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“Making it work” to leave home?: Students in wheelchairs’ experiences and decision making regarding the residential college experience.

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Abstract:

Students with disabilities attain a 4-year college degree at only 12.5% of the national average (“Fast Facts: Students with Disabilities,” 2021). By studying the intersection of inclusion, higher education, and disability studies, my capstone explores a subset of this dilemma to focus on students in wheelchairs’ decision-making process about where to attend college and their subsequent time at college.

My research makes space for the complexity of students in wheelchairs’ lived experiences across the United States (U.S.) to enlighten stakeholders about the current landscape and opportunities to better support these students. For this study, I explored: what are the recent experiences of U.S. undergraduates in wheelchairs who attended residential universities versus those who lived at home during college? How can we use these experiences to deliver more responsive support these students? Commuting and residential students have inherently different experiences in college, which might include investment in college, social life, time spent at an institution, and extracurricular involvement. When combined with the unique considerations of students in wheelchairs—i.e. care, accessibility, transportation—that may implicate a residential experience, focusing on the residential distinction is important in illuminating how wheelchair users understand their choices and experiences in college.

Interviewing nine students who used wheelchairs—living with Spinal Muscular Atrophy (SMA), Muscular Dystrophy (MD), and Cerebral Palsy (CP)—and graduated from an American college or university in the last ten years revealed wheelchair users’ tremendously complicated decision-making and experiences in college along with aspirations they shared with other college student. Confounded often with a heightened need for students in wheelchairs to attend college to gain a sense of independence they may especially lack due to disability-related dependence, this capstone is critical in making a supportive residential college experience possible (Landre, 2019). This research will hopefully inform policy recommendations related to care, accessibility, and inclusion that supports students in wheelchairs by minimizing disability-related burdens.

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This capstone is a work of Yale student research. The arguments and research in the project are those of the individual student. They are not endorsed by Yale, nor are they official university positions or statements.

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INTRODUCTION

I used to attend a summer camp for people with muscular dystrophy, and another camper was my academic inspiration: she was at the top of her class and took immense pride in her learning. Yet, she solemnly told me one day that she was attending her local community college despite being admitted to several top-ranked colleges. When I asked if she was excited, she said, “no, I just couldn’t make leaving home work.”

As someone who has been in a wheelchair and required 24/7 care since early childhood, I grew up intimately invested in the experience of students in wheelchairs accessing education.¹ I frequently wondered as a child: why am I the only person in a wheelchair at school, at summer camp, and at pre-college summer programs? Why do I have to struggle to balance my medical needs—i.e. 24/7 care, doctor’s appointments that caused me to miss a third of every school year—with the desire to fit in among my peers and keep up with the rigor of the private school education system I was part of? From a young age, I cared about school more than most of my peers: school was the one thing I felt I had control over and made me feel capable when I felt helpless and dependent in much of my life. Yet, even still, the odds felt stacked against me and it felt like much of my academic success came down to luck, such as good health and understanding teachers. Nonetheless, candidly, for most of that time, I felt confused about this underrepresentation yet complacent in accepting it as the status quo.

At Yale, that underlying curiosity and disturbance grew as I saw peers in wheelchairs *really* struggle to choose a college that was feasible given their needs and subsequent ability to

¹ For the purpose of consistency, a wheelchair user will be defined as a person who expected to and did use a wheelchair in college as a necessary vehicle of independence.

make it through their four years at college. I knew of a student at a peer institution who would only drink two cups of water a day because she could not afford a personal aide to help her use the bathroom. Another student spent months fighting Medicaid to expand her personal care hours so that she did not need to drop out of college and noted the “it becomes emotionally draining at times” (Samee Ali, 2020). These experiences served as the impetus to commit to understanding how people of similar hopes, dreams, and ability could face such an opportunity gap. In all of these cases, students in wheelchairs were intellectually and socially able to fully participate at elite institutions, but the inability to source and finance their personal care prevented them from doing so. Thus, I learned that real barriers exist for students in wheelchairs that ought to be addressed to reduce this disparity, and that the first step is making room to hear these students’ lived experience. Meaningful changes require the input of the students impacted—who know their needs best—in their design.

Research corroborates students in wheelchairs’ pervasive disadvantage that I have observed. While the number of students with disabilities is increasing over time to keep pace with a growing American population, the opportunity gap—graduation rates, enrollment rates—between non-disabled and disabled students has remained stable (Toutain, 2019).² Relatedly, research has found consistent under-matching—a phenomenon in which well-qualified students attend selective schools at disproportionately low rates—of students with physical disabilities in attaining higher education (Hudes, 2019). Even when adjusted for institutional selectivity, studies find that “students with disabilities undermatch at a greater rate than the overall studied

² This capstone will adhere to the American with Disabilities Act of 1990’s (ADA) definition of a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activity” (“What is the definition of disability under the ADA,” 2022)

sample” and that there exists a stark gap between the “desire and potential to enter into higher education and actual enrollment” (Hudes, 2019).³ There is a clear disparity in the potential and actualization of potential related to a college experience for students with physical disabilities.

For many, the process of solidifying logistics for going to college is simply too much and the anxiety does not justify the risk (Fichten, 1998). Logistics often include moving medical equipment and medications to college, finding healthcare providers, and being able to adequately set-up a college space that meets the student’s needs (Fitchen, 1998). Once a student is at college, accommodations are often insufficient to support student success (Losinsky, 2003). The 360-degree logistical set of needs students in wheelchairs have require enormous amounts of coordination among stakeholders (healthcare providers, administration at college institutions, caregivers, educators, parents) that are often overwhelming for students to navigate (Losinsky, 2003).

For many students in wheelchairs living away from home for the first time, care consists of a 24/7 home health aide who assists in daily acts of living (ADLs) such as changing, getting out of bed, using the bathroom, and eating. In fact, disability rights scholars acknowledge that for many students, access to 24/7 care is a fundamental necessity, and without such, “individuals with severe physical disabilities simply cannot attend and graduate from postsecondary degree programs” (Stumbo, 2009). Yet, the costs of care are tremendous and often unaffordable for even middle-class families, with a 2015 study finding that the median average cost of a home health aide is \$54,912 annually, which was 80% the median middle-class annual income in 2019

³ Important to note, when research specific to students in wheelchairs is not available—which is frequent given the limited research conducted on the topic—this capstone relies on the broader international field of research on students with disabilities.

(Genworth, 2015; Vega, 2021). The strain—economic, opportunity, health—this puts on entire families is undeniable.

The all-encompassing complexity inherent in the college process—from application to graduation—makes the decision to attend a residential institution or live at home for college not a choice, but a simple reality check for many students. Residential institutions are meant to instill a sense of autonomy in students that prepare them for adulthood (Mulder, 2002). In many ways, these needs are elevated for students in wheelchairs who may have been previously unable to access feelings of independence due to their disability (Landre, 2019). Among many student-reported benefits of living at college, some included “encouraging students to take risks and learn how to fail” and “providing cross cultural experiences” (Bryant, 2014). The ability to have an experience that contrasts the sheltered environment of home is invaluable and oftentimes something that only a residential college experience provides for wheelchair users.

The stakes for students in wheelchairs are high and unavoidable. One in five students with all disabilities report never receiving accommodations that they are approved for (Stumbo, 2009). At the same time, studies show a direct correlation in grade-point-average and the uptake of accessibility accommodations, suggesting that students in wheelchairs are able to thrive when adequately supported (Schruer et. al. 2014). More broadly, supporting students in wheelchairs throughout their time at college achieves a wider good and reverberates for students across the university. Consistent with the Universal Design for Learning—education can be accessible when adequately altered in its delivery and assessment based on need—creating systems that allow students with disabilities to share their experiences and voices with non-disabled peers encourages growth for all students by promoting diversity on campuses (Rose, 2002).

My research will centralize students in wheelchairs' experiences and voices to give them agency in promoting support structures that let these students flourish in college given complex considerations, needs, and experiences. This will depart from the dominant narrative that merely underscores the failures of systems and circumstances that prevent these students from crossing the finish line. *By interviewing nine students who used wheelchairs while attending a college in the U.S. in the last decade, I found that wheelchair users have a uniquely complicated college experience related to managing medical needs, social life, and academic rigor. Given that these students also emphatically believe that a residential college experience is invaluable—especially for wheelchair users who may have been deprived independence otherwise—this research mandates more comprehensive support structures especially related to care and accessibility to ensure that a residential experience is an option for all wheelchair users.*

LITERATURE REVIEW

History of disability-related legislation

Understanding the history of the disability rights movement—including landmark legislation such as Section 504 of the 1973 Rehabilitation Act, Individuals with Disabilities Education Act, and Americans with Disabilities Act—is critical in situating the current landscape of higher education for students in wheelchairs. Ultimately, its history shows how people's ideas regarding disability changed overtime and how that change resulted in advocacy and legislation. Grassroots organizing directly led to legislation, showing the sheer power of “thousands of people who make up the disability rights movement” (Mayerson, 1992).

The Civil Rights Act of 1964's exclusion of disability—only accounting for “race, color, religion, sex or national origin”—yet concurrent dogma of zero-tolerance for discrimination

inspired advocates to fight for similar disability-related legislation (“The History of Disability Rights in the United States,” 2022). Moreover, many goals and beliefs were shared among disability rights and Civil Rights advocates; both required “challenging negative attitudes and stereotypes, rallying for political and institutional change, and lobbying for the self-determination of a minority community” (“A Brief History of the Disability Rights Movement,” 2022). Thus, sit-ins and protests were popular, with the longest ones—28 days in San Francisco with 150 people and a march in Washington, D.C.—contributing to the subsequent passage of Section 504 of the 1973 Rehabilitation Act shortly after (Mayerson, 1992;). Thus, people’s changing mindsets towards one of consideration and advocacy for the rights of people with disabilities was critical in changing culture and inspiring legal action.

Section 504 of the 1973 Rehabilitation Act was monumental in first defining people with disabilities as a minority group and prohibiting discrimination on its basis (Mayerson, 1992). The Act explicitly states that “no otherwise qualified individual with a disability in the United States... shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance” and includes “college, university, or other postsecondary institution, or a public system of higher education” (“Section 504, Rehabilitation Act of 1973,” 1973). This law represents the government’s first formal response to disability being a government problem that required a government solution. Thus, the Act rendered discrimination of people with disabilities illegal for any institution receiving federal funding; given that many universities and college receive federal funding, this was critical in advancing higher education for students with

disabilities by setting an expectation of inclusion. The Act's provisions set a precedent for future legislation to build upon.

Subsequently, the Individuals with Disabilities Education Act (IDEA) of 1975 built upon Section 504 of the Rehabilitation Act to focus specifically on supporting students with disabilities. IDEA mandates that students with disabilities receive a "free and appropriate education" ("About IDEA," 2018). Included in IDEA is the mandate that students with disabilities receive an Individualized Education Plan (IEP), an educational plan tailored to each student based on their needs to maximize success while providing proper accommodations ("A Brief History of the Disability Rights Movement," 2022). Additionally, IDEA required students with disabilities to be educated in the "Least Restrictive Environment," which mandates that they are integrated into general education classrooms "to the maximum extent appropriate" and that segregation of students with disabilities only occurs if extra support services cannot meet the needs of students with disabilities ("Sec. 300.114 LRE Requirements," 2018). Ultimately, IDEA made inclusion simply a matter of meeting legal and moral standards that reject discrimination and ensure that people with disabilities receive and equal services and opportunities.

Finally, the Americans with Disabilities Act of 1990 was perhaps the culmination of previous legislation in expanding prohibition of discrimination towards people with disabilities in *all* areas of public life and some areas of private life (Meldon, 2022). In particular, Title II "requires public entities to make their programs, services and activities accessible to individuals with disabilities" while Title III "sets the minimum standards for accessibility for alterations and new construction of commercial facilities and privately owned public accommodations. It also requires public accommodations to remove barriers in existing buildings where it can be done

“without much difficulty or expense” (“An Overview of the Americans With Disabilities Act,” 2022). These provisions applied to colleges and universities—both private and public—in legally mandating that they make their spaces and services accessible to students with disabilities.

However, it also left caveats for institutions to use in avoiding renovating buildings. For example, it requires accessibility if it does not involve “much difficulty or expense” and rather sets “minimum standards” (“An Overview of the Americans With Disabilities Act,” 2022). Yet, no definition or threshold were set for either, leaving institutions negotiating room to avoid costly reorganizing to make their spaces more inclusive. Though “minimum standards” were critical in ensuring at least some protection for students, recent student experiences show that students often require more than “minimum standards” and that, more often, “minimum standards” are simply subminimal. Yet, the Act itself has experienced growth in recent years, with 2008 amendments expanding the scope of “disability to ensure that definition would be broadly construed and applied without extensive analysis” (“Final Rule Implementing the ADA Amendments Act of 2008,” 2008). This provides hope that the Act will continue to evolve to meet the growing need for people with disabilities in years to come.

Ultimately, the history of the disability right’s movement—including game changing legislation—both show the important ways our culture and legal system have changed for the better yet continue to have opportunity for betterment. One on hand, legislation has essential provisions to better support, consider, and protect students and people with disabilities and sets a standard against discrimination and towards inclusion. However, legislation’s ambiguity continues to disadvantage the same people that it protects, thus leaving room for more robust

support systems in future years. Nonetheless, disability is on the public and government's radar in a way that continues to grow and remains unprecedented.

Barriers through physical inaccessibility

Existing literature explores and uncovers the disparity between theory and practice with regard to physical accessibility on college campuses (Chiwandire, 2017). Surprisingly, much of the limited research on physical (in)accessibility on college campuses stems internationally, specifically South Africa (Chiwandire, 2017; Losinsky, 2003). In South Africa, despite a constitutional mandate of equitable education for all people, including students who use wheelchairs, campuses remain physically inaccessible, often by relying on "preservation and heritage justification for failing to modify older buildings" (Chiwandire, 2017). This research bears consistent themes with accessibility issues in the U.S. where there are also exemptions that excuse historic buildings from complying with accessibility standards mandated in the ADA, thus showing the global relevance of issues related to physical accessibility on campuses (Milley, 2000).

Additionally, while many colleges meet legal requirements of accessibility, they often provide students with dehumanizing, disruptive, and bare-minimum accessibility (Piro, 2017). Often times, college campuses that are technically physically accessible still pose unrealistic and ostracizing burdens on students in wheelchairs. Research finds that on public university campuses in South Africa, "the total mean distance traveled between lecture theatre changeover by wheelchair-bound students was 402 metres, which was a mean difference of 66 longer than for ambulant students. The mean time taken was 17 minutes, which was 11 minutes longer than for ambulant students" (Losinsky, 2003). These same college campuses often allot ten minutes

for students to transition between classes (Losinsky, 2003). Thus, students in wheelchairs are literally unable—due to university infrastructure—to attend classes in full. Moreover, these students are isolated from their non-disabled peers, late to class thus perhaps missing key educational content or appearing tardy, have an added time burden, and are largely helpless in rectifying the situation.

These issues are not isolated to South Africa. There is not comparable research for college students in wheelchairs in the U.S., but student narratives reaffirm this disheartening and isolating experience in which physically accessing campuses that meet bare minimum standards simply takes more energy and time than for nondisabled peers. In recounting her experience touring three U.S. colleges, Valerie Piro describes having “to circle around the campus before I found a flat entrance....I needed to wait about 15 minutes before a security guard showed up. He said the [elevator] button ... was broken” (Piro, 2017). Situations like Piro’s discourage students in wheelchairs from attending universities that are not set up for, and show no effort to support, their success. In aggregate, failure to make college campuses physically accessible culminates in the fact that “universities are still not places where all students are equally able to integrate socially” (Chiwandire, 2017). Too often, accommodations are withheld from students—whether on an individual, institutional or governmental level—and thus students who use wheelchairs are unable to reach their full potential.

Care challenges

Additionally, many students in wheelchairs need personal care to physically survive in college; the inability to source this care prevents many students from attaining a college degree. People in wheelchairs often require “heavy reliance on personal and technological assistance”

that often results in “access to personal assistance is necessary 24 hours a day, 7 days a week, 365 days a year” to assist them in Acts of Daily Living that are inherently part of the college process (Stumbo, 2009). Without having access to assistance in tasks such as toileting, changing, feeding, and showering, these students cannot function at college. Thus, meeting this need is perhaps most imperative in supporting students in wheelchairs at the college level. In fact, Anna Landre became an internet sensation when sharing her “despair, helplessness...anger and rage” towards a Medicaid decision that cut her personal care by a third, almost leaving her unable to continue her education at Georgetown (Landre, 2019). For hundreds of students like Landre, the U.S. government is failing students in wheelchairs, leaving them in constant fear of loss of an education and independence. Landre writes, “the stakes were high: losing the appeal would mean that I wouldn’t be able to return to college in the fall, or live independently in any context. Instead, I would have to move back to New Jersey to rely on unpaid care from my family, likely forcing my mom to quit her full-time job” (Landre, 2019). Thus, accessing care can quite literally make or break a highly qualified student in a wheelchair from being able to attain a residential college.

Withheld accommodations

Beyond physical need, institutionally provided accommodations must be granted but are often withheld. These accommodations might include test-taking accommodations, note-taking assistance, housing accommodations, etc. Even when accommodations are approved and verified, gap exists between approval and actualization of accommodations (Toutain, 2019). A recent study found a two-fold disparity in accommodations related to implementation and efficacy; faculty frequently refuse accommodations, and other times, accommodations “aren’t

functional or helpful” to students, which understandably discourages students from believing that their success can be supported (Toutain, 2019). Yet, a recent study found that when accommodations *are* thoughtfully and effectively implemented, their impact on student achievement is astonishing: higher uptake in efficacious and reasonable accommodations “revealed significant correlations between the use of accommodations and Grades Point Average, participation in student experiences, satisfaction with participation, and appraisal of the institution as a facilitating environment” (Schreuer, 2014). These findings support the urgency and potential that reasonable accommodations can and should have in the U.S. and only make more salient the need to ensure that students can easily access necessary accommodations.

Inclusivity versus stigma

Current literature also suggests that the challenges for college students in wheelchairs extend beyond physical to include social-emotional challenges of inclusivity, which leads to detrimental impacts on students’ mental health. In a recent study, scholars found that when asking for directions on college campuses, students who used wheelchairs were consistently talked to as if they were “helpless and incompetent” by their non-disabled peers (Wang, 2019). This attitudinal inequity among disabled students and their peers prevents mutual exchanges and relationship building. Earlier studies suggest that these attitudes may be motivated by anxiety from non-disabled peers (Fitchen, 1998). This anxiety reverberates to students in wheelchairs, who often feel feared or unwanted by their peers (Fitchen, 1998). At the same time, studies concurrently show the necessity to create mutually respectful and engaging relationships among disabled peers and their nondisabled peers and faculty (Fitchen, 1987). The pervasive stigma

preventing the actualization of fulfilling relationships among students with and without physical disabilities is clear.

Student reflections on the status quo

Ultimately, current literature reflects the fact that many students with physical disabilities are frustrated with the status quo. One student laments a university using wooden planks instead of durable ramps, which engender feelings of dehumanization and disregard for students in wheelchairs (Piro, 2017). Others believe that colleges do the bare minimum, which implies a lack of care, leaving students in wheelchairs isolated; for one student, even though there was one accessible dorm on her campus, she was never able to visit her friends (Samee Ali, 2020). Many students in wheelchairs on college campuses feel as if colleges just are not where they should be with regard to accommodating students with physical disabilities; “It’s about going beyond compliance in terms of what the Americans with Disabilities Act really means and what it means in terms of disability and inclusivity,” one student said (Samee Ali, 2020). Even at Yale, students in wheelchairs express immense frustration at what they feel to be lacking institutional commitment to be inclusive. Only a few years ago, students from Yale’s student organization for students with disabilities “put up a display of wheelchairs and signs in the Morse College courtyard on Wednesday morning to protest the lack of wheelchair access along the Morse–Stiles walkway” (“Students call for ramps,” 2018). Across the U.S., students express disappointment and resentment in systems that fail to support them in their success, leading to tremendous opportunity costs—time, relationships, social-emotional well-being—for these students.

Ultimately, this literature is helpful in framing the varied and pervasive barriers and burdens shared by many students in wheelchairs to develop an understanding of the current landscape, what research is lacking, and how to best support students going forward. Yet, prior research is predominantly conducted and written from someone without a disability.

Additionally, research historically has centered the failures of systems to facilitate success among students in wheelchairs without focusing on ways these systems may be improved or the greater complexity inherent in students' experiences. Finally, the majority of prior research is written from an international standpoint. While this literature is invaluable in further situating similar issues in the U.S. (where there is a dearth of formal research done), my research will add to previous literature by complementing it with interviews that centralize the human experience and narrative told by U.S. students in wheelchairs themselves.

METHODS

For this study, nine people who graduated from a U.S. college in the last ten years and used a wheelchair were interviewed to understand the unique complexity of experiences, considerations, and decision-making that students in wheelchairs accessing higher education face. As a wheelchair user with SMA in college myself, I was able to intimately empathize with many of the participants' experiences; I believe that having this shared identity allowed participants to feel more comfortable in being vulnerable and openly sharing their experiences. After gaining approval from Yale's Institutional Review Board (IRB), interviewees were recruited via social media (Facebook and Instagram) and direct messages (email, text, direct messages on social media). Interviewees represented a snowball sample consisting of people with various forms of MD and CP from a summer camp I was part of dedicated to children with MD, patients from the SMA Clinic based at Columbia Hospital, Yale, and Facebook. The

interviews ranged from 30 minutes to an hour and were conducted through Zoom; recordings were kept on an audio recording app on an iPhone and anonymized via only using participants' initials. After completing all interviews, I manually coded interview transcripts (transcripts via Otter.ai) for key reoccurring words (i.e "care," "distance," "accessibility," "family"), which I used to thematize topics to organize my analysis (i.e social life, care, health, etc).

Interviewees were diverse with regard to gender, type of institution (i.e. college versus university, recognized prestige, size of institution), and their residential versus commuter status (see next page):

Figure 1: Participant basic information⁴

⁴ One participant did not use a wheelchair full-time while in college.

Gender

M 5

F 4

Hometown region

Northeast 7

South 1

West coast 1

Student type

Commuter 4

Residential 5

Student type College/University

Commuter City College of New York, Montclair State University, Moravian College,
Ramapo College

Residential Georgetown University, Harvard University, Sienna College, Stanford
University, University of Arizona

Importantly, in considering the makeup of interviewees, two limitations ought to be acknowledged: geographic and racial diversity. This study was limited in geographic diversity with regard to interviewees' hometown; though interviewees collectively represented three geographic regions of the U.S., a disproportionate number of interviewees considered the Northeast their home. This is likely because most of the personal connections I had were from the Northeast as I am from New York and attended the Muscular Dystrophy Association camp in New Jersey, where I met many of the study's participants. Another limitation of this study was limited racial diversity: all interviewees were white. Both of these limitations undoubtedly

hindered the ability to gather completely holistic and diverse experiences and perspectives.

Finally, socioeconomic status was not explicitly asked, though most students noted paying for care as a significant barrier in attaining higher education. Nonetheless, given the small sample size of the study and specific parameters of the study, limitations in the sample are not completely surprising though important to consider in evaluating this research.

FINDINGS

Interviews of residential and commuting students revealed that wheelchair users face uniquely complicated considerations, decisions, and experiences that necessitate more policy-based support—specifically related to care and accessibility—to maximize the potential for a fulfilling college experience. All interviewees were confident in their decision to attend college to some capacity. Factors contributing to the decision of where to attend college slightly differed among commuting and residential experiences. Students who left home for college believed a residential experience was completely critical and thus committed to the extensive planning that would be required and accepted limiting factors, such as climate, in their decision-making process. For students that commuted, care was too vital to sacrifice, and leaving home was simply not a possibility. However, for *all* students, care remained the paramount stressor throughout college. Socially, all students noted physical accessibility as a barrier to socialization and felt forced to assume extra vulnerability in forging relationships, while commuting students noted a more limited college experience socially. Finally, when asked to evaluate the experience of balancing the academic, physical, medical, and social needs of college in a wheelchair, all students expressed that doing so was incredibly taxing and mandated tremendous amounts of self-advocacy.

Ultimately, and perhaps most importantly, *all* students believed a residential college experience was worthwhile despite facing significant challenges, encouraging future students to find ways to make one possible. Thus, interviews collectively revealed that students in wheelchairs must have more comprehensive support—especially related to care, transportation, accommodations, and social activities—to lessen the burden of having a residential college experience, which clearly is invaluable yet sometimes out of reach for students who use wheelchairs.

The decision to go to college

All of the students interviewed were highly motivated to attend college either on the basis of familial expectation and disability – none had even considered foregoing a college education. For Robert, “college was just the expectation; I was 100% going to college, it was just a matter of where.” Another mentioned that “college was assumed in my family, that had nothing to do with disability” (Louis, 2022) while another mentioned “college was just cultural in my family” (Gregory, 2022). Not going to college was out of the question for these students. Thus, though socioeconomic status or familial education status were not explicitly requested, several students made clear that college was simply a family expectation that they needed to meet. Like many students across the U.S., college was simply part of the growing up process that their community had for these students after graduating from high school.

For other students, their disability dictated that decision. Delilah knew she wanted to be independent after college, and knew that if that were true, “care would be expensive; if I wanted to work at all, I would get no financial help to pay for care.” Given Medicaid’s threshold laws that require an “incredibly low income to qualify for compensated care,” Delilah knew she would be paying out-of-pocket if she worked at all. Thus, she knew she wanted to attend a

college that was well-recognized enough to help her get a high paying job. Relatedly, Susan understood that logistically, “as a disabled person, I knew I needed a college degree to do most jobs I could physically do.” In her mind, most jobs that did not require a college degree involved physical labor, which simply was not an option for her. Ultimately, though for differing reasons, the decision to go to college was unquestioned and felt important.

Factors contributing to a residential or commuting experience

While all students were committed to earning a college degree, the decision to live at home or at college ultimately came down to a difference in how interviewees weighed factors of independence, care and its related costs, and distance from home. The majority of residential students believed that a residential college experience was highly important for independence. Students interviewed noted that “I had never had that my whole life, this was a real step towards adulthood after my mom doing all of my care” (Delilah, 2022). Many students shared the sentiment that due to their disability and thus physical dependence on their parents, having the experience to live independently was even more “critical” than for most of their peers (Delilah, 2022). In fact, Delilah felt so strongly about making a residential college experience possible that after being admitted to the institution she ultimately attended, she used her Make-a-Wish Foundation wish to visit to ensure it was physically possible. Like many students applying to college, living at college was important as a stepping stone towards adulthood; yet, for these students, that need was heightened due to a life of dependency prior to college and ensuring doing so could be a reality took extra effort, time, and cost.

To make the ardent prioritization of a residential college experience possible, many students noted the need for a highly complicated planning process to meet their medical needs, starting with weather. In fact, most students considered climate a “make or break” factor that

largely dictated choices about where to attend college (Robert). For Robert, “warm weather was the determining factor.” Similarly, Gregory only looked at universities with a “warm and dry” campus. Thus, for some students, weather completely decided the set of schools that they applied to. For Susan, even if not the sole factor, weather was also at the top of her considerations in choosing where to apply to college; in fact, she decided to apply nowhere north of New York City given she could not put on a jacket independently. To Susan, a warmer climate led to independence, and independence was “absolutely essential” to her college experience.

In addition to climate considerations, students also noted the financial planning needed to pay for care in college, forcing 17 year-old students to navigate a complicated healthcare reimbursement system—Medicaid. Importantly to note, care is essential for college students who use wheelchairs to live independently; all interviewees required Personal Care Assistants (PCAs) for many hours of each day to assist in activities of daily living (ADLs). For Delilah, she found that applying for Medicaid took months to receive approval. The process was so intricate that when asked to give advice to future students in a similar situation, she said “I’d provide a crash course on Medicaid.” Similarly, Susan battled with Medicaid to get care for months leading to college. She ultimately needed to read through Medicaid’s entire administrative code after being told she could not receive care out of state. While her peers were enjoying their last summer before college, she was reading legal documents and anxious if her care would get covered until three weeks before school. Similarly to Susan, when asked what advice she would give to prospective college students in wheelchairs, Delilah said “start early with coordination –you can’t coordinate it in summer before college like everyone else, start at least a year in advance.” Thus, the commitment to attend a residential college experience was matched with a lengthy list of unique considerations and stressors for students in wheelchairs.

Importantly, commuting students shared care as a key consideration in decisions about attending college, so much so that it dictated their decision to stay at home for college. Prior to college, all interviewees' families—primarily parents—had done all of their care. For many, the “unknown was scary and uncomfortable. I wasn't willing to do it” (Louis, 2022). Similarly, John noted he just “didn't feel comfortable leaving home and having other people do his care.” Parents providing care added a source of comfort and stability that students were not willing to risk. For example, Louis recalls “horror stories” of people in similar situations being “left in bed” or “not able to use bathroom” if their caregivers would not arrive on time. For others, having anyone but one's family members provide care simply was not an option financially. Amanda noted that “it would have cost too much to have aides full time and would have been too much coordination, it just wasn't an option.” Thus, for some, the logistical challenges compounded the emotional and physical security that familial care provided to make leaving home seem unrealistic. Additionally, for many, the distance from home and care were intrinsically related. For George, he “knew I needed my mom to drive – the Paratransit system was really bad” and thus attending a school that his mother could easily drive to was critical. Similarly, for John, “it was easier to care for me at home than stop on the way from work.” Thus, being close to their care resources—family members—was essential and anything but that was infeasible.

When asked to consider if students had considered going away for college, commuting students unanimously communicated that doing so was not truly a choice given the gravity of the stakes they were facing. For some, the decision to stay at home was made far before even looking at schools. George noted that given his prognosis was originally that he would die before the age of 18, “being alive was the reason I went to college” and that thus the prioritization of a residential experience was quite low. Finally, John actually did attempt to attend college

residentially—he lived on campus his first semester—but found it nearly impossible to manage his care needs with his parents who would come before and after work to assist him. Thus, commuting students often felt that ultimately, their care and physical wellbeing just mattered more than a residential experience and living at home was just a necessity.

Care as a constant stressor

The plight of securing care continued through college for all students with many students attributing sourcing care as the greatest unique stressor to their college experience. For all students except one, families provided some—if not all—care in college and consequently complicated much of the college experience. Ultimately, challenges related to care were heightened for residential students.

For residential students, the most straightforward option was often having a parent move to college with their student to provide care. For 80% of residential interviewees, a parent provided care for some of their college experience. This was draining, emotionally fraught, and simply less than ideal for all members of the family. Students felt conflicted. On one hand, students were grateful for their parents and understood the significant sacrifice parents were making to support their child in having a residential experience. At the same time, having a parent provide care added to the abnormality of a first-year experience for a student in a wheelchair. Emily noted: “I was in college and didn’t want my mom there.” Similarly, parents had to adjust to their child becoming an adult in college. Gregory recalled a fight with his father during one of his first few weeks of school in which “my dad got mad one day because I was out until 2am, and my dad was waiting to take care of me. After that, I didn’t ask parents for help.” Contention arose from the uncomfortable blurring of boundaries in parent-child relationships, leading to lasting strains on relationships. One step further, Delilah noted that her first semester

of college was “one of if not my darkest period, I had a really challenging relationship with mom; it was weird to feel like I was at college but with my mom, so I was fighting with mom every other day.” Parents cared for their children out of necessity, which came at the cost of challenging students’ mental health and relationships with their parents.

Finding care outside of the family was also challenging for students in wheelchairs, adding even more stress to an already stressful transition to college. Generally speaking, colleges did not provide any assistance to students seeking care. In some cases, they even hindered the process. When Emily sought to post job descriptions throughout her dorm, her institution forbid her from doing so by using privacy as a justification; this forced her to outsource care using Care.com and a nursing agency when it would have been preferable—logistically, financially, socially—for her to use care within the college. Even when care was easier to find, it was not a straightforward experience; for example, Robert’s aide moved with him and they shared a single room with two beds. Despite being grateful for his care, Robert noted that this made socializing difficult. In another situation, a student shared an aide with another student in a wheelchair, “which really wasn’t great” due to conflict of interest and social reasons (Delilah, 2022). Care conditions were suboptimal.

Yet, in some notable instances, colleges did help find care for students. Gregory communicated that his institution actually paired students with disabilities who needed care to other undergraduate students studying medicine. While this program was extraordinary in helping establish care, it still came with social difficulty. Gregory mentioned that having an undergraduate provide his care was challenging given that they were inherently “untrained to provide such intimate care” for their peers, which at times led to uncomfortable relationships. Clearly, finding care was challenging and tumultuous for each student.

Regardless of how care was established, it took a colossal amount of effort, time, and energy from students. As Susan describes, “managing my care was a part-time job, and adjusting to an environment of trusting that someone will show up was hard.” While other students had part-time jobs on campus they got paid for, students in wheelchairs spent that same time and energy merely organizing essential care. Additionally, relying on other people for survival took immense trust and, at times, blind faith. Emily added to this by emphasizing the emotional difficulty inherent in the process; “the idea of not having aides is really scary, I am so reliant on them.” Relying on strangers for survival added great elements of fear and insecurity to an already tumultuous period for any student starting college.

Commuting students also had to rely on strangers. Louis remembered “sending messages to freshman year class about [his disease] asking if anyone would help get him lunch.” Additionally, he remembers “his head falling during the first week of class and having to ask a stranger to pick it up.” Similarly, commuter George recalls “always asking the person next to me to help get out book, notebook; having to be on my own but rely on other people forced me to be independent.” For these students, meeting basic needs that most students never think about required discomfort, foresight, trust, and vulnerability on a scale beyond comprehension for many. Other times, students quite literally went without meeting their care needs. One commuting student mentioned “not using the bathroom while on campus” (Louis, 2022) while another recalls “waiting hours in the snow and rain” or being stuck on campus when the paratransit system was slow or when class suddenly got canceled (John, 2022). Ultimately, the process of setting up and managing care was very difficult for students and their families from a logistical and emotional standpoint regardless of where they lived.

Physical inaccessibility limiting social interaction

With regard to students' social lives, all students pointed to physical inaccessibility as a major stressor in having a completely fulfilling social life. The examples were dishearteningly numerous. For example, Emily recalled going to a basketball game and having to sit in isolated seating away from peers. To Emily, the main reason to attend this event was to make memories with friends, so being deprived of that was upsetting. Socially, Robert rushed a fraternity but could not physically live there given the house's inaccessibility, preventing him from becoming as close to his peers as he knew he would be if he lived there. In another instance, Delilah recalls a major University-run assembly in the fall of her first year, in which her dorm was assigned to sit at the top of a staircase. The University had blatantly made it impossible for the students described above to fully participate in organized events.

Student-organized events ostracized wheelchair users, too, given physical inaccessibility. For example, Robert often found himself in the corner at fraternity parties; "the guys were welcoming, but at the same time, parties were compact, which was difficult to physically navigate and not conducive to a wheelchair." Even when others were open-minded, physical spaces isolated students in situations they truly sought to be a part of. Similarly, Susan very explicitly recalled "social isolation due to physical inaccessibility." She described being invited to parties in inaccessible apartments, which she found challenging to navigate; on one hand, she was thankful to be invited, but on the other, she felt like she was not truly invited given the thoughtlessness related to inclusivity. In one instance, after repeated instances of this exclusion grounded in inaccessibility, Susan dropped a club "out of self-respect" after being made aware that the club had accessible options to host spaces but simply chose not to. Less overtly, Gregory recalled having to spend hours of—limited—free time scoping out bars and restaurants near campus that were accessible, creating a list of places he could access. Yet, one day, one of his

friends—not thinking about accessibility—wanted to go to a bar not on that list. Gregory did not want to be the reason people did not go out, so simply made an excuse not to go. In another instance, Gregory was invited to a rooftop party at a location that *was* on his list. When he got there, the building manager refused to give him a key to the lift since he was not a resident; Gregory had to turn around and go home. Similarly, at one institution, Final Clubs represent a major social activity that upperclassmen often take part in. Yet, Delilah could not even go through the process of Final Clubs given that she could not physically enter the houses, forcing her to get coffee with the Finals Club President instead of mingling with her peers as the normal process would dictate. In all of these instances, physical inaccessibility fueled exclusion for students in wheelchairs that compounded the already stressful experience for these students.

Commuting students also faced barriers to social interaction from physical inaccessibility, which when compounded with living at home resulted in a limited social experience. Primarily, students pointed to missing out on activities related to orientation, nightlife, and events requiring flexibility. For example, Louis mentioned many “freshman orientation activities that I couldn’t participate in because they were physical, so I would go home and miss out on connection building time.” Amanda added to this narrative by mentioning missing out on a “lot of get-to-know you meetings” and “orientation activities that often included physical movement like bouncy castles, yard games, corn hole, etc” that the college had sponsored for students but were simply “out of the picture” for commuting students either due to living at home or their disability. Universities did not design social events with disability in mind. For many, this effect was reinforcing; an event was inaccessible, so they would go home, which would discourage or prevent them from attending more activities, etc. Additionally, nightlife activities—a cornerstone experience for many college students—were out of reach for

these students. For students whose parents primarily drove them, all nightlife activities were not even discussed given their parents did not want to drive late at night or students feeling uncomfortable with their parents taking them to parties. For others, nightlife parties were simply inaccessible. For example, Louis remembers “[I] thought I’d participate in more of night life, didn’t really end up doing that – a lot of dorms weren’t accessible.” Across the board, commuting students recall feeling that “social relationships were a struggle” (John, 2022).

Another significant contributing factor was the inflexibility—due to care or transit schedules—that commuting students had when most college students function on flexibility. For example, John mentioned he “never hung out with people due to scheduling – every time I tried, something would go wrong; ACCESS-A-RIDE would come too early or too late.” This inability to be flexible with time contributed to limited extracurricular commitments. For example, John mentioned he would only partake in extracurriculars “in the middle of day between classes, but didn’t consider doing anything at either end of day” for transit reasons. Additionally, George noted “if I wasn’t in class, I was at home” and Louis noted that he just did not seriously consider joining many extracurriculars.

Forging friendships and Greek life

Since physical inaccessibility clearly added an extra barrier to students wanting to form relationships, all students took extra initiative to forge relationships perhaps more intentionally than most students. Most of the students in wheelchairs interviewed found their orientation groups and freshman dorms an especially helpful place to find friends. This is likely related to the fact that having friends in one’s dorm was more physically accessible and convenient, and that having a built-in network of people was easier to navigate than finding a completely new social network.

However, many students noted the process of making friends taking longer than they had hoped for or expected. Gregory strongly committed to forming relationships: he left his dorm room open for all of first year and even bought chairs and tables from Target to “make my room the social room.” Ultimately, after realizing that joining an existing fraternity would be difficult due to accessibility, he even “created [his] own with friends; [he] got a house on Greek Row and found a firm to build the frat.” This leap of faith and proactivity led to Gregory’s best moment of college, in which he recalls 600-700 students attending one of his parties. It was in that moment in which Gregory “realized that no one cares if I can’t walk; the great equalizer is mentality.” This sentiment reflects the notion that many of the students interviewed commented on: “The world is designed to not have a wheelchair, so if you want a good experience, you need to make one your own experience” (Gregory). Despite this being unfair and creating a greater burden for wheelchair users, students in wheelchairs largely accepted and embraced this fact to make the best of it: they decided that the extra work and vulnerability was worth it. Similarly, commuter Amanda remembers feeling “sick of not being connected” and ultimately joined a sorority when her aide on campus—another student—joined the same sorority. She attributes her best moments of college with her sorority and notes how refreshing it was to “find people who didn’t think the chair was super weird.” Perhaps unsurprisingly, these students feeling the most comfortable in communities and moments that did not define students in wheelchairs based on their disability, but rather accepted them as a peer with a life that extended beyond disease. Ultimately, students in wheelchairs used the resources they had to make these experiences possible and “make it work” socially.

Consequential tradeoffs

Fighting for the support necessary to make a college experience—residential or commuting—doable took immense amounts of energy and sacrifice. Delilah thought of it as “a matter of survival” in which she had to consistently make tradeoffs to even make it through. Navigating college in a wheelchair caused her to simply not be able to put in as much time into academics as she would have liked to. Similarly, Robert never compromised on his physical needs—skipping a 9:00am class when it took too long to get ready, use the bathroom, or stretch—but put social priorities ahead of academic priorities. On the contrary, Gregory “let my physical be the part that wasn’t working.” He forewent much of his physical therapy, stretching, and his medical care to save time and energy for other aspects of college. In all these cases, students made important decisions and sacrifices, yet those judgment calls differed in terms of priority among students.

Even still, students remembered being overwhelmed when getting sick. For many wheelchair users with SMA and MD, their musculature is weak, and thus getting a cold is often more severe—in some instances life-threatening—and takes weeks or months, instead of days, to recover. Commuter Amanda recalled taking a “full course load for the first time, struggling with mental health aftermath of breakup, catching the flu last day of finals from being so run down, and I ended up in hospital for three months.” She continued to describe the constant struggle of choosing to do “homework or be social; I rarely had the energy to do both, also given I was squeezing in calls to Medicaid.” It was very clear that for Amanda, balancing all of her needs came at enormous costs and that she “constantly felt like I was grasping for straws; it was exhausting, I wouldn’t do it again.” The experience was traumatic and exhausting both physically and mentally. Similarly, Susan recalls falling and breaking her femur during the first few weeks of school, almost needing to take a leave of absence after missing so much school. In

any case, students constantly had to make difficult decisions about how to manage their various and complex needs, and at times did not even have a choice when fate decided for them.

Balancing competing needs—academic, social, physical—was simply too much to handle and had serious consequences.

Self-reliance

Self-reliance was a clear theme among all interviewees. Consequently, students almost unanimously agreed that full support could not be expected, but rather was created by students themselves. Robert accepted this fact as no one's fault, but rather that just "when you have such a severe disability, the school can only do so much." He did not think it was fair to rely so heavily on others and felt as if a lot of what it took to "make it work" truly was his responsibility. Commuter Louis added to this when referencing that the school he attended simply had "zero infrastructure to have a disabled student live on campus." Anecdotally, he recalls seeing that the disability's office quite literally had stairs leading to the office; though the office ultimately moved, Louis noted this as a moment of clarity that the school was simply not able to support him. Louis thus took it upon himself to coordinate his care and decided living at home was necessary for him to have the care he needed. Robert similarly noted "support didn't come from all the same place; you have to leverage all the assets you have." Others agreed, with Susan noting, "I wasn't given support, I had to rip it out of various systems that were supposed to give it to me." Students fought to survive and thrive, and often did so without structures that were supposed to offer support.

Residential students' differing experiences with institutional support—specifically the institution's disability's office—also impacted their necessity for self-reliance. All students reported their college having a disability office but differed in their views on the office's

helpfulness. For some students, their disability office was “fantastic and absolutely appropriate” (Gregory). However, for others, the experience was drastically different. One student describes her University’s office as a “nightmare. The office was one person, and it became apparent really quickly that the office’s job was to protect [the institution], not students.”⁵ In one instance, Delilah asked if there were other students in wheelchairs whom she could be connected to, to which the University refused despite her later finding out that there were several wheelchair users. In other instances, students were less critical of the office itself but rather the system at large. Susan describes that “the office just had no power to handle physical concerns; the people who cared were powerless,” leaving her to deliberate with facilities while faculty at the disability office continued to turnover. Thus, even at their best, disability offices were often underfunded and lacked the capacity to make structural changes to support accessibility, leaving students to rely tremendously on themselves.

College being worth it

Ultimately, and perhaps surprisingly, when reflecting on their experiences, students unanimously—residential and commuting students alike—emphasized the value of a residential experience. In doing so, they stressed a narrative of self-reliance and persistence while accepting that the college experience for students who use wheelchairs is likely different in some ways. All interviewees conclusively stressed that a residential experience is possible and worthwhile.

Comparing residential and commuting students’ advice perhaps most powerfully reflects the overlap among the two groups that emphasize possibility for a residential experience and vulnerability being worth it. Residential students noted: “You have to go into it with an open mind; you’ll be independent, but you’ll still need extra help and that’s okay” (Emily, 2022);

⁵ This quote is intentionally left without a source name to preserve anonymity.

“Don’t doubt your ability to go to college – do it. College is like ‘adult bootcamp’ for people with disabilities” (Delilah, 2022); “There’s no avoiding uncomfortable moments and you just have to get through it. Go out, join a club, and get yourself out there; expose yourself and make yourself vulnerable to meeting new people and having new experiences” (Robert, 2022). To all of these students, a residential experience was worthwhile—even more so for people in wheelchairs—yet required a certain degree of accepting risk, vulnerability, and understanding of the unique circumstances that wheelchair users face.

Commuting students shared the exact sentiment. Students ardently encouraged students “Don’t confine yourself to home - you can be independent” (John), 2022; “Know it’s possible and find out how” (Louis); “Go out, do more, and have fun” (George, 2022). Thus, for commuting students, too, a residential experience was worth –with regard to independence, being able to share in similar dreams and experiences as any other college student—the extra challenge and complexity.

CONCLUSION

Ultimately, the college experience for college students who use wheelchairs was highly complex and involved important tradeoffs that students had to grapple with. In all of these cases, tenacity and acceptance of an inherently unique—and at times with extra challenge—college experience were apparent. Interviews of college students in wheelchairs revealed the several barriers and challenges that systems must address in future years to reduce barriers for students. Yet, at the same time, all students saw the value of a residential experience, inclusive of challenge. If commuting and residential students can already see a residential college experience as worthwhile given the extensive and exhausting burdens that currently exist, creating more comprehensive support structures is only that much more important to make this experience that

much more fulfilling. Interviews revealed that future support systems and policies should focus on compensating care and creating networks for students who wish to out-source care; accessible transportation; physical accessibility; and workshops on inclusion of students who use wheelchairs for non-disabled students and faculty.

This research supports the experiences of students in wheelchairs at the college level from an asset-based orientation by empowering students, listening to, and empathizing with students who largely have felt underheard and underserved. Interviews supplement previous literature that emphasizes the failings of our current system without guidance from students in wheelchairs by more fully encapsulating the multifaceted lived experience of college students in wheelchairs to illuminate more comprehensive structures. By providing a more comprehensive understanding of students in wheelchairs' experience, this research will hopefully lead to policies that are more responsive to student needs and allow "colleges [to] look beyond meeting a checkmark to approach inclusion of students with disabilities" to promote inclusion (Samee Ali, 2020).

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