ensure inclusion, there is a difference between “‘legally guaranteed’ access and functional access. Just because a law \*says\* disabled people are entitled to something does not mean that we actually receive it” (Facknitz 2021<sup>2</sup>). While we know this was the case pre-COVID-19, we do not know how this virus affected access and inclusion for disabled students. Lockdown and quarantine most likely disrupted access to medical care. Did DSOs and professors continue to demand medical documentation for accommodations? Likewise, remote learning removed many physical barriers to participation, but did it create new virtual ones? How likely were professors to trust students and extend grace as students grappled with a deadly global pandemic alongside new technologies?

### **Methods and Data**

#### *Analytical Approach*

In order to address the above questions, as well as our overall guiding research question, “what does the social model look like in a digital world, under COVID-19?,” we utilized Jackson and Mezzei’s (2011) thinking with theory methodology. This technique involves plugging in theory to blur the lines between data and theory, researcher and participant. The goal of thinking with theory is to reach a “threshold,” or point of intersection in order to better

<sup>2</sup>Twitter. <https://twitter.com/HannahtheWolf/status/1409918464161062917?s=20>

approximate the shared power of qualitative research and meaning-making. Or, as the authors phrased it, a threshold is a place where “things enter and meet, flow (or pass) into one another, and break open (or exit) into something else” (Jackson and Mezzei 2018: 721). We identified the social model as our theory to “plug” into the interviews. However, even the model’s creator admits that it is less of a theory than a tool (Oliver 2004), in part because it was not designed for non-physical disabilities. We began with the general question, “what does the social model look like in a digital world, under COVID-19?” One aspect of thinking with theory is this methodology encourages the creation of new questions and iterative understanding, rather than grounded theory construction. As a result, we saw the social model as more of a heuristic device—a lens we could impose on our interviews, and then chip away at using the atheoretical lived experiences (data) of our respondents. As interviews progressed, we found ourselves with more questions than we started with. This process will be more fully-detailed in the results, as it is part of the research process.

### *Sample*

Interview participants were recruited through our institutional student (graduate and undergraduate) listserv, as well as through social media. We initially had 27 students sign up for interviews, but only 17 students completed their interviews. The sample was largely comprised of graduate students (only 3 were undergraduates), and 10 out of the 17 students interviewed were from our institution. The sample was predominantly white (only 4 explicitly identified as at least partially non-white) and female (11 out of 17).

Interviewees completed an online survey prior to scheduling their interviews, which asked for consent to participate, basic demographic questions, and to pick a method of interview (focus group or individual), along with a date/time they were available. They were also instructed to select a code name that would be used in the interview and this manuscript. Despite having some rather silly responses (Deadlegs, DanDan Noodles, Helena Handbasket), we will honor their choice in names. We elected not to ask any questions directly about participants’ disabilities. Many chose to self-disclose during interviews. Of those who did, six had Ehlers Danlos Syndrome (EDS), making it the most common disability, followed by attention deficit hyperactivity disorder (ADHD). Other conditions disclosed included chronic pain, complex post-traumatic stress disorder (cPTSD), depression, postural tachycardia syndrome (PoTS), obsessive-compulsive disorder (OCD), autism, and several fine-motor disorders. Most participants were multiply

disabled. Although we targeted a minimum of 20 interviews, we felt we were reaching saturation by the end of the 15th interview, as the content covered by the participants had begun to repeat, rather than reveal (Jackson and Mezzei 2011, 2018).

### *Interview Questions and Process*

In thinking of our original research question, and the way the social model functions in terms of identifying physical barriers, we asked specific questions about experiences with DSOs, instructors, and courses. The interview schedule was split into 3 sections: before, during, and after COVID-19 (see Appendix A for full interview schedule). Our questions dealt with interactions with others on campus, the accommodations acquisition process, how students manage their disability themselves, what changed during COVID-19, and what they want to see as colleges return to on-campus classes in the fall.

Although we conceived of this study as consisting of approximately 5 focus group interviews, most participants indicated that they preferred individual interviews, and of those who indicated they would be fine with a group interview, most had specific needs when it came to dates and time, so only one interview ended up being a focus group. Interviews were divided in thirds, with both researchers completing 5-6 individual interviews each, and the remaining ones were completed together. Interviews lasted from thirty minutes to one and a half hours, with the majority lasting about an hour. All interviews were conducted virtually with Zoom. We asked respondents about their access needs prior to the interviews. We offered CART services for those who indicated they required captions, but all offered to complete their interviews with auto-captions enabled, rather than wait to schedule communication access realtime translation (CART) services. In hopes of creating a safe, welcoming interview environment, we began each session with an accessibility statement and question about pronouns, along with a statement about identity- or person-first language (the researchers both use identity-first, but we invited participants to use whatever language they felt most comfortable with). We also disclosed our disabilities to respondents early in the interview, and worked to make the interviews both safe and conversational.

### *Researcher Positionality*

Both researchers are disabled. One is a 39-year-old cis het white male, the other is a 32-year-old cis het Black woman. Disability features quite prominently in both of our lives, professionally and personally. Undoubtedly our status influenced the interviews,

**Table 1. Interview Participants**

Code Name	Age	Race	Gender	Year
Kay	33	Caucasian	Female	Sophomore
C. James	31	White	Trans man	Graduate Student
Ally	27	White	Woman	Graduate Student
McKenna	22	White	Female	Senior
Morgan	35	White	Female	Graduate Student
Dandan Noodles	25	White	Nonbinary	Graduate Student
Bloom	43	White	Female	Graduate Student
Joe	61	White	Male	Graduate Student
Sabra	69		Female	Graduate Student
C	36	White	Trans Man	Graduate Student
Helena Handbasket	36	White White and Native American (Chickasaw)	Woman	Graduate Student
Deadlegs	29		Male	Graduate Student
Chad	33	Black	Male	Graduate Student
Natasha	20	Asian	Female	Junior
Ann	26	Hispanic	Female	Graduate Student
Hermione	40	White	Cis Woman	Graduate Student
June	45	White	Female	Graduate Student

from question creation to recruitment to the actual interviews themselves. This would make our research what Savin-Baden and Major (2013) call “insider fieldwork,” which can be advantageous because as an in-group member, we are more sensitive to coded language, have more shared cultural capital, and just generally know more about the subject than an out-group member. This is also why we chose thinking with theory as our qualitative approach, because it accounts for the role of the researchers in analysis. Consequently, due to our insider status, reflexivity is important in this study to understand how we participated, rather than objectively lead, the interview process (Finlay 2002). In order to document our role in the research process, we both made notes as we processed the interviews, and communicated about our experiences asynchronously via Marco Polo (a

video/voice messaging app), creating a kind of mixed-medium memoing process.

Both of us have been impacted by the COVID-19 pandemic, as it relates to access to classes. Given the nature of our disabilities, both of us actually feel more accommodated than we were pre-COVID-19, so one of our goals was to try not to let our behavior during the interviews discourage participants from sharing their negative views of remote learning, or inject our beliefs into the analysis process. Additionally, both of us are active in our local and school disabled communities, and want to see greater access for all disabled students and educators. We do not feel that this biased our analysis, but it is a driving point for this research. One feature of this research that we were not prepared for was how enjoyable these interviews would be. Just speaking openly to other disabled people in academia about their experiences was

incredibly refreshing, and really stood out as unique compared to the DSO programming and disability-related university-contracted training Dr. Bones was participating in at the same time. The timing of these two semi-related events (conducting interviews alongside participating in DEI and continuing education) did affect the analytical process, as the centering of disability was quite distinct between event types. We will return to this idea in policy recommendations, but did want to briefly note how the context of being disabled, and actively participating in school programming on disabilities affected this research.

**Table 2. Acronym Glossary**

Acronym	Meaning
ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactivity Disorder
ASL	American Sign Language
BIPOC	Black, Indigenous, People of Color
CART	Communication Access Realtime Translation
cPTSD	Complex Post-Traumatic Stress Disorder
DEI	Diversity, Equity, and Inclusion
DIY	Do It Yourself
DSO	Disability Services Office
EDS	Ehlers Danlos Syndrome
OCD	Obsessive-Compulsive Disorder
POTS	Postural Tachycardia Syndrome
UDL	Universal Design for Learning
UPIAS	Union of the Physically Impaired Against Segregation

**Results**

As discussed above, we began with the basic research question of “what does the social model look like in a digital world, under COVID-19?” To us, this meant determining how the ableist norms of society (including higher education) create access barriers. When it comes to accommodations, we see these as housed more in the social stigma component of the social model, as accommodations exist to address the

inaccessibility of higher education. The social side of disability also comes into play when considering how accommodations are gatekept. We chose to focus on shared experiences, rather than distinct incidents because although disability is deeply personal, interactions with social institutions, such as education, can result in similar patterns. We identified five major categories, which we will describe below, as well as the way respondents shaped the direction of our research. The five major themes are self-accommodations and planning, “setting the table” and spoon conservation, disability as a bodily commitment, redefining fairness in academia, and creating a culture of trust.

Our initial plan was to ask respondents just about their experiences with official accommodations. However, our first (and only) joint interview involved two individuals who did not have any formal accommodations or paperwork with the disability services at their institution. In fact, several students stated that the formal accommodations process was either too difficult to manage, too expensive, or that arguing with either professors or staff was an extra hassle that was not worth it. In their words:

I haven't reached out to get accommodation since I started my program [...] just because I haven't seen a doctor in... quite a few years because I kind of got to that point where I was tired of being poked and prodded and all the blood work, [...], I don't want to go into a doctor's office, even if it means I could get these accommodations like it was just such a strain on my mental health to try to have to deal with that all over again. – Ann

I think we should listen to our students. I think that the DSO process is convoluted and expensive, and you know if you don't have an ADHD diagnosis as an adult and you're trying to get one you have to spend a lot of money. – June

While others bemoaned the complicated process that is acquiring accommodations.

And I know I didn't even know some of the resources existed, that exist, quite frankly, and this semester when I went back to school and I was just like, having so much trouble with everything. –Bloom

Or convinced themselves they did not “deserve” any accommodations.

But I, you know, I just put myself down. I'm like I don't actually don't qualify. It would just be me complaining. Right? And I think, I think that's something that we're kind of trained to think, when it comes to disability is “Oh, somebody else has so much worse. I'm fine.” I don't actually need it. I don't actually need what I need, basically. – C James

I was just trying to pretend to be a normal student and get all of these things done and was failing horribly. – Kay

Even when students acquired accommodations, sometimes they proved to be less than helpful. For example, Sabra needed a textbook for a course, but her DSO said it would take nine weeks for her to receive the material. Helena also had this problem with getting digital versions of her textbooks through her DSO, as she was told some would take six months before she would be able to get her hands on them. When faced with situations like these, it is easy to see why many college students decide to forego the accommodations process all together. This altered our focus from thinking about virtual barriers to access towards questioning the nature of access and accommodations in general.

#### *Do It Yourself*

The pandemic fundamentally shifted the location of education from shared classrooms to homes and dorms. This had the potential to make the social model irrelevant, as many physical barriers to inclusion were removed. However, the sudden onset of new technologies and digital learning created as many virtual barriers as it erased physical ones. This allowed students to utilize the informal accommodations they already employ when completing schoolwork at home. This “do it yourself” (DIY) approach to accommodations took several forms. For some students, working from home meant an ability to tailor spaces to allow for productivity, while also ensuring greater comfort. One interviewee even went so far as to proudly show off her accommodated space:

Okay, for starters right now I am wearing sweatpants [...] and my favorite pajama shirt, which looks enough like a shirt on Zoom that like so I'm in bed right now I have a pillow. I have a weighted blanket. I have a body pillow. And then I have my computer, I will show you where it is it's in the window well here. I have it here, and you can kind of see my house. Hopefully you can't tell him in bed because my body kind of blocks that out. And

I'm looking outside, there's beautiful park and there's often some nice birds to look at and trees and sky. Yeah, and I can turn my camera off if I need to. [...] Oh actually also I have a like a window over your face so I don't have to look at you. I don't want to see people, I do not want to see people. It is like sensory overload, it's too much input, like I'm just lowering the amount, like, I'm. You can see me and my cameras on I'm talking and I'm staring out the window at trees. – Hermione

Other students incorporated technologies into their routines, such as using audiobooks along with physical textbooks, or would replay recorded lectures while completing school work or just when they realized they missed something important.

I can have the book in front of me and read the page nine times, and none of it will be retained, but with an audio book just listening to it, it just, I can actually understand what's happening. – Kay

I've got some accommodations yeah, [...] I've got my little field notebook I carry with me all the time, constantly making notes. I have both a paper planner and digital planner, I've got a smartwatch, my smartphone. A voice recorder, I use Otter AI a lot. – Joe

And I also found that like, like crocheting during class, I could do it without like...I can be like... yeah you know you can't, you can't see what I'm doing. And that, you know, if I needed to, like, I could turn my camera off, and if I...I guess what's the word? Like if I was struggling with paying attention during a lecture. You know I could go back and watch the recorded one later when I have more spoons to do so. Umm and so honestly like remote learning was the best for me. And I wish I could be all the time. – DanDan

Not all of these were expensive technological adoptions, some were simple acts that may seem minor, but can significantly improve a student's ability to learn.

I do try to wear looser clothing just because especially when I'm having a flare up that involves a lot of nerve pain so if I'm wearing like uhh...leggings that are very fitted, umm, it exacerbates the pain a lot more. So I'll probably put shorts on or just very loose minimal clothing so that way I have less



things rubbing on my body that makes the pain even worse. – Ann

So things that I do, I manage my office lighting so I have instead of the bright overhead lights in this really small closet. I have, you know, lamps that I use to kind of manage that sensory overload. [...] I don't turn TVs on. Like, I keep, I try to manage quietness, and that's been the hardest part about reintegration is, I was able to manage that sensory information at home, can't manage it out in the real world. – Morgan

Having control over one's environment may seem like a small thing, but in congregant settings, we surrender our needs in favor of what the majority prefers. This is a disability access issue because basic things like expected dress codes, lighting, and sound can be barriers to inclusion. Though we often assume accommodations are tools given by powerholders to ameliorate specific needs, most disabled students were practiced in creating their own access on their own terms. The downside to DIY accommodations is that they require the cost to be paid entirely by the student.

It was nice in the way like things are flexible and you could set up your own environment but also like, I don't have an amazing office chair, like I it's like expensive to set up your whole life at home as an office, when you...instead of like going to a school where there's infrastructure. – Ally

I set up a projector, like pointed at the ceiling, so that I could project, like, students would turn in their papers and stuff online so I could project their papers on to the ceiling and lie down on my couch and like mark papers that way because I couldn't frickin sit up because I was so I had been made so sick. [...] Nobody paid for that projector, I did. – C.

I requested like a miniature or small keyboard, and the company that my institution uses required me to purchase it regardless of if it was going to work or not. And it was like \$350, which is cost prohibitive. – Helena

However, not all students felt accommodated by being constrained to a home work environment. Students with ADHD in particular voiced frustration at the loss of routine, with C. James saying, “I full disclosure, I hate online classes, I hate them I hate them I hate them. Because one of the lovely side

effects of ADHD is out of sight, out of mind.” But, most reacted to this temporal anomie by leaving notes around the house or setting alarms to make sure they did not forget anything. So even where the pandemic brought new challenges for disabled students to contend with, most found ways to accommodate them on their own terms. Left to their own devices, many disabled students found ways to thrive during COVID-19 since they could make school work for them, on their terms, instead of having to accommodate themselves to the norms of higher education. Instead of relying on passive, one-size-fits-all accommodations that may have only worked in specific contexts, students actively found ways to center their learning in the midst of a global pandemic. This is not particularly surprising, as disability makes one dynamic, able to find solutions to the troubles caused by one's body and the social barriers of disability.

### *Setting the Table*

Disabled people often use the spoons metaphor to describe the limited amounts of energy they possess, and how a disability flare can rob one of their “spoons” before the day even begins (Miserandino 2003). The strict deadlines that often accompany higher education act as a barrier, placing real strains on disabled students, as they are often faced with either missing assignments due to a lack of spoons, or pushing themselves too hard, and dealing with the aftereffects later. For students who deal with disabilities that vary day-to-day, the pandemic allowed them to better plan their spoon usage, to “set the table” if we want to stick with cutlery metaphors.

Like I could do my like physical therapy during the day, I could do my...I could like cook lunch in a certain way. There was like a lot of things that I had a lot more I guess flexibility to do when we were at home. [...] I have a lot of control over how much I umm move, I know sounds weird but it's like, how much I walk around and do stuff and how much I sit down I really need to have like a little delicate balance of that, of doing too much of either is not good so that that's a good thing. – Ally

Removed from the norms and conventions of higher education, some students even realized how much better their health has been over the past year. On student (Ann) with EDS and POTS talked about the tremendous toll traveling to-and-from class in a densely populated Southwest city took on her health, while another (C.) went so far as to state that his health

has never been better; removing the barriers of a shared physical presence allowed him to prioritize his health in a way that he has never been able to before. For students who felt in better health and better accommodated by remote learning, not having to commute to school (or walk around campus) played a major role, as students were able to save spoons spent on travel for coursework.

So, umm during COVID, it's actually been I feel a lot easier for me personally just because I can attend class, sitting in bed, if I'm having a flare up you know I can opt to have my camera off, I had just been crying for three hours because I was in such bad pain but I feel better now and not have to worry about looking presentable. I can just okay I'm good now I can go to class, or even if I'm having a really bad flare up, at least I have the option to comfortably listen to lecture, and a lot of my classes are discussion based so we do a reading and then we come to class and discuss so it wasn't anything too, I guess, strenuous and I feel like the main reason why pre-COVID that I wouldn't go to classes because I didn't have the physical means to get there. – Ann

And so, uh I also found like during COVID, the umm managing of my schedule and everything to be a lot easier. I have a lot more free time, because instead of having to schedule the time to go to class and like do all these things, I come back to my apartment and like do all these things. And just so much time going places and waiting for things to start. I was able to spend more time on my assignments and, you know, focus more on studying. – DanDan

As with the previous theme, there were differences in how ADHD student and physically disabled students<sup>3</sup> approached spoon conservation and planning during the pandemic. Several students described “chunking” work, or going from assignment to assignment as their brains wanted, which is a more natural way to learn for them. We include this under the theme of setting the table, even though it does not directly relate to spoons, because absent a busy, rigorous schedule, students were able to take their learning into their own hands, and do things on their terms, which also required careful planning.

I work better in multiple short increments than I do in long time things. Like, it's very

hard for me to just sit for three hours and work on one thing. So I might work on, like, five different things within an hour just because I like start something, move to another thing, start that. And I'm sure to somebody else that probably sets their anxiety on fire, but I find that I actually am able to think through the thing I was working on previously as I'm working on this other thing because I'll find connections in between the two. – Chad

I hope online classes stay around, especially the asynchronous ones where you can kind of work at them at your own leisure, to make it actually fit with your life. – Kay

Several students even went so far as to say that they no longer felt they needed accommodations when learning was transitioned online, and they could self-pace.

A lot of my classes didn't have lectures, and a lot of my classes stopped having PowerPoints. So, which is good, but it's also not good because it just confused the teachers a little bit they were like, “wait, you have so many accommodations on here but you only need one now?” Umm, I think it made it easier just because like now that it was online, it was, it was self-paced, and I didn't really need as much assistance. – Natasha

My accommodations did change, in that I actually need fewer accommodations, and that professors were much more willing to work with me. – McKenna

I definitely felt more accommodated at home. I no longer required my accommodation, because I didn't need to go anywhere. – DanDan

As important as informal, DIY accommodations were to disabled students during COVID-19, allowing students greater control over how they use their spoons may have been the greatest adaptation, as it brought mastery in a time of great uncertainty. But this benefit went beyond “feeling in control,” as many students were actually able to bring balance to their lives, and prioritize their health, instead of having to borrow spoons (use their finite energy on one day, feeling the effects for several days after) to make it to classes. From a social model standpoint, spoon conservation

<sup>3</sup>Many students in the sample have both physical and mental disabilities. The difference here has to do with which condition needed accommodation at that time.

bridges the gap between impairment and disability, as the former is fundamentally caused by a person’s specific condition(s), but in reality, the demand to be present is rooted in social concepts about work that are ableist in nature. The very idea that learning can only take place when all parties are in the same geographic space ignores the burden this imposes on disabled students. The loss of autonomy, accompanied by the return to the physical demands of school and work routine, was one of the most common fears for the future, and it is easy to see why. Students are very adept at doing what is best for their bodies and their education, when they are allowed to do so.

### *Disability as a Bodily Commitment*

As mentioned above, disabled students see autonomy as the best way to accommodate their disabilities. But this raised a new question, are disabled students the only ones with access issues? If not, who deserves autonomy and flexibility when it comes to the barriers created by higher education? And what does this say about the relationship between higher education and disability in general?

Students praised the ethic of care exhibited during the pandemic, both for themselves and non-disabled students. For a population that is well accustomed to the unpredictability of life, having grace and flexibility universally offered during this time was a dream come true. The emphasis on not just disabled students, but all students was somewhat surprising given that interviews focused only on the experiences of disabled students. Rhetorically, many students spoke of the challenges of non-disabled students when it comes to work, family, and social commitments, likening these to disability. Consequently, they seemingly frame disability as just another life event, or long-term commitment which one has to prioritize at times.

I think with college students, whether they are graduate or undergraduate, you know, most everyone has outside things that impact their life because [...] most public institution students have some sort of commitments outside that’s going to impede whatever “strict schedule” you want to stick to. [...] Life doesn’t stop because you assign a paper, or quiz or something. – Chad

This challenges the narrative of disability in higher education from a constant burden or as a condition unique to disabled students to a shared experience, as disabled students recognize that everyone has access barriers. Professors like to see education as the most important part of a student’s life, when in reality, it’s one of many things they have going on. Disabled

students want to see the totality of a person recognized, as was the case during the pandemic, when professors seemingly acknowledged for the first time that students have lives outside of the classroom, and that they are valid.

Everybody has something going on, and I’m just like, man, I wish this was the mentality all the time because everybody has something going on, no matter what, even though, yes we’re in a global pandemic, but even before global pandemic people need mental health days. – Ann

We have been under utilizing technology, I think up to this point, to let people who are not just disabled people either—although I think they’re a big beneficiary—and all kinds of people. Students with children that have to work and take care of their children who might not be able to do on campus classes, could really benefit from this technology, people who want to go to a particular school and do particular program, but they can’t live there physically, they live where they live and that’s where they need to live. – Deadlegs

The professors were way more flexible, even if you didn’t have, you know, like a medical reason to need these accommodations or like students, you know, might be supporting their families they might be helping younger siblings out with homework attendance was a lot more flexible classes were meeting one to two days a week instead of two to three. – McKenna

So it wasn’t an individual thing they did it for the entire class. And I felt like that’s really what was incredible about it, it wasn’t for individuals, it was how can we get through this together. So what do we all need? – Morgan

Thinking of disability as a commitment to the self or to one’s own body, similar to how we think of a work, family, or even (to a lesser degree) a social commitment illustrates how disability should be viewed by professors. This represents a true normalization of disability, as it is seen as a regular part of life, not a tragic event or something to tiptoe around. And if disability can be seen as one of many commitments or social roles, complete with obligations, then perhaps professors can better understand how it can create role

conflict (when social expectations are at odds with one another) for students, who desperately want to live up to educational expectations, but have to handle a disability flare first.

My health has never been better. It's, I've, I've been able to meet my needs, I've been able to pay my bills, and I've been able to take care of my health, which is not something I've been able to do simultaneously for many years now. – C

I think that professors should continue to be flexible, because over this past...you know...15 months we've realized that not everybody has the same access means, but everybody does have some kind of access need or can benefit from Universal Design. – McKenna

I...I am scared that my classes will be restricted and I won't be able to take them because I won't be able to fit them in around a job. – Kay

Of course, higher education has not been great at understanding that students are complete people, with full lives, as many professors (and lay-persons) still refer to students as “college kids.” The pandemic in many ways broke down the walls between the professional and personal lives of professors and students alike, as we met in the virtual spaces between a professor's couch and a student's dorm. After watching students contend with many of the same work/life balance issues as us, we hope that the humanity of students is not lost once we “return to normal.” This includes extending grace when family, work, or bodily commitments create role conflict with education.

### *Redefining Fairness*

In addition to shedding light on the totality of students (and professors), the pandemic provided space for students to reflect on the norms of academia. Most students who had a negative experience with asking for accommodations from professors were denied on the grounds that it would be “unfair” to all of the students, or that they could not make exceptions for one student.

Um, I think the biggest one or the one that I have overheard, although not personally encountered, is that students who are receiving accommodations are doing so to get a leg up over non-disabled students. I mean, we know that's not true, but that's the sort of rhetoric or the discourse I hear a lot.

And the other one that comes up less frequently, but I think is still quite prevalent, is that disabled students tend to be less competent than others. – Helena

Like if there's 25 questions and [50] minutes, the teacher will go, “Oh, you have no time to look it up.” And so, if say I get time and a half right? So that's 75 minutes, and teachers go, “Oh well now you can cheat.” No, now I can actually read and think about the question. – Natasha

When in the real world, you're never, ever going to be in an exam condition. Like, I don't know why exam conditions are an assessment of what you can do when we're not being prepared for it. I mean, we're not doing brain surgery where you memorize all the parts of the brain because somebody's brain is cut open and you can't look it up right now. – Hermione

We all have different abilities and strengths, and these accommodations just help us be on an even playing field with people that are not disabled. [...] it's not a special privilege. – Natasha

Many academic norms are rooted in the assumption that only non-disabled students will be in classrooms. This coupled with the tendency to “do things as they've always been done,” or treat pedagogical preference as fact means that the institutional norms of higher education are themselves a barrier to access. Just consider the way that poor (performing) students are described: lazy, disinterested, taking the easy way out, and not wanting to do the work. Most of these terms are also used to describe disabled people in and out of academia.

All of the codewords and dog whistles in terms of, you know, like lazier and uninterested or undisciplined, like just all of the things that's like no like actually you're talking about disability and accessibility. [Referencing a former professor whose name he couldn't remember] She thinks all the time about how so many of the things that she thought were academic rigor were just ableism. And so I think that, like, so many of the misconceptions and everything about disability in higher ed kind of boils down to what even are we calling disability? So, it's like, either, it's, it's not actually disability so we don't have to accommodate it. And if we

do have to accommodate it, it's, you're getting something for free. So it's like, you go to one of those two camps and you can't win. Either way. – C

The onus is on the disabled person to “overcome” their disability umm and to act in an abled society in the way an abled person would. Umm and that the ultimate goal for a disabled person is to be “productive,” to contribute to a capitalist society, in a way ...umm... that you know is equivalent to how an abled person would function, whether it's with accommodations or whatever. Instead of how can we improve quality of life for disabled people? What does quality of life look like outside of, you know, capitals production and you know job, the kids, marriage, white picket fence, that sort of societal ideal? How can we imagine what life could look like outside of that? – DanDan

I think accommodation is a lot more than about disability, I think it's about everybody. And I think that by being more flexible, by maybe questioning this idea we have about the standardized, the routine, the norm in education (and really just in general, in our society) [...] I think we're going to help everybody. I think what we will realize is that yeah, the line between disabled and non-disabled is very arbitrary and that it's really contextual, it's socially constructed. I really hope that we see that. – Deadlegs

In advocating for a continuation of grace and understanding, many students were in fact addressing the ableist concept of “fairness” in higher education. In reality, though professors may want to be fair to everyone, the way that academic rigor and standardization are deployed acts as a gatekeeping mechanism to keep disabled students on the margins of higher education. We know that all students are not the same and have different needs. This is actually why accommodations exist in the first place—to level the playing field. For professors to insist that a student with fine motor skill problems (Deadlegs) complete the same timed, in-class activity as his non-disabled peers is not ensuring academic fairness, it is preventing a student from succeeding. The problem is that many professors do not realize that “making things easier” really means removing barriers to success related to disability.

This pandemic was a disabling experience for educators and students alike, as we all grappled with inaccessible spaces, new forms of content, and

unfamiliar technology. Consequently, the shared anomie of COVID-19 created parity for many disabled students, erasing the social component of disability from a social model standpoint. Physical conditions no longer prevented students from attending class or participating in extracurricular activities, students were no longer singled out or forced to disclose if they could manage their conditions on their own, and many professors offered a previously unseen level of flexibility to all students. In other words, a global pandemic actually managed to remove many of the impacts of impairment and minimize the social stigma of disability.

Just being told like oh we don't we don't record lectures. Along comes COVID, turns out you do turns out you do. And it's just a matter of whose bodies are at stake. – C.

So yeah, I just I've been more fully included, and we're fully a part of the life of the department, I finally got into experience with grad school supposed to be. And I should have been having that experience for many years now. And instead I got it for the first time during COVID. – Hermione

Comments like these lead us to question, what if this was the norm? Not forced Zoom university, but centering student needs in higher education. The COVID-19 pandemic showed that we can redefine what is considered “fair” and “appropriate.” Disabled students noticed, and fear that as we return to old routines and in-person learning, we will also see the reemergence of the old idea of fairness, the one that was anything but.

### *Creating a Culture of Trust*

Overall, students were less concerned about paper accommodations, and devoted their time to speaking of cultures of inclusion. This primarily took the form of desperately wanting to be believed by professors, and hoping their disabilities would be acknowledged.

I think one of them is to, you know, we've brought up several times about professors trusting their students. And I think one of them is that you know I...I hope that professors, understand that even if you don't have, you know, an accommodations letter, you may still be disabled. And you know your own body. And it's, you know, your own limitations. And you also know what limitations can be pushed safely and which ones, if you push them will lead, literally to a break. – C. James

But I think that's looking at the problem, looking at the situation, backwards. Instead of being like, “why do I have to give you this accommodation?” look at it as, “how can I best accommodate my students to facilitate their learning?” – DanDan

So, just believing your students. And don't automatically assume the worst, like most students are not trying to pull a fast one on you. They're really not. – C. James

The accommodations process is needlessly trying. As previously discussed, not everyone has equal access to medical care due to financial, geographic, stigma, and other concerns. Requiring students to verify what they know about their own bodies breeds distrust. Disabled students really want to be recognized as experts on their own bodies. DanDan spoke of having to retrieve an autism diagnosis, one that was no more than five years old, while living in a different part of the country than he grew up. Autism is a life course-persistent disability, so why did it have to be a recent diagnosis? Ann also had issues with access to a recent diagnosis while she was living hundreds of miles away from her doctor, now without insurance. Again, these were for conditions that do not go away. Even when it comes to episodic conditions, students said they had learned how to explain disability flares so that professors would believe them.

So generally, what I will do is say, “I'm not feeling well,” rather than like “I'm having panic attacks.” Or, I mean, the fewer details you provide somebody with, the better because the more details you give them the more opportunity you are giving them to tell you that it's in your head, it's fake, it's not real. Or to try to come up with their own little fixes that aren't going to fix it. Whereas if you just say “I'm not feeling well.” “I'm feeling sick right now.” “I have a migraine.” And usually like my nervous system, mental health stuff is what causes the migraine so it's I'm not lying. – Hermione

This gets at a larger desire on the part of disabled students to be believed. Almost every student we interviewed mentioned the most damaging stereotype of disabled students is that they are lazy and trying to game the system. This was echoed in their responses to the question, “Is there anything you'd like to share with educators about accommodations, disability, etc.?”

Students are not lazy, students want to learn. We're paying thousands and thousands of dollars for this. Like, we want this information. We want to do this work. And, you know, humans are fundamentally curious. So, if your students are not doing their work and, like, totally blowing things off, why? [...] Instead of putting up barriers, offer solutions. - DanDan

Umm, I think sometimes a little more patience and understanding would go a long way. Umm, ADHD isn't something that's just in children. It's not that I'm forgetful or lazy, it's that I have a neurodiverse brain. And just a little more understanding would be great. – Kay

Ultimately, that is what disabled students want: to be believed. Students, with or without a disability, are all paying to be in higher education. They want to learn. The accommodations process is not about cheating the system, it's about creating conditions where disabled students can succeed. And isn't that the entire point of college?

Listen to your students because they are the experts on what they need and what is best for their bodies, their minds. And even if you have the same condition of them. You're not the expert on their bodies, and you will never be. Also, if you're not a doctor, a medical doctor, keep your mouth shut, don't suggest yoga, it don't work. [...] You know, it's an issue, it's a barrier issue for people with chronic illness because they know their bodies, oftentimes better than doctors. It's a class issue because doctors are expensive and we do not have universal health care, even for disabled people. – McKenna

This was particularly true for students with invisible disabilities, who felt like they constantly had to “prove” or explain their impairments. With no visible, recognizable signs of impairment, they were most likely to fear being accused of faking their illness. One reason for this is because disability is dynamic (Benness 2019), meaning that it varies day-to-day.

Well, and especially someone with invisible disability, like that's probably the hardest part about having a, like, not being in a wheelchair, because if I was in a wheelchair...if I were in a wheelchair...they'd be like, “Oh! obviously we have to make some accommodations for you because you're in a

wheelchair<sup>4</sup>,” you know? And so, yeah, I don't know, just looking to the future be really nice if people are more educated about invisible disabilities. And the fact that people with them, still, yeah, they deserve compassion. – Bloom

One day I can look completely “normal,” and then the next day I show up with a cane or a brace of some kind, you know because I may be having a flare up that day, and that's when you get bombarded with questions like, “Oh, what's wrong [did you] hurt yourself?” And “I'm like no I didn't hurt myself,” And then when you tell them, you know, it's chronic pain, they're like “Oh have you tried this remedy? I heard turmeric is really great! You know?” and I'm just like... – Ann

Except, then I would have a flare up or whatever, and they'd be like, “well I saw you, you know, going to a class this morning but you didn't go to my class this afternoon.” I'm like, yeah, I you know sprained my knee or whatever at lunch, and it wasn't an option. – McKenna

When asked about positive experiences with professors, before or during the pandemic, students were most likely to tell stories about someone who simply said “I believe you,” or stated they were willing to listen. DanDan described his favorite class, stating that his professor “did not accommodate me specifically; she deliberately designed her class to be as accommodating as possible to all students.” This gets at the crux of the issue of accommodations. While the social model is concerned with understanding impairment vs. disability as a means of removing physical barriers to access, most disabled students are not concerned with what is on paper, so much as how they are treated by persons in positions of authority. Belief and trust are the most important accommodations educators can make because they speak to the whole person, not just how they approach one specific task. Students notice, and remember, professors who treat them fairly, who believe them, and who build a working relationship on mutual trust.

## Conclusion and Discussion

Disabled students were, largely, an afterthought during COVID-19, despite being the most likely to be directly impacted by the virus and changes to course delivery. Despite these challenges, disabled students were able to not just survive, but in many cases thrive during this time. We interviewed disabled students about their experiences with accommodations and inclusion in higher education before, during, and (presumably) after COVID-19. Using Jackson and Mazzei's thinking with theory approach, we sought to see how the social model of disability played out during COVID-19, paying particular attention to issues related to access and accommodations. As part of the collaborative generation of data, our research question shifted from narrowly defined barriers to more general thoughts and expressions of what it means to be disabled, what inclusion looks like, and how disabled students manage and succeed in higher education. In their 2018 chapter on thinking with theory, Jackson and Mazzei provide examples of how to plug in theory, and pull what are often relatively simple, one word concepts which center the issue at hand. If we were to complete this exercise, that word would be “autonomy.”

Accustomed to relying on their own skills and ingenuity in the face of inaccessibility, disabled students took their education into their own hands by creating their own accommodated spaces. The pandemic removed many physical barriers, such as constant travel to and from campus, strict schedules, and forced routines. Free of these burdens, many students were able to center their own bodies and learn on their time, mitigating many of the new virtual barriers they experienced. This is not to say that all disabled students want to remain remote, or that self-paced asynchronous learning works for everyone. Several said they desperately want to go back to normal, but a different kind of normal than we had pre-COVID-19. They said they want a new normal that embraces the flexibility and grace that had previously been denied to them.

It was interesting to note how disabled students advocated for increased accessibility for not just themselves, but all students. Recognizing that they are not the only group that has to deal with disruptions to education, and role conflict due to commitments, this shows how disabled students view disability: as just a part of life. That being said, this pandemic also laid bare the ways that ableism is woven into the fabric of academia. The standardization of assessment, and how it is cast as necessary rigor, disproportionately affect disabled students. It bears repeating, disabled students

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<sup>4</sup>Wheelchair users prefer this terminology (user), rather than being “in” a wheelchair. Additionally, at least 2 of the interview participants are wheelchair users, and still face barriers. That said, Bloom is correct in stating that the perception of disability legitimacy varies by visibility, as do barriers to inclusion.

who not want an advantage over non-disabled students, they simply want to be allowed to learn. Going forward, students now know that asynchronous classes are possible; that remote learning can easily be a normal part of higher education. They also know that professors can take them at their word, and extend kindness when disability flares happen. The question then becomes, how do professors support disabled students in a post-COVID-19 world?

### *Policy Recommendations*

Given the larger than expected number of students who did not have formal accommodations, it is clear that we need to rethink the DSO model. Not all students have access to regular medical care, which creates an unnecessary barrier. Disabilities exist whether one has a note from a doctor (that is less than 5 years old) or not. Students should not have to grapple with issues related to geography, prohibitive costs, stigma, and negative medical experiences just to prove something that could fairly easily be dealt with by a basic needs assessment administered by the university through a DSO. Although self-diagnosis is a controversial concept, many disabled people would tell you that they know their bodies, and are the ones best qualified to say what they can and cannot do (Sarrett 2016). The argument against self-diagnosis is that certain conditions could be over-diagnosed or misdiagnosed (Tyrer et al. 2019, Eysenbach and Diepgen 1999), but given that universities do not prescribe medications, the only “risk” would be that perhaps some students would get more time on exams or be allowed to take them in a distraction-free environment. To us, these risks seem rather low-stakes, and well worth it if it ensures disabled students have equal access to course materials and assessment. If universities are not willing to institute a self-diagnosis or more cooperative, needs-based mode of accommodations assessment, then funding needs to be made available for disabled students to acquire necessary medical paperwork. College is already expensive for students, and disabled students should not bear another financial hardship just to learn.

Second, it is clear that disability needs to be better addressed by universities, particularly when it comes to educating professors. Disabled people make up 26% of the US population (CDC 2021), and it is estimated that 20% of US college students have a disability (US Department of Education). And yet, disability is frequently left out of the Diversity and Inclusion discussion. Professors need training on disability, particularly invisible disabilities, which may not align with what a non-disabled person “sees” as a real disability. Instructors also need to learn about the purpose of accommodations. As we saw in our

interviews, too many instructors see accommodations as ways to not do the work or as something that is fundamentally unfair to non-disabled students. This could not be further from the truth. Accommodations are access, and an inclusive classroom demands that everyone be able to access the material. While it may seem unfair for some students to have different tools to ensure that access, this is precisely what a just classroom demands. Likewise, there needs to be better outreach about disability directed at students. Several participants mentioned that they were unaware of services their DSO provided, even after going through the accommodations process. Others suffered in silence, blaming themselves rather than their need for access because either they did not think that an adult could have ADHD or that they “weren’t disabled enough” for accommodations. We need more plain language, direct outreach when it comes to informing students of their rights, and the assistance they have access to.

Any potential new programs, be they outreach or DEI, need to be made by disabled people, and those people need to be compensated for their time. In particular, schools need to recruit (and compensate) disabled BIPOC. Disability is an intersectional identity, not a monolith, so an all-white disability panel will fail to represent a vast array of experiences with disability. Anecdotally speaking, DEI made by non-minoritized populations for non-minoritized populations comes across very differently than when it is created by in-group members. Insistence on person-first language and a refusal to even say “disabled” creates more stigma than it dissolves, even if the intention is to treat disabled students as “persons first.” Likewise, framing disability as a “challenge” can actually lead students to avoid accommodations because they feel like they just need to step up and do more. Any discourse that frames disability as a “special need” reifies the idea that disabled students are asking for extra privileges and ignores the fact that everyone, regardless of disability status, has needs. Finally, most accessibility training includes pitches like “universal design helps all students!” While this is true, and we want to see all students succeed, the focus on non-disabled populations when talking about access methods specifically designed for disabled students can also be othering. Disabled students are in your classes, and their experiences matter. That alone should be enough of a sell to create accessible content. In other words, professors should not need to center non-disabled students in order to see value in inclusive pedagogy. Disabled faculty, students, and instructional designers all have more cultural capital and can better reach disabled students on their level, because we know what it’s like to be them.



Finally, we recommend educators use this period, as we return to campus, as a reflection point. So many educational norms have just been “the way we’ve always done things.” COVID-19 fundamentally disrupted the status quo, and gave us an opportunity to rethink our pedagogy. During this period, we saw grace, forgiveness, and flexibility normalized. Will that remain when we go back to “normal?” Although online education has been, admittedly, a pain born of invisible labor (labor which has been ridiculed in popular media pieces about “Zoom University” and social media critiques of paying full tuition for online classes), it is going to be difficult to go back to pretending that remote learning is not an option. Although hybrid models of education do require more work on the part of instructors, we now understand that maintaining a physical presence in a classroom is not a prerequisite for learning. Virtually all of our sample advocated for the continuation of virtual options (either hybrid or dedicated online sections of classes), as well as the sustained use of accessible technology, particularly caption, in online and in-person classes. They also strongly professed a hope that professors would continue to understand that students are whole people with lives outside of academia; that life sometimes happens and education cannot always be the main commitment for students. As educators ourselves, we know that a lot of this grace, flexibility, and accommodations has come at the expense of instructor’s free time. We also know that, just as with students, not all delivery modalities will work for all instructors. But over and over again, we heard students’ desire for more options when it comes to higher education, in hopes that they can find a model that best helps them succeed. For educators who care about student success and wellbeing, doing what they can, with what power they have, can make or break the return to campus for so many disabled students.

#### *Weaknesses and Strengths*

This study does have several weaknesses that must be addressed. First, our sample size was small. We had twenty-four students sign up for interviews, but were only able to complete 17 interviews. The seven missing interviews were contacted multiple times, and all had an interview schedule at least once. We are unsure what caused the high rate of no-shows. We are dealing with a college population, who we are told tend to avoid emails. Interviews also occurred at the conclusion of the Spring 2021 semester, which marks almost a year and a half of online pandemic learning, therefore Zoom fatigue may have been a factor. As a result, we drew from our personal social media networks more than we would have liked, but still have plenty of respondents recruited through more

traditional means. We must note that even as a convenience sample, our respondents tended to be more likely to be graduate students than undergraduates, and we were unable to recruit a large number of BIPOC for this study. Disability is intersectional and future studies need to recruit and listen to non-white disabled voices.

Third, we did not collect data on disabilities from our sample, but relied on respondent decisions to self-disclose. We feel this was actually a strength of our study, as it gave interviewees more autonomy when it came to how they presented their disabled selves, but it may have obscured some themes by disability type. Relatedly, the most commonly self-disclosed disability in the sample was EDS. Given that this is considered a rare disease, we either accidentally tapped into the EDS community, supplied evidence that persons with EDS are more likely to talk about their disability, or our study may suggest EDS is not as uncommon as previously thought. In all likelihood, a combination of all three was at work. Fourth, our survey relied on retrospective data and self-assessment, neither of which may be the most reliable indicators (Bell and Bell 2018). However, negative (and positive) events related to higher education and disability likely are associated with a strong emotional response, and stand out in the minds of those who experience them. Additionally, as our respondents insist, disabled people should be considered the authority on disabled knowledge, including over one’s own body. Despite these weaknesses, we feel confident that this study supplied novel information, and allowed disabled students to speak on their terms about their experiences.

There were several strengths to this study we would like to highlight. In 1998, James Charlton released the book *Nothing About Us Without Us: Disability and Empowerment*. The phrase “nothing about us without us” has become a motto for the disability rights movement, and a call to center disability discourse on disabled voices. We feel that this study does just that. At a time when the disabled community has experienced so much loss and uncertainty, the creation of crip spaces to allow for an #OwnVoices (Duyvis, n.d.) approach to accessibility was a true joy for the researchers, and hopefully, the interviewees. As previously mentioned, far too much of the narrative of disability has been led by non-disabled experts telling disabled people how to feel, along with what they are and are not capable of. Putting the disabled students themselves at the center of this conversation is a small step to correct this wrong going forward. Relatedly, we hope that our own experiences with disability allowed us to see and understand the interviewees in ways that abled researchers would not. Disability is still highly

stigmatized (Bogart, Rosa, and Slepian 2019), and having a place to be openly and unapologetically disabled, with researchers who were familiar with PoTS, EDS, ADHD, depression, etc. helped us to move past the medical model. We also tried to make the interviews as accessible as possible. Although we initially envisioned focus groups, we pivoted to interviews based on participant preference. We also offered CART services for Deaf, deaf, hard of hearing, and students with auditory processing disabilities, but no one took us up on this offer. We did provide live auto-captions. These are, admittedly, inferior to CART live transcription, but due to the last-minute nature of most interview scheduling, they were acceptable. Finally, although we intended this study to focus on the experiences of just disabled students, most of our sample had experience with teaching as well. This actually made for a more robust discussion of disability in higher education, as participants could talk about how they approached access in their classrooms.

The social model has benefits for understanding the disabled experience, but it also fails to consider how it feels to be disabled in higher education. As our interviews showed, the strict binaries of the impairment vs. disability narrative can help to inform how disability operates in higher education, but ultimately disabled students hold a much more complex understanding of disability, impairment, access, barriers, and inclusion. This is because it functions better as a heuristic device, rather than a pure theory. Removing the artificial lines created by the theory, we see how students live at the threshold of impairment and disability. This is why autonomy is so important for disabled students. When an impairment flares, professors can use their power to enforce the social control of disability, or listen to students and respond to their needs. Likewise, professors can build flexibility into their courses to transfer power to students, and allow them to prioritize which ever commitment most needs their attention at a given time. Empowered, centered, autonomous students are most likely to maintain engagement and succeed. Ultimately, it is up to educators to decide how to treat their classrooms in a post-COVID-19 world. Do we increase access and let students use the tools that have helped them succeed over the past year and a half, or do we go back to “normal”?

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### Author Biography

**Paul D.C. Bones, Ph.D.** is an Assistant Professor at Texas Woman’s University in Denton, TX. His primary research areas are disabilities, ecological predictors of crime, and hate crimes. His publications have appeared in *The Journal of Quantitative Criminology*, *The Social Science Journal*, *The Journal for the Scientific Study of Religion*, *Sociological Spectrum*, and *The Journal of Transformative Learning*. He has also published chapters in *Hate Crimes* (Carolina Academic Press) and *A Legacy of Gloria E. Anzaldúa: “May We Do Work that Matters”* (Texas A&M Press). He is co-editor of the forthcoming *Redefining Disability* (Brill/Sense).

**Vanessa Ellison** is a sociology doctoral candidate at Texas Woman’s University. Her research interests include food culture, disability, sustainability and veganism. When she has free time, she likes to read for leisure, eat vegan ice cream and travel with her partner of 14 years, Landon.

### Appendix – Interview Schedule

- Ice Breaker: Hello, I’m Dr. Paul Bones and this is Ph.D. Candidate Vanessa Ellison. We are both disabled. Both of us use identity-first language, feel free to use whatever language/terms you feel most comfortable with.
    - Just to start things out, what do you feel are some of the misunderstandings/stereotypes about disability you feel should be addressed in college?
  - Okay, let’s start with life before COVID.
    - How often did you interact with professors, administrators, staff, and other students who are disabled?
      - How out were you?
    - How easy/difficult was it to acquire necessary accommodations? What did the process look like for you?
      - If not, do you do things to manage your disability on your end?
    - How did having a disability affect your ability to successfully function academically, and generally?
    - Did you ever encounter resistance when trying to get accommodations? Do you have any examples?
    - How supported did you feel in your classes and on campus?
      - Did you feel like you were a part of the overall campus community?
- Now let’s switch to during COVID.
- What changes did you experience in terms of access to your classes?
    - Did you require new accommodations or did your accommodations change at all?
  - How accessible do you find online education versus in-person classes?
  - Were teachers willing to accommodate your online learning?
  - Do you have any examples of how a professor either went out of their way to help you, or to refuse you?
  - Did anything change with your overall connection to the campus and your fellow students?
- Moving outside of education,
- Were there any accommodations you saw businesses make that benefited you (like contactless delivery, more delivery options, etc.)?
- Many campuses are planning for a full in-person return to campus in the fall. How do you feel about this?
- What do you hope sticks around post-COVID, in terms of access, technology, etc.?
  - What do you fear will be taken away?
  - What do you want to see go away?
- This study is fundamentally about you, and your experiences. Is there anything you’d like to share with educators about accommodation, disability, etc.?
- Are there other things that would make your learning more successful that don’t fall under the category of “accommodations”?