Making It Work for Students in Wheelchairs to Leave Home:

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. By studying the intersection of inclusion, higher education, and disability studies, my capstone explored a subset of this dilemma to focus on wheelchair users' decision-making process about where to attend college and their subsequent time at college. In this capstone I adhered to the American with Disabilities Act (ADA) of 1990's definition of a disability as "a person who has a physical or mental impairment that substantially limits one or more major life activity." 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. Interviewing nine students who used wheelchairs living with Spinal Muscular Atrophy (SMA), Muscular Dystrophy (MD), or 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 students. 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 their disability-related dependence, this capstone is critical in making a supportive college experience possible. 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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Research corroborates that students in wheelchairs face pervasive disadvantages in college (Fitchen & Amsel, 1998). While the number of students with disabilities is increasing over time to keep pace with a growing American population, the opportunity gap (e.g., graduation rates, enrollment rates) between non-disabled and disabled students has remained stable (Toutain, 2019; Pendharkar, 2023). Relatedly, research has found consistent undermatching—a phenomenon in which well-qualified students attend selective schools at disproportionately lower rates—of students with physical disabilities in attaining higher education (Hudes & Aquino, 2019). Even when adjusted for institutional selectivity, studies find that "students with disabilities undermatch at a greater rate than the overall studied sample," suggesting a gap between the ability or commitment to earning a higher education and actual enrollment rates (Hudes & Aquino, 2019, p. 180). 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 & Amsel, 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 (Fichten & Amsel, 1998). Once a student is at college, accommodations are often insufficient to support student success (Losinsky et al., 2003). The 360-degree logistical set of needs students in wheelchairs have require enormous amounts of coordination among stakeholders (e.g., healthcare providers, administration at college institutions, caregivers, educators, parents) that are often overwhelming for students to navigate (Olumolade, 2021).

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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 acknowledged that for many students, access to 24/7 care is a fundamental necessity, and without such care, most people with severe physical disabilities find it almost impossible to attend and graduate from postsecondary degree programs (Stumbo et al., 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 (Genworth Cost of Care Survey, 2015; Vega, 2021). The strain (e.g., 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 & Clark, 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, 2021). 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, para. 5 and 6). Based on my interviews and literature review, I have concluded 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 any disability report never receiving accommodations for which they are approved (Stumbo

et al., 2009). At the same time, studies show a direct positive correlation in grade-point-average and the uptake of accessibility accommodations, suggesting that students in wheelchairs are able to thrive when adequately supported (Schreuer & Sachs, 2014). More broadly, supporting students in wheelchairs throughout their time at college achieves a wider good and reverberates for students across the university. Schreuer and Sachs (2014) found that effective accommodations not only improve individual outcomes—such as academic performance and satisfaction—but also enhance the overall institutional climate. Their research highlights how inclusive practices contribute to a more supportive and equitable learning environment for all students. 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, which encourages growth for all students by promoting diversity on campuses (CAST, 2025).

My research centered on 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 was a departure 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 United States in the last decade, I found that wheelchair users have uniquely complicated college experiences related to managing medical needs, social life, and academic rigor. Given that these students also emphatically stated that a residential college experience is invaluable—especially for wheelchair users who may have been deprived independence otherwise—the results from this study have led me to vigorously recommend more

comprehensive support structures especially related to care and accessibility to ensure that a residential experience is an option for all wheelchair users.

Methods

For this study, nine people, who had used a wheelchair and who graduated from a U.S. college in the last 10 years, were interviewed to understand the unique complexity of experiences, considerations, and decision-making that these students in wheelchairs accessing higher education faced. 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 (Parker et al., 2019). 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 (e.g., "care," "distance," "accessibility," "family"), which I used to thematize topics to organize my analysis (e.g., social life, care, health).

Interviewees were diverse with regard to gender, type of institution (e.g., college versus university, recognized prestige, size of institution), hometown region of the nation, and their residential versus commuter status (see Table 1). The institutions that were included in terms of

commuter participants included: City College of New York, Montclair State University,
Moravian University, and Ramapo College. The institutions in which the student participants
were residential students included: Georgetown University, Harvard University, Sienna College,
Stanford University, and the University of Arizona.

Table 1

Participant Demographic Data

Demographics	Categories			
Gender*	<u>Female</u>		Male	
	4	5		
Hometown Region*	Northeast	South	West Coast	
	7	1	1	
Institution Type*	<u>College</u>		<u>University</u>	
	3		6	
Student Type*	Residential		<u>Commuter</u>	
	6 Residential		3 Commuters	
Prestige of Institution**	<u>Top 30</u>		<u>Under Top 30</u>	
	Colleges 2 Universities 3		Colleges 1 Universities 3	
Size of Institution***	Less Than 6,500 Undergraduate Students		More Than 6,500 <u>Undergraduate Students</u>	
	Colleges 2 Universities 1		Colleges 1 Universities 5	

Note: *Data from interviews; **Data from US News World Report 2025; ***Data from institution websites

Importantly, in considering the characteristics interviewees, two limitations ought to be acknowledged: geographic and racial diversity. This study was limited in geographic diversity NEW ENGLAND COLLEGE JOURNAL OF APPLIED EDUCATIONAL RESEARCH Volume 5 Number 2

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with regard to interviewees' hometowns; though interviewees collectively represented three geographic regions of the United States, 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 my 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 faced uniquely complicated considerations, decisions, and experiences that necessitated 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 between commuting and residential experiences. Students who left home for college believed a residential experience was completely critical and thus committed to the "extensive planning" (Louis) 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 in their circumstances. However, for all students, finding and paying for 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 since they could not fully immerse themselves into the social aspect to the college experience. 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" (Delilah).

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. Commuters, such as John, felt their college experience lacked its "full potential socially" and with regard to fostering independence, residential students, such as Delilah, overwhelmingly felt the residential experience—and all the relationships, memories, and independence that came with it—was "worth the challenges" to obtain it. 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 or 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." Louis mentioned that "college was assumed in my family, that had nothing to do with disability;" while Gregory added, "college was just cultural in my family." 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 United States, 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 the decision about whether to attend college, where to attend college, and whether to attend college as a residential or commuter student. 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, their related costs, and distance from home. The calculus was different for each student, often motivated by family and financial resources. All college residential students believed that a residential college experience was highly important for independence. Delilah noted about her lack of independence, "I had never had that my whole life, this was a real step

towards adulthood after my mom doing all of my care." All residential 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. 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 and ensure that living on campus 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, all 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. 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 to which they applied. 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 up 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 about whether her care would get covered until 3 weeks before school. Similar 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 Louis, like others, the "unknown was scary and uncomfortable. I wasn't willing to do it." 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 some students were not willing to risk. For example, Louis recalled "horror stories" of people in similar situations being "left in bed" or "not able to use the 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 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 all students attributing securing 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 that consequently complicated much of the college experience. Ultimately, challenges related to care were heightened for residential students, such as Susan and Delilah, who felt they needed to become

"experts" on Medicaid reimbursement policies, or other students, like Gregory or Susan, who felt they must "choose" between "straining" familial relationships or lack the necessary support via part-time aids.

For residential students, the most straightforward option was often having a parent move to college with their student to provide care. For five of the six 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 an argument 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 2 a.m., 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 negative step further, Delilah noted that her first semester of college was "one of if not my darkest periods, 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 forbade 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 in 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. 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 with 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 described, "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 significant 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 who would help get him lunch."

Additionally, he remembered "his head falling during the first week of class and having to ask a stranger to pick it up." Similarly, commuter George recalled "always asking the person next to me to help get out a book or 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," while another recalled "waiting hours in the snow and rain" or being stuck on campus when the paratransit system was slow or when class suddenly got canceled. 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

recalled 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 in which they sought to attend. 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 he 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 in which upperclassmen often take part. 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, which 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 oftenincluded 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 often 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 felt uncomfortable with their parents taking them to parties. For others, nightlife parties were simply inaccessible. For example, Louis remembered "[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 recalled feeling that "social relationships were a struggle."

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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 the day between classes, but did not consider doing anything at either end of the 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 especially helpful places 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 that the process of making friends took longer than they had hoped for or expected. Gregory strongly committed to forming relationships: he left his dorm room open for all of his 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 that 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 remembered feeling "sick of not being connected" and ultimately joined a sorority when her aide on campus—another student—joined the same sorority. She attributed her best moments of college to her sorority and noted 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 9:00 a.m. 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 on the 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 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 that 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 described 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." 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 described 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 turn over. 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 emphasized possibility for a residential experience and vulnerability being worth it. Emily, a residential student, 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;" "Don't doubt your ability to go to college—do it. Delilah expressed the feelings of all of the participants when she stated, "college is like 'adult bootcamp' for people with disabilities." Robert put it this way, "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." 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); "Know it's possible and find out how" (Louis); "Go out, do more, and have fun" (George). Thus, for commuting students, too, a residential experience was worthwhile—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 with which students had to grapple. In all of these cases, tenacity and acceptance of an inherently unique—and at times with extra challenge college experiences were apparent. Interviews of college students in wheelchairs revealed several barriers and challenges that systems must address in future years to reduce barriers for students. These challenges included finding and paying for care; physical accessibility and climate of campuses; forging relationships; burdening familial relationships; and balancing medical, academic, and social priorities. 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 as fulfilling as possible. 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.

Literature reviews and qualitative interviews from this research support 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 underserved.

Interview data supplemented previous literature to emphasize that the multifaceted lived experience of students with physical disabilities must be centered in educational guidance and decision-making to ensure these students are afforded the necessary support to thrive in obtaining higher education. 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 approach this not as a legal check mark but as a diversity initiative, otherwise schools are not providing a welcoming space for all students" (Samee Ali, 2020, para. 25).

Based on findings from this research, it is clear that making a residential college experience a viable option to students in wheelchairs is critical for feelings of independence and fulfillment but is often out of reach. Recommendations for colleges to consider in making a residential college experience possible include:

1. Providing remote options or excused absences to students with physical disabilities in bad weather or when sick. Multiple students noted weather being a factor in their college choices since the snow and rain can make it difficult to travel in a wheelchair, and people with physical disabilities are often at higher risk for illness in colder weather. Providing an attendance accommodation to students in wheelchairs if their unique circumstances make it too challenging to attend classes due to weather or sickness is critical.

- 2. Ensuring that accessible transport is available to students. The majority of students interviewed, specifically commuter students, noted physically getting to class was challenging as many students in wheelchairs cannot independently drive, open doors, or take out books from their backpack. Ensuring accessible transportation (e.g., Access-a-Ride) is available will be critical in supporting students' ability to get to class, especially in bad weather. Likewise, having a peer or aide available to help open doors, get materials from the student's backpack, etc. is important.
- 3. Prioritizing plowing the paths for students in wheelchairs to classes or extracurricular engagements in snow. To help alleviate the need to miss class or extracurricular engagements as noted in number 1, paths used by student in wheelchairs should be prioritized by institutional ploughing teams in winter weather. This is already being done in at least two Ivy League institutions and should be widely adopted.
- 4. Offering additional financial aid to students in wheelchairs so that proper care can be obtained. Finding and paying for care was a constant stressor for residential students, and not being able to do so was a key motivator in students in wheelchairs choosing to commute instead of reside on campus. Offering financial aid to students will allow them to find care that feels comfortable and safe, as comfortability with the source of care represented a main reason students cited for choosing to commute. This is similar to universities and colleges offering financial aid to low-income student to relieve the financial burden of attending college.
- 5. Ensuring physical accessibility of campus for all students. While ideally all campuses should be physically accessible, many are not, which students cited as a major barrier to social immersion. Recognizing the difficulty in fully making a campus accessible,

schools should commit making legitimate efforts to ensure students with disabilities have their classes, dorms, dining halls, and college-sponsored extracurricular events physically accessible so that they can fully immerse themselves in their college experience. Further, a map outlining the physical accessibility of campuses should be provided to students in wheelchairs for their convenience.

- 6. Encouraging college-sponsored social life. Multiple students noted that orientation groups, freshman dorms, and Greek Life were helpful in forging friendships. Thus, prioritizing and emphasizing these opportunities to students, such as being particularly thoughtful in pairing for orientation groups and dorm-mates will offer critical support to students in wheelchairs.
- 7. Creating a guide for students with physical disabilities including a map of physical access, accessible transportation options, resources for finding care, recommended social opportunities, contact information with disability office resources.

This research supports the facts that students with physical disabilities are committed to pursuing higher education and can thrive when adequately supported, offering institutions of higher education a unique opportunity to intervene in a way that promotes equity. Colleges and universities can offer students with physical disabilities equal opportunities to their non-disabled peers through straightforward support systems in a way that mirrors support already made towards other student groups—such as offering financial aid to low-income students in order to remove the burden of financing education in the college decision-making process. Ultimately, institutions of higher education have the opportunity to create a system in which the decision to attend college for students with physical disabilities is not driven by access issues—financial, social, physical—but rather, driven by a student's academic aspirations that their non-disabled

peers enjoy. Taking advantage of this opportunity can position universities and colleges to be leaders in promoting equity and closing the gap of achievement that continues to exist between students with and without physical disabilities.

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